An Exploration of the Nature of Patient Participation within the Context of the Acute Surgical Care Setting – A Grounded Theory Study

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Contents

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ABSTRACT

Patient participation is a central theme in health care policy in the United Kingdom (U.K.). Indeed, there is a trend in health care policy and practice towards encouraging patients to participate actively in their care, treatment and the services they use (Department of Health, 1989, 2003; 2004; 2005; 2006; 2008; 2009; 2010; 2011; 2012). Despite the current popularity surrounding such an approach to care, the concept remains elusive. Patient participation in nursing care specifically has not been examined adequately and remains one of the least understood ideas in clinical practice. The contribution that nurses make to this important activity has also not been explored. Furthermore, only a few studies have examined the nature of patient participation in nursing care from the frame of reference of the acute surgical patient (Henderson, 1997; Sahlston et al., 2008 and Larsson et al., 2011). Most studies have targeted clinically distinct patient groups and discrete aspects of patient participation within the context of chronic illness or medical and primary care practice. They are therefore limited by their precision and narrow focus (Cassileth et al., 1980; Haug & Levin, 1981; Vertinsky et al., 1984; Caress et al., 2005; Entwhistle et al., 2004; Collins et al., 2007; S. Parsons et al., 2010). Most have also drawn on positivist epistemologies and derived data from self-completed fixed choice questionnaires. An empirically grounded theory that explains the process of patient participation in surgical nursing care within the empirical world has yet to be published.

The purpose of this grounded theory study was to explore the nature of patient participation in nursing care within the context of the acute surgical care setting. Ultimately the aim was to generate a substantive theory that could account for, and explain, the process by which patients' participate in their surgical nursing care. A qualitative, inductive design, based on the classic grounded theory approach to data collection and data analysis (Glaser & Strauss, 1967; Glaser, 1978) was employed to examine the complex nature or natural history of patient participation within the context of contemporary surgical nursing practice.

The informants of the research were patients and nurses on three acute surgical wards in an NHS Trust Hospital. Data were collected through 61 unstructured, audiotaped interviews (47 patients and 14 nurses) and 72 hours of participant observation. The interview and observational data were analysed using the constant comparative method of analysis (Glaser & Strauss, 1967; Glaser, 1978). The analytic process generated a substantive theory, labelled *Engaging in Nursing Care.* The theory explains how patient participation in nursing care within the acute surgical setting is established, developed, maintained or inhibited. It reveals an evolutionary context-sensitive process, which describes the complex and

challenging nature of patient participation in nursing care as experienced by patients and nurses in the pre and post-operative period.

Three dynamic phases: *Establishing Readiness, Shaping Work and Incurring Rewards and Costs* describe how patients engage in their nursing care prior to and after surgery. The phase *Establishing Readiness* describes the structural, organisational and environmental antecedents of patient participation within the context of the surgical care setting. *Shaping Work* describes the range and variation in participatory behaviour and the levels at which patients participate in their own nursing care throughout their surgical experience. The phase *Incurring Rewards and Costs* explains the varied effects of patient participation in surgical nursing care on the individual patient, the nurse and surgical ward performance and resources. A number of recommendations are made to enable nurses, educationalists, health care managers and policy makers to develop substantiated strategies and initiatives for the effective implementation of patient participation in modern surgical nursing practice.

A NOTE ON PRESENTATION AND TERMINOLOGY

- Italics have been used throughout the thesis to denote points of emphasis or to amplify comments made by informants.

- The first person pronoun has been used in parts of the thesis to signal the voice of the researcher and promote an engaging style of narrative.

- When talking about or referring to patient participation within the context of the present study reference is being made to patient participation in surgical nursing care specifically.

- The term 'nurse' has been used to describe all nurse informants irrespective of seniority or registration status. Where the status of the nurse informant was found to be significant, direct reference has been made to the particular designation of the nurse informant.

- When presenting raw data the capital letter P has been used to denote a patient informant, the number that follows the letter refers to a specific patient interview. The capital letter N has been used to denote a nurse informant; the number that follows refers to a specific nurse informant. The capital letters FN have been used to denote field notes; the number that follows the letters refers to a specific page from the bank of field notes. The capital letters AM have been used to denote analytic memos; the number that follows refers to the specific memo. The capital letters SFM have been used to denote self-reflective memos; the number that follows refers to the specific memo.

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CHAPTER 1   INTRODUCTION

1.0   Overview of the Chapter

This chapter provides an overview of the background to the present study and justifies why the research was needed. The context in which the research was conducted is described. The objectives for Phase 1 and Phase 2 of the study are presented.

1.1   The Study in Context

While some researchers have argued that patient participation in nursing care is a primitive ideology as a basis for nursing philosophy and practice (Collins et al., 2007) it has grown in popularity over the last four decades. Hickey (2008) attributed this popularity to increased consumer knowledge, an increased awareness of consumer rights, movement towards self-help, accelerated health care costs and an increasing awareness of the fallibility of health professionals. Successive Governments in the U.K. have in recent years prioritised patient participation in health care policy (Department of Health, 2007; 2009; 2010; 2011; 2012). Such policies are based on the assumption that patient participation in general is valuable and universally welcomed by all patients. Certainly, there is some evidence to suggest that such an approach to care is valued by both patients and nurses alike and that it can contribute to improved outcomes of care (Coulter, 1997; Muir-Gray, 2007; Hibbard et al., 2004; Picker Institute Europe, 2010). However, the evidence is incomplete, at best suggestive and far from conclusive.

Much of the literature that has examined patient participation in nursing care specifically reflects personal opinion (Cahill, 1996 – see Appendix 15 page 276 refers ; Baynton-Lees, 1992; Gallant et al.; 2002; Hook, 2006), anecdotal experience (Glenister 1994, Saunders, 1995; Copperman & Morrison; 1995; Lathlean et al., 2006) or estimates of the patients' perspective from the nurses' frame of reference (Lott et al., 1992; Jewell, 1994; Sahlston et al., 2007). Studies examining patient participation in nursing care from the perspective of the patient have largely been neglected. Consequently, there is a deficit of richly textured portraits of the process of patient participation in nursing care, a premise supported by Meyer (1993) and more recently Coulter (2011). According to Coulter, there is insufficient empirical evidence about patient participation in care at the individual patient level.

Published literature reveals that a wealth of research has examined the role preferences of patients, nurses and doctors (Spears, 1975; Citron, 1978; Pankratz & Pankratz; 1979, Brooking, 1986; Faden et al., 1987; Deber et al., 2007; Thompson, 2007). However, most

studies in examining preferences for patient participation have been undertaken within the context of distinct activities, such as: information exchange (Little et al., 2001), self-medication (Barlow et al., 1999), discharge planning (Kadushin & Kulys, 1991), goal setting (Janz et al., 1984), clinical audit (Kelson, 1996), clinical governance (Litva et al., 2009) and decision making (Cassileth et al., 1980; Vertinsky et al., 1984; Greenfield et al., 1985; Larsson et al., 1992; Thompson et al., 1992; Edwards & Elwyn, 2006; O'Donnell et al., 2007). Few have explored the course of patient participation in care from admission to discharge. Studies have also tended to be undertaken within specific contexts such as medical and primary care practice (Kendall, 1993; Agass et al., 1995; Elwyn, 1996; Elwyn et al.; 2000; 2001; 2003; 2004; 2005; Rycroft-Malone, 2002; Jones et al., 2004; Entwhistle et al., 2004; Hayward et al., 2006; Collins et al., 2007; Deber et al., 2007; S. Parsons et al., 2010; Eldh et al., 2010). Furthermore, most have been undertaken with patients experiencing long term illness, namely chronic hypertension (Strull et al., 1984; Beisecker, 1988), renal disease (Caress, 1997), cancer (Blanchard et al., 1988; Degner & Sloan, 1992; Evans et al., 2003; Beaver et al., 2005) and mental health disorders (Eisenthal et al., 1993; Eisenthal & Lazare, 1977; Sainio et al., 2001; Truman & Rein, 2002; Hack et al., 2006; Hui & Stickley, 2007). Most have also failed to acknowledge sufficiently the health care context in which participation occurs and the extent to which patient participation is influenced by the meanings and perceptions of those involved.

The eclectic nature of patient participation in nursing care has resulted in many nurses at the bedside having only a cursory understanding of what patient participation in nursing care means. Furthermore, it is clear that a diversity of opinions exist in the way both nurses and patients view the concept (S. Parsons et al., 2010). The lack of clarity associated with the concept has resulted in patient participation becoming a nursing rhetoric or cliché. Lewin et al. (2001) reported that the misconceptions about the meaning of patient participation generally have contributed to many negative reactions by health care professionals and patients alike. Henderson (1997) declared that the different orientations towards patient participation in nursing care have resulted in role confusion and conflict between nurses and patients. This in turn has contributed to inadequate patient-nurse communication and general patient-nurse dissatisfaction. Indeed the lack of any empirically grounded theory to explain the process of patient participation in nursing care, the failure to appreciate the nature of the concept and the lack of consensus regarding its meaning suggests that it is a modern day icon in need of closer examination. To maximise the benefit of collaborative relationships for individual patients and nurses the paradigm and practice of patient participation in nursing care needs to be based on sound scientific evidence, which does not have a monolithic viewpoint or technocratic bias.

Most studies that have examined the nature of patient participation in either medical or nursing care have also drawn on positivist epistemologies (Linn & Lewis, 1979; Strull et al., 1984; Brooking, 1986; Blanchard et al., 1988; Cassileth et al., 1980; Entwhistle et al., 2004; Brink-Muinen et al., 2006; Deber et al., 2007; Hamann et al., 2007; Eldh et al., 2008; 2010) and used structured data collection tools. Brooking (1986) acknowledged that structured data collection tools were not the best means to collect data about the complex concept of patient participation in nursing care. She, like many exponents of patient participation, advocated that a more qualitative approach was necessary and that the methodology for obtaining views and exploring actions, interactions and practices associated with patient participation in nursing care should be extended to include unstructured interviews (Martin et al., 1998), focus groups (McIver, 1991) and other forms of qualitative methodology (Judge & Solomon, 1993; Kendall, 1993; Williams, 1994; Collins et al., 2007; Coulter, 2011). Bugge and Jones (2007) suggested qualitative methods might be more appropriate for opening up a new field of study or identifying and conceptualising salient issues relating to patient participation in nursing care.

Some researchers have explored the concept of patient participation within the context of nursing practice using qualitative methods of inquiry however, most have been undertaken in the health care arena outside of the U.K. namely Australia (Henderson, 1997; 2002), Sweden, (Larsson et al., 2011; Sahlston et al., 2009), Finland (Timonen & Sihvonen, 2000) and New Zealand (Christensen, 1993). A few qualitative studies have examined the practice of patient participation within the context of nursing care in the U.K. However, most have explored only isolated components of patient participation, such as participation in the bedside handover (Cahill, 1998a – see Appendix 16 page 287 refers) and decision-making (Waterworth & Luker, 1990; Biley, 1992; Avis, 1994; Brooks, 2008), as opposed to the full complexity of participation in nursing care during the entirety of a patient's hospital stay. Few studies have explored the totality or course of patient participation in surgical nursing care specifically. How patient participation in surgical nursing care is established, developed and maintained from admission to discharge has not been investigated. Indeed studies that have examined the process of patient participation or assessed critically its relevance and application to a particular service such as surgical nursing practice are rare.

This gap in the literature is extraordinary when such an approach to care has been popularised through many government directives, most notably the NHS Plan (Department of Health, 2000). Since patient participation has over the last four decades been a dominant theme in health care policy in the U.K. an exploration of the definition, elements and processes associated with such an approach to care within the context of an acute surgical

care setting was deemed important. It was against this backdrop that an investigation of the nature of patient participation in nursing care during a period of acute illness was considered an area worthy of investigation.

Finally, the development and move towards evidence based practice and thus the need to reform clinical decision making and place it on a more solid footing also demanded that the underlying rationality of patient participation in surgical nursing care be determined. A study, which sought to explore the nature of patient participation in surgical nursing care, would enable nurses to make sense of, respond to and cope with such an everyday nursing practice. The plethora of patient participation activity within the N.H.S. also demanded that research, which describes the progress made in relation to the bringing of patient participation into the mainstream of NHS business, needed to be commissioned (Blaxter, 1994; N.H.S. Executive, 1996; Department of Health, 2003). Coulter (2011) maintained recently that such an inquiry is still a research priority since current and future strategic investment decisions are determined by the viewpoints of users of the service. Indeed the patient orientated developments in the N.H.S. and the associated tensions that continue to exist between nurses and patients demand that increasing attention be paid to the nature and application of patient participation in nursing care and the effectiveness of such an investment in order that the N.H.S. and nurses specifically can become more hospitable to such a policy and practice priority.

1.2　　　Professional Background of the Researcher

The researcher is a registered general nurse with 12 years clinical experience within the context of intensive care, medical and surgical nursing practice. Over the last 19 years, the researcher has held a number of positions within the nurse education arena and for the last eight years has worked specifically within the quality assurance and enhancement field. Whilst working in clinical practice the researcher developed a professional interest in patient participation in nursing care, which stemmed initially from the introduction of the bedside handover. Within the context of education, the researcher's interest in patient participation and the patient's role has continued as increasingly patients or users of the health care service are being involved in curriculum design, delivery and evaluation.

During the present study, the researcher assumed the role of clinical link lecturer (0.1 f.t.e.) for the surgical unit where the study was undertaken. This role did not involve practitioner duties but did involve supporting pre-registration students undergoing their surgical care experience. While supporting students during their surgical placement, the researcher

engaged with nursing staff within the surgical unit primarily in terms of preparing them for the role of mentor and/or practice assessor. The challenges associated with the 'joint role' will be explored further in Chapter 3 (Section 3.2.5.6 page 78 refers).

1.3   Intent of Study

1.3.1   Phase 1 (January 1996 to February 2006)

The broad purpose of Phase 1 of the study was to develop a theoretical analysis of the nature of patient participation in surgical nursing care. The aim was to elicit a grounded theory, a theory that is inductively derived from data obtained in the field, to describe and explain the process by which patients participate in their care within the context of an acute surgical care setting. Table 1 identifies the broad objectives for Phase 1 of the study.

Table 1   Broad Objectives for Phase 1 of the Study
- To ascertain what surgical patients understand by participation in care.   - To interpret the meaning that surgical patients give to participation in care.   - To describe and explain how patient participation is executed in the pre- and post-operative period.   - To describe how patient participation is established, facilitated and maintained   - To make explicit the outcomes or effect of patient participation in surgical nursing care.   - To identify and provide justification for the elements of participation with which patients express satisfaction/dissatisfaction.   - To illuminate the interpersonal skills and strategies that are/are not employed by nurses to facilitate effective patient participation in surgical nursing care, if it is so desired.   - To identify elements of patient participation where further research, practice and policy development is required.

Since the central purpose of using the grounded theory method is *discovery*, the objectives were sufficiently broad in nature to facilitate emergence, flexibility and freedom in the exploration of the phenomenon under study. Such openness was deemed essential for an investigation that was to capture and interpret all variation in patient participation actions and interactions. Objectives too well defined at the outset would have constrained and focused data collection and lead to a loss of sensitivity and openness to emerging theory.

The significance of flexibility and only loosely defining the boundaries of a grounded theory study at the outset was reinforced in the present study after only four patient interviews. The original intent was to explore the concept of patient *involvement* in care and make its conceptual meaning as explicit as possible. However, analysis of the emerging data revealed that the term *involvement* was elusive to patients. *Involvement* was a misnomer and not part of the vocabulary of many patients in the surgical care setting. Patients spontaneously substituted the term *involvement* with *participation*. Any action or interaction on their behalf was referred repeatedly to as *participatory* behaviour. *Participation* was a term used to describe all patient actions and interactions whether it was of a physical or intellectual nature. Accordingly, the concept of *patient participation* became the central focus of the present study. As Glaser and Strauss (1967) asserted, no tightly formed objectives should be formulated at the inception of an inquiry, as the focus will emerge when the researcher goes directly to the real world. They maintain that the intent should be to enter the field with no precise idea of what is to be studied until it emerges.

On the contrary, while a 'purist' would argue that in generating inductive theory the formulation of objectives at the commencement of a study should be avoided, reality dictated that some degree of focus was necessary to gain ethical approval, secure funding and lead the researcher to the phenomenon to be studied. As recommended by Glaser (1978) the broad objectives for Phase 1 of the study addressed <u>c</u>ause, <u>c</u>ontext, <u>c</u>ontingencies, <u>c</u>onsequences, <u>c</u>o-variances and <u>c</u>onditions. Glaser (1978) asserted that "if one is forced to preconceive data the use of theoretical codes such as the '6 Cs' gives the researcher something to say when he does not know anything about the data to be collected" (p. 73).

In the present study the '6 Cs' developed in me sensitivity to a range of potential determinants that might have an impact on the phenomenon of patient participation in surgical nursing care. They provided a useful framework whereby initial research questions could be generated that could give freedom and flexibility to the exploration in a way that would not exclude discovery nor inhibit emergence. However, caution was exercised in not being too reliant on the questions identified. Table 2 overleaf illustrates the original broad research questions for Phase 1 of the study that were generated from the '6 Cs coding family.

The Six Theoretical Codes (6 Cs)	Meaning Applied To Each Code	Initial Research Questions
Cause	Reasons or explanations for the occurrence of the phenomenon	• Do all patients want to participate in their nursing care in the pre and post-operative period, and if so why – if not why not? • What events, incidents or happenings (if any) lead to the occurrence/non-occurrence of patient participation in surgical nursing care?

Consequence	Results, outcomes or effects of phenomenon	• What are the actual or anticipated consequences of patient participation in surgical nursing care?
		• What is the impact (if any) of patient participation on
		   • The nurse-patient relationship?
		   • Health care communication/ behaviour?
		   • Patient outcome or experience?

Context	The effect of the social world of individuals engaging in the phenomenon understudy.	• What do individual patients understand by patient participation in surgical nursing care? • Do any events or incidents in the surgical care setting or the broader context of the world impinge on patient participation? • In what context does patient participation in nursing care occur/not occur?
Conditions	Instances under which the phenomenon occurs or does not occur.	• Under what conditions does patient participation in surgical nursing care occur/not occur and why? • How is patient participation in surgical nursing care facilitated?
Covariances	Explanations of the nature and extent of the relationship between variables.	• What is the nature of patient participation in nursing care – is the nature of patient participation related to any specific factor? • Is the extent of patient participation in surgical nursing care influenced by any particular factor?
Contingencies	Unanticipated or unplanned happenings that bring about a change in conditions.	• What contingencies (if any) impact upon patient participation in surgical nursing care? • What circumstances or events (if any) account for or contribute to a change in the nature of patient participation in a surgical care setting.

Table 2   The Six Cs and the Original Research Questions

1.3.2   Phase 2 (September 2009 to July 2012)

Owing to an unconnected necessary interruption to the study from February 2006 to September 2009, the theory that had emerged during Phase 1 of the study needed to be challenged for relevance and currency through further data collection and analysis and a critical review of the current literature. The specific objectives for Phase 2 of the study are presented in Table 3.

Table 3   Objectives for Phase 2 of the Study
• To evaluate the density and explanatory power of the original theory or more specifically its direct relevance to current clinical practice and the extent to which the original theoretical explanation explained variations and specificities in patient participation behaviour and interaction in modern day surgical nursing practice;
• to explore the potential impact of health care regulation and policy changes (Department of Health, 2007, 2009 and 2010,) and account for any potential conceptual variations that may have emerged as a result of policy amendments; and;
• to report the potential contribution that the emergent theory could make to the contemporary knowledge base of nursing, nursing practice, education and policy development.

The specific timeline for and features of each phase of the study are depicted in detail in Chapter 3 (Table 7 page 64 refers).

1.4   An Outline of the Thesis Chapters

The thesis is presented in seven inter-related chapters. The content of each of the proceeding chapters is summarised below.

Chapter 2 discusses how literature was used and searched in the present study. Previous scholarly literature and empirical studies are reviewed. The importance of the present study and how it will advance nursing knowledge is made explicit.

Chapter 3 provides an account of the design of the study and provides justification for the approach chosen. The process and strategies employed for the purpose of data collection are examined. A detailed account of the decisions made and the progression of events that emerged during the process of data collection is provided.

Chapter 4 describes the constant comparative method of analysis and seeks to explain how it was operationalised in the present study. The audit trail and particular challenges associated with the analytic process are made explicit.

Chapter 5 presents each of the three conceptual categories (*Establishing Readiness*, *Shaping Work* and *Incurring Rewards and Costs*) that emerged from the analytic process. Segments of raw data are used to illustrate how the emergent categories are grounded in the data.

Chapter 6 presents the theory that developed from the process of constant comparison. The theory labelled *Engaging in Nursing Care* is examined in detail. Literature is used to refute, enrich and provide authentication for the emergent theory.

Chapter 7 presents an overview of the contributions made to the advancement of knowledge and understanding. The implications of the findings for nursing practice, nurse education, policy development and future research enquiry are discussed. The extent to which the objectives of the study were achieved is also discussed.

CHAPTER 2   REVIEW OF THE LITERATURE

2.0   Overview of the Chapter

This chapter presents an overview of the research and scholarly literature surrounding patient participation in care. By way of introduction, the theoretical debate about how literature should be used in a grounded theory study is explored. Details are provided on how literature was approached in the present study to ensure that theory was systematically developed from the empirical data and the cognitive analytical practices employed. The search strategy and scope of the discursive literature review are discussed. As it was impossible at the outset of the study to predict how the emergent theory would relate to existing knowledge and understanding, specific literature that was reviewed and used as a source of data once the emergent theory was grounded sufficiently in a core category will also be discussed in Chapter 6.

2.1   Preconception vs. Theoretical Sensitivity

According to Glaser and Strauss (1967), unlike theory verifying and hypothesis testing studies, when discovering grounded theory no previous research is reviewed prior to data collection. This dictum is brought about by the concern not to "contaminate, constrain, inhibit, stifle or otherwise impede the researcher's effort to discover emergent concepts, hypothesis, properties and theoretical codes from the data that truly fit, are relevant and work" (Glaser, 1998, p. 68). Glaser & Strauss (1967) in their original work asserted that "it is hard enough to generate ones' own ideas without the rich detailment provided by the literature in the field" (p. 31).

The grounded theory method stresses discovery and theory development. Theory is derived inductively through systematic data collection and analysis. The goal is to generate a theory from raw data that accounts for a pattern of behaviour, which is relevant and faithful to the everyday realities of a substantive area. Theory is shaped from raw data rather than the literature or preconceived logically deduced theoretical structures.

The grounded theorist should be sufficiently theoretically sensitive in order that a theory can be conceptualised and generated as it emerges from the data. According to Bryant and Charmaz (2007), theoretical sensitivity is defined as the ability to see *relevant data* and ensure the emergence of categories is not contaminated. Glaser (1978) asserts it relates to the ability to have insight, understand and give meaning to data. It requires analytic temperament and competence to allow the researcher to maintain analytic distance from the

data and develop theoretical insights and abstract ideas from the data itself. Such sensitivity thus enables the researcher to capture subtle nuances of, and cues to, meaning in the data. It is about being mindful of the risks of tainting views from the field and hindering the development of categories (McCann & Clark 2003). A cautious and sceptical attitude towards the literature needs to be maintained throughout the research process and particularly at the inception of the research when the researcher can consciously or unconsciously close off analysis, shut down creativity or theory development and look for those variables, concepts and relationships identified in the literature.

In keeping with the spirit of symbolic interactioninsm (Blumer, 1969), the philosophical perspective which has a strong compatibility with grounded theory, emphasis needs to be placed on the empirical world, the actor's point of view and situational and contextual variables as opposed to preconceptions or presumptions gained from the literature. Glaser and Strauss (1967) in their original work posited that "an effective strategy is at first literally to ignore the literature of theory and fact on the area under study, in order to assure that the emergence of categories will not be contaminated by concepts more suited to different areas" (p. 37). Holton (2008) asserted that a pre-study literature review should always be avoided since it will inevitably lead to pre-judgement, the closing of ideas or the use of literary sources that are partially or wholly inaccurate or inappropriate. However, Glaser (2005) asserted the intention is not to overlook the literature completely but delay the discursive literature review until a fresh set of categories have developed that can be compared with concepts in the literature and placed in the study appropriately.

Of significance is that Strauss and Corbin (1990a) in their explication or reformulation of grounded theory encouraged the use of acquired knowledge from the literature "during all phases of the research process" (p. 56). They maintained that literature should be used before and during the study to stimulate theoretical sensitivity and questioning and direct theoretical sampling. They came to the position that researchers are unable to assume a naïve or atheoretical stance with regard to a phenomenon and that *a priori* theoretical commitments or literature reviews should not be suspended but used positively in the interpretative process. In the same vein, they asserted that a degree of detachment from the social world under investigation must also be maintained so as not to "block seeing what is significant in the data" (p. 95).

While a difference of opinion has evolved between the co-originators of the grounded theory approach in relation to when and how literature should be used in a grounded theory study, what remains important is that every effort be made to be true to the data and to develop an

end product of quality and use. Essentially the researcher's school of thought, which provides the conceptual roots for the categories to grow, is central to the development of a theory that is faithful to the empirical world. A level of theoretical sensitivity needs to be developed that enables the researcher to look beyond the literature and see with analytical depth what meaning the data have. Such sensitivity is developed through continual interaction with the data, possession of a sceptical disposition and use of the constant comparative method of data analysis discussed in Chapter 4. Sensitivity can however, also be achieved by being well grounded in the literature but not to the extent that literature contamination occurs. The forcing of data into preconceived categories must be kept to a minimum, as far as possible. Theoretical sensitivity or more specifically interpersonal perceptiveness, intellectual patience, courage and an ability to enter the research setting with as few predetermined ideas as possible are essential attributes required of a grounded theorist. They enable the researcher to minimise the impact of literature contamination and let theory emerge from the data at the proper time. However, difficulties abound in attempting to achieve the necessary level of theoretical sensitivity.

Acknowledging that a *tabula rasa* ideal cannot be applied to researchers examining their own area of professional practice and that objectivity is an epistemological ideal that can only be approximated, during the present study I made an attempt to remain 'grounded' in the field or achieve an appropriate level of theoretical sensitivity in a number of ways. I avoided a discursive review of the literature before starting the present study so as not to violate the basic premise of classic grounded theory that being that theory emerges from the data not the existing theory.

Delaying the discursive literature review at the outset enabled me to gain an in-depth understanding of the realities and issues at hand. It also prevented over-immersion in the literature and thus an uncritical accepting of other writers' discourse of meaning. I did however, have to conduct an initial literature search and broad preliminary review of the literature (Cahill, 1998b – see Appendix 17 page 296 refers) for the sole purpose of providing a sound rationale for employing the grounded theory approach and satisfying ethical reviewers. Writing for funding agencies and academic purposes also required me to demonstrate knowledge of the phenomenon under study and thus a concept analysis (Cahill, 1996) was undertaken. Both 'academic' activities focused on facets of patient participation in general. The intent was solely to situate the present study within the broader landscape of participation in health care practice. In spite of the strongly held view that a premature literature review can colour data analysis even luminaries such as Glaser (1998) warned that such demands are inevitable in the real world and that "fighting such requirements is most

often a useless waste of time" (p. 72). Indeed Glaser advised that "one should give them (referring to funding bodies) the forcing they want as preconception will be neutralised by what is generated" (p. 72).

In the present study, my allegiance to capturing reality and my desire not to stifle discovery resulted in literature not being reviewed in a comprehensive manner until the core category had emerged and was developed enough to accommodate other work through constant comparison. As Suddaby (2006) asserted, conceptual comparison to existing literature is vital however, relevant literature for this sole purpose can only be identified once the conceptual theory has emerged in the later stages of the research process. In the present study this point was reached after thirty-seven interviews with patients, the first 48 hour participant observation experience and eight interviews with nurses (for ease of understanding, the end of Phase 1 of the study). It was at this specific conceptual point I formulated a theoretical path detailing the emerging theory and was able to minimise the impact of literature contamination. Furthermore, it was at this stage in the collection and analysis of data that I needed to use literature as a data source for the purpose of clarification, verification and refinement of the emergent theory. As Annells (1996) asserted, literature carefully scrutinised at the right time helps to expand the theory and add completeness to the emergent theory.

Keen to be true to the substantive nature of grounded theory and stay open to informants' perceptions I made a serious effort to regard all practitioner, theoretical and empirical knowledge as provisional not fixed. I acknowledged, in self-reflective memos throughout the process of inquiry, personal and professional reflections and exposures to preconceptions, disciplinary perspectives and previous readings. I also made honest records about assumptions and premises from the literature and thus I was able to keep track on the impact of literature contamination. Indeed one of the major challenges I faced in the present study was to set aside, as much as possible, theoretical ideas and notions so that analytical substantive theory could emerge. As Christensen (1993) asserted, "the powerful voices speaking from the literature have to be considered with considerable caution" (p. 233). Indeed, it was only through self-awareness of mind-set that I was able to seek out and understand the world of patients and nurses.

2.2   Search Strategy and Scope of the Literature Review

2.2.1   Initial Literature Search and Broad Preliminary Review of the Literature

For the initial search and broad preliminary review of the literature the major nursing, medical, psychology, allied health and social science databases were searched for empirical studies and scholarly writing relating to the concept of patient participation. At the time of undertaking both activities it was not convention to maintain specific records relating to database searches consequently, details of the on-line searches I undertook and more specifically the parameters and number of citations I identified and screened during the search process cannot be provided.

2.2.2   The Stages of the Discursive Literature Review

Following the emergence of the core category, I revisited, extended and refined the broad preliminary literature review. Figure 1 overleaf depicts the flow of activity and outcome associated with the five stages of the discursive review process.

Figure 1   Flow of Activity and Outcome Associated with the Five Stages of the Discursive Literature Review Process

Stage 1
Development of Inclusion Criteria

Stage 2
On-line Database Searches (Total Hits 25,275)

Stage 3
Scanning of Database 'Hits' for Potential Inclusion on Basis of Relevance/Appropriateness (n=604)
114   studies using a Qualitative Approach
213   studies using a Quantitative Approach
36   Literature Reviews
187   Theoretical Discussions /Anecdotal Accounts
54   Government Reports/Policy

Stage 4
Application of Inclusion Criteria and Critical Review (n=263)
31   studies using Qualitative Approach
78   studies using Quantitative Approach
18   Literature Reviews
115   Theoretical Discussions /Anecdotal Accounts
21   Government Reports/Policy

Stage 5
Integration of Literature into Emergent Theory

Memo Writing

2.2.2.1 Stage 1 - Development of Inclusion Criteria

I made no *a priori* decision to exclude any study design from the discursive literature review. All study types were included and screened for their potential to contribute to the refinement of the emergent theory. The inclusion criteria I developed are outlined in Table 4.

Table 4   Inclusion Criteria for the Discursive Literature Review
Empirical and scholarly literature were included if one or more of the following criteria were met – namely that the literature: - explored the multi-faceted nature of patient participation in care and provided advanced understanding in terms of meaning, components, levels of participation and contexts in which such an approach to care was adopted or neglected;   - examined the expressed view of patients and health care professionals regarding patient participation in care;   - resulted in a comprehensive and sophisticated analysis of the concept;   - focused on the practice of patient participation and the experience of patient participation from the perspective of patients and health care professionals;   - explored the desired and achieved levels of individual patient participation in care;   - focused on professional responsibility and behaviour and the roles patients and health care professionals assume to engender and also restrict patient participation in care;   - evaluated the outcome of different forms and levels patient participation in care;   - measured concepts and activities associated with patient participation such as information exchange, decision making, patient enablement, verbal and communication rapport and control;   - focused on conceptual models of patient participation and interventions to promote forms of participation in care;   - explored contextual influences and the context-sensitive properties of participation and its interactive and dynamic form;   - provided robust evidence for the clarification and verification of the emergent theory and/or   - challenged the emergent theory.

2.2.2.2   Stage 2 - On-line Database Search

A summary of the outcome of the database searches that I performed during the process of conducting the discursive review is presented in Table 5.

Table 5 Database Searches for Literature		
Database	**Dates**	**Results (Total Hits)**
Cumulative Index to Nursing and Allied Health (CINAHL) Plus	1970 – 2012	8968
Medical Literature Analysis and Retrieval System Online (MEDLINE)	1970 – 2012	9132
PsycINFO	1970 – 2012	1301
Social Sciences Citation Index	1970 – 2012	2669
PubMed	1970 – 2012	1680
Applied Social Sciences Index and Abstracts (ASSIA)	1970 – 2012	1012

I also searched the website search engine Google and SIGLE to locate grey literature including theses, reports, fact sheets and conference proceedings and retrieved 417 publications. In addition, I searched government publications including bulletins and circulars on the Department of Health Website; http://www.dh.gov.uk and the website for the National Centre for Involvement in the UK, http://www.nhs_centreforinvolvement.nhs.uk prior to it becoming non-operational on the 31st August 2009. From these two specific searches, 96 publications were retrieved.

Since patient participation is a modern day term that is conceptually similar and often used interchangeably with keywords such as client, user and customer involvement, collaboration, engagement, consultation and partnership, in the online searches I conducted, I used a combination of keywords. I employed different permutations to identify the combination of terms that were most sensitive to each database. The use of analogous terms and the distinct lack of consensus concerning the meaning of the term patient participation made the search using computerised databases very challenging. Patient participation was not always used as a key term within the title or abstract of any study.

Searches were limited to publication dates ranging from 1970 to 2012. Empirical and scholarly literature were searched over the last 42 years as the concept emerged as a topic for debate in the late 1970's. The adoption of patient participation in care was most

pronounced during the 1980's when the government recommended that views and wishes of consumers should be taken into account when planning and delivering health services (Department of Health, 1989). At the same time, patient participation was placed high on the nursing agenda with the emergence of a new nursing philosophy, which sought movement away from biomedical domination towards patient centred care (Beardshaw & Robinson, 1990). Consequently, I felt that an in-depth review of the literature from 1970 to the present day had the potential to make a significant contribution to the present study.

I did not review literature prior to 1970 as essentially prior to this date a paternalistic approach to patient care was adopted. In the main, the accepted assumption prior to 1970 was that illness could only be effectively diagnosed and treated by expert professionals. Patients were regarded as passive recipients of care and decisions regarding their care were the domain of the professional (Roberts & Krouse, 1990). I did however review some earlier work such as that of T. Parsons (1957) and Szsaz and Hollander (1956) owing to its seminal nature and frequent citation by a number of authors.

Searches were not restricted exclusively to U.K. literature as patient participation in health care is not just a U.K. initiative. Patient participation in health care has been reported as a growth area in Europe (Saltman & Figueras, 1998), the United States of America (USA) (Lagoe et al., 2005), Canada, Germany, Australia and New Zealand (Coulter, 2006). However, owing to the lack of translation facilities my searches were limited by language of publication. I included literature if it was published in English.

2.2.2.3   Stage 3 - Scanning of Database 'Hits' for Potential Inclusion

The scanning of the 'hits' generated from the database searches (n=25,275) resulted in 604 publications being retrieved on the basis of potential relevance and appropriateness to the broad aim of the present study and most importantly the emergent theory. During this stage of the discursive review process the inclusion criteria identified in Table 4 were not applied, as there was a need to adopt a pragmatic approach and assemble a more manageable dataset while at the same time being mindful of the need to conduct a thorough search to identify and retrieve relevant literature. No study was excluded on the basis of design and no particular informant population was disqualified. Empirical and scholarly literature were scrutinised and included if the focus was on direct, individualised patient participation in care within the context of any health care setting. More specifically, if the focus was on participation at a strategic level for example the study related to patient participation in health care policy and purchasing, service design and development or it related to collective

participation such as the work of patient support groups I excluded such literature from the review. I also excluded publications which focused on the more formal arrangements of patient participation such as work associated with state sponsored arrangements like Community Health Councils and Patient Forums although there was a need to extract from this dataset how patient participation evolved within the context of health care practice. This initial screening process enabled me to retrieve a dataset that was manageable and directly relevant to the present study.

2.2.2.4   Stage 4 - Application of Inclusion Criteria and Critical Review

During this stage of the discursive review process, I applied the inclusion criteria identified in Table 4 to the dataset assembled from the potential inclusion list. Two hundred and sixty three (263) publications formed the basis of the final dataset, which will be discussed in this Chapter and Chapter 6.

2.2.2.5   Stage 5 - Organising References and Integration into Emergent Theory

As illustrated in Figure 1 (page 15 refers) memo writing was an activity that pervaded all stages of the discursive literature review process. The development of a memo bank in the course of the review resulted in relevant literature being woven into the analysis and contributed to a richer more complete theory. As literature informed memo development, my memos grew in complexity and abstraction. The activity of memoing discussed in more detail in Chapter 4 (Section 4.1.1.2 page 104 refers) was highly motivating as it enabled me to make explicit the contribution of the emergent theory to existing knowledge and practice.

2. 3   The Literature Reviewed

2.3.1   Defining Patient Participation

The Oxford English Dictionary (2012) states that the word participation is derived from the Latin *participate* which means to take part in (part = part and capare = to take). According to Sinclair (1993), participation relates to the act of participating, which implies that one becomes actively involved in, or shares in the nature of something with others. Brownlea (1987) contended that participation means "getting involved or being allowed to become involved in the decision making process or the delivery of a service or the evaluation of a service or even simply to become one of a number of people consulted on an issue or matter" (p. 605). Although these early definitions have the advantage of brevity, they do not embrace the complexity of participation within the context of contemporary nursing practice. They neglect to consider that participation is dynamic in nature, waxes, and wanes in

synchrony with a number of factors such as an individual's desire to participate in their care, illness type and severity, resource availability and the existence of infrastructures to promote patient participation.

In general, patient participation at an individual level suffers from lack of clarity. Definitions are limited, diverse and even ambiguous in terms of action, interaction and intention. It would also appear that there is no consensus on what patient participation at an individual level means or how far it should extend. No single term comprehensively describes this movement, which is so widespread at present. Despite the general failure to describe sufficiently the parameters of patient participation at an individual level, some movement towards explaining the intricate, multi-dimensional nature of patient participation has been achieved. According to McEwen et al. (1993), patient participation in health care relates to:

> "The activities performed by an individual in the maintenance and promotion of health, the prevention of disease, the detection, treatment and care of illness and the restoration of health, or, if recovery is not possible, adaptation to continuing disability" (p. 2).

Although McEwen's definition lacks currency and it can be criticised for its lack of explicit detail about how an individual participates in their care, it does acknowledge that patient participation is an active process that can be achieved in many health care contexts. In a covert manner, it also implies that participation involves the adoption of a non-directive approach to care, whereby nurses or health care professionals give patients greater choice and freedom. Implicit in the definition is also the requirement to address traditional power relations and refine professional boundaries. If patient participation as described by McEwen is to be effective, it inevitably calls for changed health care relationships. There needs to be a move towards care being more patient centred or consensual in nature as opposed to paternalistic or expert directed. The patient must no longer be viewed as the passive client as suggested by T. Parsons (1957) but more the active consumer.

Although serious attempts to capture the intricacy and subtleties of patient participation have been made, the nature of patient participation remains obscure. Most definitions or analyses present a theoretical, static or invalidated view of the concept with little if any attention being paid to context or the empirical world, a view supported by Christensen (1993); Henderson (1997) and Coulter (2011).

The term participation within the context of nursing practice is frequently used with little precision or is unconsciously buried in innocuous euphemisms such as involvement,

consultation, collaboration and partnership (Cahill, 1996; 1998b, Elwyn et al., 2000; Larsson et al., 2007; Sahlsten et al., 2008). While each term shares some underlying principles such as ethical commitment to respecting people and an attempt to acknowledge individuals' capacity for autonomy, there is little agreement on appropriate usage. According to Collins et al. (2007) in an extensive collaborative project on patient participation, drawing on the perspectives of patients, professionals and academics the conceptualisation of patient participation in most contexts is poorly developed and ambiguities with respect to the concept abound.

2.3.2   Conceptual Models of Participation

Many of the classic models of participation (Arnstein, 1969; Feingold, 1977; Office of Public Management, 1992; Charles & Demaio, 1993; Skelcher, 1993; Taylor, 1995) and the more recent conceptualisations in the health care arena (Cahill, 1996; Hibbard et al., 2010; Henderson, 2002; Entwhistle and Watt, 2006; Thompson, 2007; Centre for Advancing Health, 2010; Gruman et al., 2010) have described the nature of participation as being developmental and comprising of discrete levels of activity. Pre-existing models in the main describe and assume that participation should be a continuum, which is often hierarchical in nature. Control has been prescribed by most as being the ultimate goal of participation with non-achievement of full control implying automatic failure of the participatory process, even though those engaged may be content with whatever level has been attained.

The seminal work of Arnstein (1969) identified a typology of eight levels of participation. The typology is presented in the form of a ladder with each rung of participation corresponding to the extent of power and influence involved. Figure 2 delineates the eight rungs of Arnstein's ladder.

Figure 2   Arnstein's (1969) Ladder of Participation

8	**Citizen Control**	
7	**Delegated Power**	*Degrees of citizen power*
6	**Partnership**	
5	**Placation**	
4	**Consultation**	*Degrees of tokenism*
3	**Informing**	
2	**Therapy**	
1	**Manipulation**	*Non-participation*
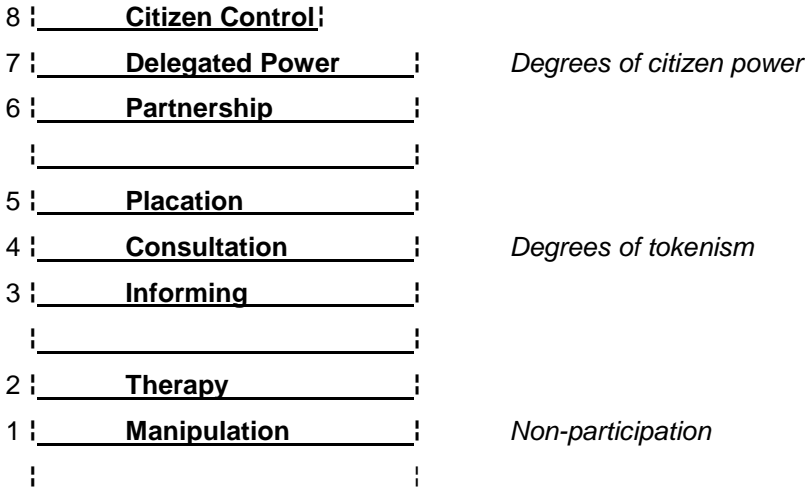
The bottom two rungs of the ladder are manipulation and therapy, which are classified as levels of non-participation. They are exercises designed to ensure a feel-good factor, giving people a voice as a way of making them feel involved, improving their skills in working together or ensuring their compliance. This level of participation involves little commitment to, or possibilities for, real influence. Rungs three and four progress to levels of tokenism that allow the 'have-nots' to have a voice. The participants are asked to identify their needs and preferences but those in power reserve what they see as their right to decide on strategy and policy. The third rung on the ladder is specifically about information giving, with the power to define what information will remain in the hands of the instigators of the exercise. The fourth rung consultation, which seeks to listen to the views of participants before decisions are made, is a further move up the ladder particularly if accompanied by a commitment to act on the views expressed. Rung five, placation is the next step, offering a very limited role for participation within a much wider area of decision making. The higher rungs of the ladder, partnership, delegated power and citizen control identify forms of participatory activity in which participants have greater power, where there is a commitment to on-going activity and where a developmental approach exists to integrate the views of participants fully within the wider decision making process.

Arnstein's model although essentially a prototype for consumer participation in the business arena provides a useful framework for understanding patient participation in health care. The emphasis on an incremental approach and thus the need for long-term commitment is a strength of the model. However, in assessing the contemporary relevance of the model it can be criticised for its oversimplification, the lack of a sharp distinction between the rungs of the ladder, the general failure to emphasize the significance of context and capture the role of professional expertise within the participatory process and the underlying assumption that consultation equates with tokenism. Tritter and McCallum (2006) asserted that Arnstein's model treats participation too simplistically as the linear conceptualisation does little to emphasise the importance of process and the total participatory experience. They also contended that it neglects to consider the complex relationships that exist in many participatory situations. Furthermore, it is clear within the current health care climate that consultation is also not always tokenistic. Finally, while it may be relatively easy for an organisation such as the health service to involve patients to a level of consultation, placation, partnership, delegated power and citizen control demands a culture change that values patients' views over the providers. For such a change to be accepted by all concerned it would need to be engineered incrementally and very slowly to be successful. As Collins and Ison (2009) pointed out this serves as a reminder that models of the consumer that are

appropriate to the business context might not translate too easily to the area of human service delivery.

Some useful models of patient participation have been developed in the context of health care. However, most have only focused on discrete behaviours expected of 'engaged' patients from the perspective of the health care professional rather than process and the considerations of *both* patient and health care professional (Hibbard et al., 2005; Centre for Advancing Health Care, 2010). In the main, they have also been developed within specific contexts such as primary care and in health care settings in the United States. To place reliance on such findings is not without difficulty due to the differences in health care infrastructures and policy. Indeed Coulter (2006) using data from surveys carried out in six countries including the U.K. reported that international comparisons in respect of any element of patient participation are fraught with difficulties owing to the subtle differences in health care systems and processes.

2.3.3 Substantive Theories related to Participation

In the same way that no one conceptual model of participation was found to focus solely on the *process and totality* of patient participation at an individual level in the acute surgical care context, no empirically grounded substantive theory was located that provided an abstract construction of patient participation within the context of surgical nursing care. No one theory was sufficiently generalisable or of a level of conceptualisation that could describe and account for how patients might participate in their nursing care within the acute surgical care setting. The underlying assumptions associated with several theories do however, offer some description and explanation for participatory behaviour within the context of health care in general.

2.3.3.1 Engagement Theories

Engagement theories developed initially in the education arena were found to provide a conceptual view of participation within the context of learning and teaching which could account for aspects of participatory action and interaction in the health care environment. Engagement theory (Astin, 1985; 1999; London et al., 2007; Pike & Kuh, 2005; Kearsley & Schneiderman, 2011) depicts participation as a process that demands investment, motivation, commitment, preparation, competence, psychological connections, comfort, a sense of belonging and an environment characterised by interpersonal cohesion and support. However, the description of process and the situational and individual factors that influence engagement in education are naturally different from those in the health care context.

Although arguments exist to support the use of 'borrowed theories' to improve patient outcome (Fawcett, 1989; McCrae, 2011) owing to the low level of conceptualisation of engagement theories within the context of teaching and learning and the complexities inherent in the surgical care environment it would be unacceptable for nurses to use a theory which although based on extensive experience in an educational setting has not been subjected to any empirical test in the health care milieu. For application in everyday practice a more credible theory that provides a comprehensive, rational and systematic approach to patient participation is needed, one founded on the expressed views and observable practices of both patients and nurses and one which is context-sensitive and open to the changing forms of participation as opposed to a series of discrete episodes in a safe monitored environment.

2.3.3.2   Theory of Interpersonal Relations in Nursing

Within the discipline of nursing, it could be argued that some of the tenets of Peplau's theory of interpersonal relations (Peplau, 1988) could contribute to a broader conceptual understanding of patient participation. The interpersonal focus of Peplau's theory requires that the nurse attend to the interpersonal processes that occur between the patient and the nurse rather than the patient being the sole unit of attention. Interpersonal processes include; the nurse-patient relationship, communication, integration and the role to be assumed by both patient and nurse. Peplau identified the nurse-patient relationship as the crux of nursing. The relationship evolves through identifiable, overlapping phases and is not a simple linear process.

Features of Peplau's (1988) conceptualisation of the nurse-patient relationship could explain how patient participation may be promoted and maintained. An effective relationship in the case of Peplau's theory demands that the patient and the nurse know each other, work through preconceptions, begin to understand each other's roles and establish parameters associated with role. Peplau also postulated that an element of trust in the relationship is vital and that competencies need to be developed through the evolving relationship. Features such as trust and the need for an effective relationship are comparable with antecedents of patient participation identified by Brearley (1990), Cahill (1996), Gallant et al. (2002) and Henderson (2002). The development of a collaborative relationship with patients based on trust has been found to be a core value of patient centred care especially when the aim is to bring the patient's voice into the planning and delivery of health care (Speedling & Rose, 1985, Safety Net Medical Home Initiative, 2010, and Alimo-Metcalfe et al., 2011).

In summary, although the principles associated with Peplau's work do provide direction for how patient participation may be enacted in the sphere of nursing, caution does need to be exercised in applying the theory to all areas of practice. The theory is adaptable only to nursing settings in which communication can occur between the patient and the nurse and where interpersonal skills are highly developed. The theory's use is limited in working with patients such as those that are comatose, acutely ill or senile. As Mohr (2008), asserted further empirical investigation is needed to support the application of Peplau's theory in practice settings beyond those of mental health. Since the theory was also based on the assumption that nurses did not have abbreviated interactive time with the patient, relationship building as proposed by Peplau is challenging. Finally, the major limitation associated with Peplau's theory is its narrow perception of society and the environment; a view supported my many (George, 1990; Simpson, 1991; Tomey & Alligood, 2002; McCamant, 2006). The theory does not examine the broad environmental influences on the nurse-patient relationship and determinants such as ward climate and financial resources, forces critical to nursing practice today are disregarded.

A comprehensive exposition of the importance of developing a positive, trusting and collaborative relationship with patients within the context of participation specifically self-management, was made explicit by Wilson et al. (2007). Wilson et al. described the essence of self-management as being the interaction between the patient and the nurse. They described, albeit in the context of chronic illness, how the quality and characteristics of the nurse-patient relationship can serve as a real tension and may be the greatest inhibitor of patient participation. Sahlston et al. (2009) also reported on the significance of the nurse-patient relationship in stimulating and optimising patient participation. Adopting a qualitative research approach interviewing a sample of 16 nurses working on an inpatient ward providing somatic care in Sweden Sahlston et al. found that critical to the success of patient participation in nursing care was the need to "build close cooperation" (p. 493). A close cooperation was established through showing respect, courage and genuine interest. More specifically, Sahlston found that nurses predicated the establishment of patient participation on an acknowledgement that the information held by patients constituted a valid form of knowledge for shaping nursing practice.

Larsson et al. (2011) in another qualitative study (n=26) examining patients' perspectives of barriers to participation in nursing care in Sweden reported similar findings to that of Sahlston. Larsson et al. found that where nurses displayed a lack of interest and insensitivity, failed to appreciate the contribution patients could make, or the patient saw "new faces all the time" (p. 579) and did not have absolute trust in their nurse a positive relationship did not

develop. Such conditions in turn were identified as barriers to participation. The ability of a nurse to instil confidence and trust in the nurse-patient relationship was deemed essential to participatory success, a view reinforced by Kraetschmer et al. (2004) and Collins et al. (2007) who both found that a patient's trust in the health care professional influenced whether and how the patient participated in their care to the level that they desired. Of interest was that the pivotal work of Sahlston and Larsson did not address the concept of trust from a nurse's perspective. Both affirmed the importance of patients having trust in their nurse but no attention was placed on the whether the nurse needed to trust the patient.

2.3.3.3   The Self-Care Deficit Theory

The philosophical view of patient participation that all patients have a right and responsibility to participate in their nursing care can be aligned with Orem's (1991) self-care deficit theory of nursing, which based on citations in the literature, is one of the most used theories in nursing (Alligood, 2002). The basic premise underpinning Orem's theory is that all individuals have the potential to develop intellectual and practical skills to engage in self-care placing a responsibility on the individual wherever possible, to participate in their own care. According to Orem (1991) nurses and patients should "act together to allocate roles for each other in the production of patient's self-care and in the regulation of patients self-care capabilities" (p. 38). In essence, Orem believed that the function of the nurse was to act on behalf of another who is unable to perform specific health care tasks but at the same time assume responsibility for encouraging patients to participate in their care, if able. As identified by Fawcett (1989) Orem's conceptualisation focused on value judgments and rationale decision making but neglected to consider that a patient's ability to take deliberate self-care action can be interfered with by factors such as a patient's expectations of nursing goals during times of illness, emotional reactions, the failure to recognise the need for help, irrational aspects of a patient's behaviour and contextual information. Orem assumed that all individuals have the ability to make choices. The theory itself also lacks empirical grounding. Despite the comprehensive nature of the theory and widespread application, it has a limited empirical base. There has been limited reliability and validity testing of the theory therefore the theoretical base requires further development. Indeed few empirical studies have examined the theory in sufficient detail (Timmins, 2005).

Clearly, the lack of conceptual models and empirically grounded theories to guide practice associated with the process of patient participation in surgical nursing care is unfortunate as there is a danger that the debate regarding what patient participation means will remain at the level of rhetoric, a view supported by Trnobranski (1994). If nurses are to resolve to

enable patients to participate in their nursing care there is a need to achieve greater understanding of the nature of the concept and for nurses and patients alike to become educated about future roles in health care. In an attempt to explain patient participation in nursing care Jewell (2004), in an ethnographic study, interviewed four registered nurses from two elderly care wards to ascertain how patient participation was achieved within the context of a ward setting. Although the study provided a valuable emic perspective from those who considered patient participation as part of their practice, no effort was made to observe practice. Therefore, although Jewell reported that patient participation in nursing care means involvement of the patient in clinical practice and decision making via the formal structure of the nursing process or informally through on-going nurse-patient exchange, the interviews only allowed nurses' accounts of how patient participation was achieved to be considered. The relationship between nurses' views and behaviour was also not examined thus, no firm conclusions can be drawn with confidence. Furthermore, as no contextual details were provided, the only conclusion that can be drawn is that further investigation is required for conceptual clarification. A comparative study with a larger sample using a combination of data collection methods such as the interviews and observation might be beneficial, as verbal accounts could be validated accurately. Indeed, such a study would be of extreme value as retrospective verbal accounts regarding patient participation in nursing care often bear little resemblance to nursing as practised on the ward (Brooking, 1986; Glenister, 1994; Sahlston et al., 2007).

Christensen's (1993) conceptualisation of the giving and receiving of nursing does however make a significant contribution to the development of knowledge about nursing partnerships and by inference patient participation. Christensen presented a model, which was developed in the context of acute care in five surgical wards in a large teaching hospital in New Zealand. The model focused on the partnership between the provider and consumer of nursing care and how both work together through a health-related experience. Christensen's creative induction using grounded theory highlighted the working partnership and the complex contextual determinants, which contribute or act as a barrier to the development of an alliance between the patient and the nurse. The findings which emerged from data collected from patients (n=21) and nurses (n=87), the observation of 128 specific incidents and nursing documentation described the process that patients and nurses engage in from the point of entry to hospital until discharge. The pattern of work to be performed by both patient and nurse was also made explicit. The analysis also depicted the specific contextual determinants within the nursing situation, which influence the nature of the partnership as it is experienced by both patient and nurse. However, since Christensen's work was undertaken in New Zealand specific cultural and social factors would need to be explored to ascertain if

they had any impact on the findings. Before the theory could be used to guide nursing care within another context further research would need to be undertaken to establish if patient and nurse preferences and practices relating to patient participation in New Zealand were genuine or merely a learned response influenced by cultural attitudes, the health care system and/or the system of nurse education.

In essence, patient participation in care as defined in the literature encompasses many different and wide-ranging phenomena and so the conceptual meaning and nature of the concept remains unclear. Indeed, the literature appears to suggest that patient participation is one of nursing's most nebulous concepts. There is little consensus among health care professionals and indeed nurses about what patient participation is, what form it should take, how far it should extend and how interested parties should implement it. The prevalence and overuse of the term, the failure to appreciate the nature of the concept, and the lack of consensus regarding meaning suggest that it is a modern day icon in need of closer examination. The intention of the present study was to undertake a closer examination and discover the meaning and nature of patient participation within the surgical care setting.

2.3.4   The Evolution of Patient Participation

Historically, the patient's role consisted primarily of co-operating with those professionals who were deemed to have superior knowledge and special skills. The concept of the sick role developed by T. Parsons (1957) institutionalised the asymmetric power dynamics inherent in the professional-patient relationship. To T. Parsons the key to therapeutic clinical practice was the essential asymmetrical relationship that existed between the patient and the health care professional and the obligation of the patient to abdicate all responsibilities. He viewed being sick as a state in which patients were granted certain privileges including "exemption from responsibility for one's own state of health" (p. 7). Despite professional control being fashionable at the time, Parson's sociological conceptualisation of the patient role was not without criticism. Although it provided a helpful description and explanation of normative behaviours and actions during illness, when considered from an interactionist perspective, the characterisation of the patient and physician role stimulated considerable controversy among researchers with interests in medicine as a profession (Friedson, 1970).

Parson's depiction of the patient role did not account for wide variations in individual behaviour and thus did not capture the subtleties of everyday interaction. Situational and contextual variables were not considered. According to Murray (1998), T. Parsons was nothing more than an armchair theorist. Speaking from an interactionist perspective Blumer

(1969) asserted that one cannot be too prescriptive about the sick role or illness experience as a role is discovered, created, modified and defined within a given interaction. The interactionist view presupposes a diversity of sick role behaviours and diversity in central conditions that may affect sick role behaviours. It incorporates perceptions, reciprocation, motivation, communication and social circumstances and is thus dynamic and multidimensional in nature. According to Berkanovic (1972), Becker (1974) and Levine & Kozlok (1978), the standardised behaviours and one ideal-type of professional-patient relationship proposed by T.Parsons are not empirical entities as individuals vary in their perceptions and interpretation of symptoms and thus identify and enact an array of sick roles.

The influential work of Szasz and Hollender (1956) proposed an alternative to Parson's sick role model. They defined three modes of interaction, which had relevance for all health professional-patient relationships; Activity-Passivity, Guidance-Co-operation and Mutual Participation. In the Activity-Passivity relationship, the oldest conceptual model, the patient is completely helpless and passive and the physician active. Treatment takes place irrespective of the patient's contribution and regardless of the outcome. In the second type of relationship, the Guidance-Co-operation relationship, the most predominant model in medical practice both persons are active in that they contribute to the relationship. The main difference between the two participants pertains to power and to its actual or potential use. The patient can exercise judgement but is expected to look up to the physician and obey orders, thus fulfilling the Parsonian sick role. The third type of relationship, Mutual Participation, which in an evolutionary sense is more highly developed than the other two forms of health care relationship, is predicated on the postulate that equality among human beings is desirable. Crucial to this type of interaction is that the participants have approximately equal power, are mutually interdependent and engage in activity that will in some way be satisfying to both. Essentially the physician helps patients to help themselves.

Although Szasz and Hollender's model was helpfully descriptive and, unlike that of the Parsonian sociological model, recognised that variant sets of interactions exist in actual encounters between the professional and the patient, it was limited in terms of its focus and explanatory power. The exclusion of the consideration of a number of variables such as patient preferences, the interpersonal style of both participants and differing cultural values about illness draws into question the idealism and empirical relevance of the model. According to Friedson (1970), the formulation is incomplete. He maintained that two other patterns are required to complete the continuum, one which the patient guides and the professional co-operates and one in which the patient is active and the professional passive. Brearley (1990) advocated that the spectrum of patient participation needed also to include a

pattern of participation whereby the patient functions alone, without professional support. However, logically this would not be regarded as a model of interaction or participation. It would merely serve to emphasise that patients can manage health care problems themselves.

The establishment of the NHS in 1948 represented a new health care contract between the health care provider and the patient. However, the pivotal role of doctors in the management of the NHS through their membership of health boards and their ability to define appropriate health care continued to result in overt resistance of the professional culture to active patient participation (Williamson, 1999). The institutional development of the NHS served to control and reinforce the unequal power relationship between health care providers and patients.

The birth of community organisations at the beginning of the 1960's, voluntary organisations, and user groups in the early 1970's began to challenge medical domination although mainly within the context of specific illnesses and diseases (Ottewill & Wall, 1990). One of the major objectives of the 1974 reorganisation was to provide greater opportunity for the public to participate in the affairs of the NHS. Community Health Councils were thus established in each district health authority with the brief to represent consumer interest. However, the extent of public or patient participation provided by this initiative was limited, and at best ambiguous. Problems arose with constitution, funding arrangements, sectional interests of particular groups of service users and the ability to access information and act as agents to the public (Pritchard, 1979; Klein, 1989; Shackely & Ryan, 1994; Spink, 2006).

The debate about patient participation in health care gained further momentum during the late 1980's and 1990's. The reasons for this ground swell are many and varied, but the turning point, was undoubtedly the reforms of the health service between 1989 and 1999, most notably Working for Patients (Department of Health, 1989). In 1996, the Government launched the Patient Partnership Strategy (NHS Executive, 1996) which explicitly recognised the need for patient participation in decisions about their own care. The expected benefits were laid out in Patient and Public Involvement in the New NHS (Department of Health, 2003) and included improvements in service quality, care outcomes and population health.

More recently the drive and espoused commitment to patient participation has emanated from the strategic NHS Plan (Department of Health, 2000) and further government directives (Department of Health, 2001; 2002; 2003; 2004; 2005; 2006; 2007; 2008; 2009; 2010; 2011; National Health Service Confederation, 2010). Emphasis has been placed on the need for a health service responsive to the needs of patients, lay carers and the public, expecting those

on the receiving end of care to take an active role. The notable increase in lay knowledge in health care and the steady growth of information and more recently the use of the Internet (Eysenbach, 2003) alongside scandals and negative media reporting has also fuelled an increase in stakeholder engagement. Better opportunities for patient participation in health care were key recommendations of the critical Bristol Royal Infirmary Inquiry Report (UK Parliament, 2001a). Subsequently, the Health and Social Care Act (UK Parliament, 2001b) made it a legal requirement to involve patients and the public in health care provision. More recently the Mid Staffordshire NHS Foundation Trust Inquiry Report (2010) and the Winterbourne Review (Care Quality Commission, 2010) have bolstered the need to strengthen again the patient voice. Furthermore, the underlying principles of the new Health and Social Care Bill (Department of Health, 2011) are that there is a need to engage further with people and develop a health care system that is grounded in systematic patient participation to the extent that shared decision making at all levels is the norm.

Undeniably, the entry of the consumerist ethos into the British health care system has led to patients participating more in the provision of nursing care. Empirical evidence confirms a move away from the assumption that patients are passive recipients of care and that a paternalistic approach to care exists (Spink, 2006). However, the extent to which the consumerist culture of the NHS has stimulated patient participation in nursing care in the current day remains to be clarified. Lathlean et al. (2006) and Coulter (2006) reported that widespread professional commitment to the fundamental philosophical need for patient participation initiatives to be implemented is still not apparent. Indeed, there is much evidence to indicate that there is an obvious disparity between the government policy and the pragmatics of practice in general (Strickley, 2006; Coulter, 2011). From a U.K. perspective, Coulter (2006) reported that in comparison with Australia, New Zealand, Germany, the USA and Canada the U.K. performed worse than all of the other countries on health care participation indicators such as decision making despite all the political rhetoric. It is certainly the case that at a political level individual members of the public are increasingly encouraged to see themselves as active participants or consumers rather than passive recipients of care. However, it is possible that progress is much slower than perceived by health care professionals, managers and patients alike. Eldh et al. (2008) in a survey of patients (n=900) recently admitted to an acute care hospital for adults with somatic disorders found that despite attempts being made to enable people to participate in their care most patients experienced a very circumscribed form of participation. A lack of information and recognition of patients by health care professionals were found to contribute to such a confined role. However, although the survey contributes to an understanding of the progress being made in relation to patient participation in health care the study is limited, as the questionnaire with

descriptions presented of non-participation did not make explicit to patients whether the survey was examining patients perceptions of participation or their recent experience in hospital. The study was also confined to one acute care hospital in Sweden therefore given the importance of context in promoting patient participation it is hard to gauge whether the findings can be generalised to health care settings in the U.K.

In summary, it is evident that progress in respect of patient participation is being made where it is desired although progress is slow owing primarily to the influence of a professionally dominated health service culture. The present study sought to determine whether patient participation in nursing care has become a reality within the context of a surgical care environment. Since government policy now recommends that NHS organisations should encourage patients to participate in all levels of health care the intent of the study was to explore what roles actual patients want to assume and examine in-depth the extent to which individual patients actually participate in their care throughout both the pre- and post-operative period. In modern surgical practice, interventions may be classified as elective, essential or emergency. Operative procedures vary greatly ranging from the quite simple and uncomplicated, taking only a brief period, to a prolonged, complex major procedure that has severe traumatic effects. Surgical nurses thus work in a dynamic and challenging environment. Surgical nursing care is also continually evolving and becoming increasingly technologically sophisticated. Advances in surgical technology and anaesthesiology have allowed previously lengthy operations to be completed more quickly and recovery times have become shorter. Many procedures are now undertaken using laparoscopic, robotic and key hole surgery thus the length of time patients now spend in hospital preparing for, and recovering from surgery has greatly reduced (Mitchell, 2007). Improvements in anaesthesia techniques, such as regional anaesthesia and short acting drugs with minimal side effects allow larger number of patients to be ready for discharge in a matter of hours or days. This presents a challenge to the implementation of patient participation at the bedside within the surgical care context. Nurses need a repertoire of skills to foster patient participation when keeping patients in hospital beyond the acute phase of recovery is rare.

On the contrary, the significant technological, procedural and pharmacological advances has resulted in critically ill patients with complex needs previously cared for in intensive or high dependency wards having a presence on general surgical wards (Brooker & Nicol 2011). The increasing sophistication of care alongside the changing demographic profile of the surgical patient, namely more older adults presenting for surgery with often reduced physical reserves (McArthur-Rousser and Prosser 2008) and the rapidly changing climate of the surgical ward has resulted in surgical nurses being increasingly challenged to promote

patient participation in contemporary surgical nursing practice. To promote patient participation in surgical nursing care, which according to Wright et al. (2009) is critical to successful recovery, is indeed not without complication and is therefore an area worthy of in-depth exploration.

2.3.5   The Patient's Perspective

Studies addressing the patient's perspective of the nature, desirability and value of patient participation in the context of health or nursing care have in the main focused on discrete aspects of patient participation such as patient safety (Monash Institute of Health Services Research, 2008), clinical audit (Kelson, 1996), self-medication (Webb et al., 1990) decision making (Cassileth et al., 1980; Vertinsky et al., 1984; Thompson et al., 1992) and more recently health care planning and prioritisation (Cook & Klein, 2005), clinical governance (Litva et al., 2009), commissioning and service improvement (Coulter, 2011) and nurse-patient interactions (Rycroft-Malone, 2002; Jangland et al., 2010)

Few studies have focussed on the natural history or totality of patient participation in nursing care from admission to discharge and few have been undertaken in an acute surgical care setting. Principally, previous studies have been undertaken within the context of medicine, primary care (Collins et al., 2007) and chronic illness (Brearley, 1990; Alexander et al., 2012) or with clinically distinct patient groups such as cancer patients (Novack et al., 1979; Degner & Sloan, 1992). Thus, generalisation outside of the sampling frame is not without difficulty.

Research methodologies have also been limited to quantitative research where the complexity of participation has not been examined fully and in the main limited to concrete, measurable aspects of participation such as attitudes (Centre for Advancing Health, 2010), preferences (Hibbard et al., 2009), participation in decisions (Elwyn et al., 2003, Edwards and Elwyn, 2006, Beaver et al., 2005), length of consultation (Collins et al., 2007), questions answered (Little et al., 2001), behaviours such as listening (Poulten, 1996) and patient utterances (Collins et al., 2007). Such reductionism has made judgements about patient participation as an approach to care somewhat impossible. Data have primarily been derived from self-completed, attitude scales or fixed choice questionnaires, which have provided little opportunity for responses to be explained or enlarged upon. Essentially the findings albeit that they are valuable are often oversimplified, non-contextual and in some cases they have shut out reality.

Most researchers appear to have adopted a basic, static or structural approach to patient participation in care rather than an interactionist or dynamic one. Most have drawn on the

assumption that patient participation is a concrete and discrete static entity, which can be readily quantified and measured at any stage of the illness experience. Surprisingly, little consideration has been given to the fact that a patient's participatory behaviour and attitudes are not immutable, and that they proceed, directly or indirectly, from the meanings imposed on the situation in which they exist by the social factors involved. Given that human behaviour is dynamic and shaped by social interactions and that how people say they respond may well be different to what they do in practice the use of structured data collection tools at specific points in the patient's illness experience may not be the best way of obtaining data about the process of patient participation. Indeed few studies have examined how patients reported preferences or views differ from their actual behaviour in practice.

While quantitative inquiry offers a relatively simple and straightforward approach to the study of patients' behaviour, attitudes and beliefs about participation in care, when used as a substitute for observing actual patient behaviour it is less convincing. Furthermore, given the plurality of meanings of participation and the subtle, dynamic and sensitive nature of the concept any attempt to quantify and generalise seems somewhat inappropriate. To distil instances of human interaction into a statistical form denudes that interaction of its richness and subtlety and thus devalues the conclusions drawn. Indeed, there is a deficit of richly textured portraits of patients' role preferences and perceptions of the participatory process. Given the complex nature of patient participation in nursing care with all its social, ethical, historical and political underpinnings there is a need to examine the nature of the concept and conceptualise salient issues in nursing practice. To obtain a rich and complete understanding of patient participation in nursing care from the perspective of the patient the use naturalistic field methods such as interviews and observation is demanded.

Within the context of health care, the calls for greater patient participation in care are based on the assumption that patients want a more active role in their health and/or nursing care. In a classic community survey, using structured interviews Vertinsky et al. (1984) examined the role preferences of 200 citizens in Vancouver with regard to consumer desire for participating in hospital care. Findings indicated that citizens desired something more than a passive role in health care. They wished to employ physicians as information sources and decision makers but also wished to participate in the decision making process. However, caution must be exercised when interpreting the findings as the study is dated and limited by the nature of the instrument developed for the research and the fact that it was not used in a practice setting. The vignette used of a common medical situation (a patient complaining of a sore throat) presented a somewhat artificial situation. Study participants were asked to project

themselves into the illness situation. Thus, subjects who were not in the patient role at the time of the research might have responded differently if they were receiving treatment.

Most studies examining the preferences of actual patients with certain significant exceptions (Waterworth & Luker, 1989; Hanucharurnkui & Vinya-ngag, 1991; Biley, 1992; 1995; Avis, 1994; Christensen, 1993; O'Donnell et al., 2007) have centred on chronic or long-term illness. Faden et al. (1987) investigated participation preferences of patients (n=53) being treated for seizure disorders. Participants overwhelmingly affirmed a desire to be informed of benefits, risks and alternatives available to them. Ninety-nine per cent of the sample (n=48) reported that this would make them more likely to adhere to, and have confidence, in treatment recommendations. Although these respondents were less inclined to endorse an active role in clinical decision making per se about half (n=27) indicated that they preferred to make the 'final' decision about medication. However, caution must be exercised in interpreting these findings. Drawn as a convenience sample from two selected settings, the participants in the study may not be representative of patients with seizure disorders.

Cassileth et al. (1980) examined the participation preferences of ambulatory cancer patients. A total of 256 patients at a hospital in Canada completed an information styles questionnaire, designed to elicit data on patient preferences, and the Beck Hopelessness Scale, to indicate whether patients wishing to participate in treatment decision making were significantly more hopeful than others were. Patients' behaviour and beliefs were found to incorporate the contemporary standard of informed and active participation although significant age trends were found. The younger the patients, the more they wished to be informed, and to participate in decision-making. Patients who wanted to participate in their care were also significantly more hopeful than others were. Questions do however, need to be raised about the assessment of preferences in this study. Responses were based on a limited number of loosely defined forced-choice questions. No opportunity was provided for patients to consider and weigh alternative roles in decision-making. It is also probable that interpretations of the word 'participation' would have certainly influenced the response to the statement '*I prefer to participate in decisions about my medical care and treatment*'. Similarly, the definitive interpretation of hopelessness data is problematic. The high levels of hope may have represented an artefact of the research setting. A potential source of bias may also have arisen from the fact that no attempt was made to control the stage of illness at which the measurement of preferences was made. The significance of the patient's disease trajectory was not adequately explored. Furthermore, as the patients studied were under treatment in a major urban medical centre the setting itself may also have encouraged preferences for

participation. Patients who seek treatment in large medical centres may differ from those who go elsewhere for cancer treatment.

Greenfield et al. (1985) and Brooks (2008) maintained that the research setting and illness situation could have a significant impact on patient participation preferences and activity. They advocated that in the context of chronic illness in particular, a degree of patient participation is customary as the ultimate burden of care falls on the patient and their families. Thorne (1993) alluded to the fact that participation in care among chronically ill patients is often a necessity rather than a choice. She reported how patients facing serious chronic illness have more of a tendency to lean towards active participation as they have a significant stake in treatment choices than patients facing many other diseases because of the toxicity, changes in body image and lifestyle disruptions, which can occur because of the disease and the treatment. However, a number of controversies flourish in the theory-based literature on participation particularly with respect to the degree to which patients want input into their care. Within the context of chronic illness, not all patients wish to assume active roles. Some patients favour the traditionally passive, acquiescent patient role (Tagliacozzo & Mauksch, 1979). A general proposition has been suggested to make sense of such evidence in the form of the theory of regret (Shackey & Ryan, 1994). It is argued that there is a substantial burden in participating in decision making especially where important outcomes are at stake. Patients anticipate the substantial sense of regret that may occur if they select the wrong option. Being freed of responsibility can produce an immense sense of relief, as failure becomes the responsibility of the practitioner rather than the patient. Some patients even derive security from a 'nurse or doctor knows best' stance.

Strull et al. (1984) studied 210 patients who were receiving treatment for chronic hypertension. Using structured questionnaires to discover what role patients preferred to play they found that 63% of patients actually wanted the clinician to make the decision about their care using "all that is known about medicine" (p.24). Similarly Deber et al. (2007) on examining role preferences of patients from 12 different acute clinical settings found that few patients preferred to play a consumerist role. Most reported not wanting to assume responsibility for tasks or decisions that require expertise from the provider.

Two surveys conducted by Degner and Sloan (1992) in Winnipeg, Canada examined what role individuals actually wanted to assume in selecting cancer treatments. A total of 436 newly diagnosed cancer patients and 482 members of the general public participated. Preferences about roles were elicited using two card sort procedures, each of which described five potential roles in decision-making. These included preferences to make the

final selection about treatment, preferences to make the final selection about treatment after considering the doctors opinion, preferences that doctor and patient share responsibility for decision making about treatment, preferences that doctors make the final decision but consider the patient's opinion and finally preferences to leave all decisions about treatment to the doctor.

Findings suggested that the impact of being diagnosed with a life threatening illness might influence preferences for participation. The majority of patients (59%) wanted physicians to make treatment decisions on their behalf but 64% of the public thought they would want to select their own treatment if they developed cancer. Most patients (51%) and members of the public (46%) wanted their physician and family to share responsibility for decision making if they were too ill to participate. Indeed the very high proportion of cancer patients who preferred to delegate decisional responsibility is in marked contrast to the findings of Cassileth et al. (1980). Possible explanations for this are that differences in measurement technique may have influenced the results. Cassileth opted for a simple 'pick one' technique, which was applied to only two alternatives. In contrast, Degner and Sloan selected a somewhat superior method. They chose to consider five different roles in cancer treatment decision making and compared them in subsets of two in every possible combination. Indeed arranging a series of alternatives in order demanded more than the simple task of considering two options. Patients also had more opportunity to consider and weigh their alternative roles in decision-making. The method also permitted subjects to make mistakes, or to be intransitive in their preference orders. A second explanation may relate to the time of diagnosis. In Degner and Sloan's study, the psychological impact of the newly diagnosed cancer may have influenced most patients to prefer a passive role at least until they had more opportunity to learn about the disease and its treatment. Their preferences may also have reflected a learned expectation that they should assume a passive role.

Finally, one further explanation may be the cultural differences between Canada and America and/or the different health care systems. Indeed Kim et al. (1993) in a multi-national survey of Japan, Norway, Finland and the USA examined patients' attitudes towards a consumerist or participatory approach to health care and found that cultural heritage, social development and country of residence were all major structural variables that contributed to different patient viewpoints about the nature of patient participation and how it should be executed. This has recently been confirmed by O'Donnell et al. (2007) who explored preferences for participation in treatment decision-making associated with urinary incontinence. In a study of 9434 women from 15 different European countries marked variations within and between countries were found. The participatory role was the most

preferred role in Austria, Belgium, Denmark, France, Germany, Ireland, Sweden, the Netherlands and the U.K. In Greece, Portugal and Spain the passive role was most preferred.

Caress et al. (2005) in a later cross-sectional survey of 405 renal patients at a single regional unit in the north of England, using a similar methodological technique to that of Degner and Sloan - the card sort technique - found that the majority of patients (78%) still preferred to adopt the passive role type. However, as in Cassileth's study age appeared to be influential in role preference. Older patients more commonly preferred a passive role while younger patients more commonly preferred active roles. Indeed the relationship between age and participation is a recurring feature in the literature.

Thompson et al. (1992) in a mail survey (n=2002) in the U.K. examining individuals' preferences for participation in care found that age had a significant impact on role preference as younger individuals reported a higher desire to participate in care. It also emerged that better educated subjects were more inclined to endorse actions involving greater participation, a premise reported by Friedson (1970) and Agass et al. (1991). However, the limitations of Thompson et al.'s study should be noted. The response rate to the mailed questionnaire was not reported; therefore, it is difficult to make a judgement about how representative the obtained sample was relative to the projected study sample. As with other mail surveys the self-selection bias of those who returned the questionnaire could mean that the results could be generalised only to patients who are likely to return a survey. The vast majority of respondents (87%) were also reported as being white. Indeed, it would be desirable to repeat the study using respondents from a variety of ethnic backgrounds to see if the results generalise to subcultures in society. Furthermore, as with earlier studies that tended to draw on a positivist epistemology, the use of a structured questionnaire did not enable examination and understanding of why variables such as age and education were predictors of the desire to participate in care. It may be that age and education were markers of other variables such as deference to authority or confidence in one's own medical knowledge. A more recent study by Hamann et al. (2007) using data from 1393 patients with different medical conditions reinforced the significance of socio-demographic variables as it was found that younger age, better education as well as the female gender did account for a small but statistically significant greater desire to participate in their care.

In one of the few studies examining patient preferences within the context of nursing practice Brooking (1986), using an attitudinal scale, also found that patients who expressed a positive attitude and reported the highest levels of participation were younger, had increased

knowledge of their condition, were from a higher social class and were more familiar with the hospital environment. Indeed these findings have significant implications for nursing practice. It would certainly appear that patients' characteristics need to be considered when participation is offered. Furthermore, if government and nursing policy and practice is to persist in emphasising a participatory health care approach there is a need to re-educate not only the public with respect to their expected future roles in health care, but also health care professionals. Health care professionals need to learn and be better prepared for the more participatory roles, which are being advocated in current policies in the name of consumerism. However, Brooking's findings do have limited generalisability as the survey was carried out in 1986 in only 2 hospitals, both in London, and had a small sample size (n=114 patients). Furthermore, as acknowledged by Brooking herself, self-completed questionnaires at specific points in the illness experience may not be the most appropriate way of obtaining data about the sensitive and dynamic nature of patient participation in nursing care.

Given that patient participation is a subjective phenomenon and that a patient's role during an illness experience is not static the possible impact of a scaling approach on the sensitivity of the data obtained needs again to be carefully examined. While scales measure valence, that is the degree of positive or negative feeling evoked by an attitude they do not measure other dimensions of attitude such as breadth, intensity, stability, centrality, salience and behavioural expression. Structured instruments used in a single encounter are unlikely to either measure accurately patient preferences for participation in care or reveal convincingly the complexity of the practice in the real world, a viewpoint supported by Elwyn et al. (2001) who in a systematic review of instruments used to measure patient participation found that few were designed so as to measure accurately the process of participation and evaluate participation in varying contexts. Most tools had been designed specifically for the sole use of measuring participation within the context of health care consultations in general practice. To ensure that the nature of the concept, the contextual influences and interactional processes involved are examined rigorously there is a need to extend the methodology of obtaining views, preferences and insight into practice to include a more qualitative approach or, more specifically, unstructured interviews and observation.

The degree of patient participation in care has also been attributed to factors other than role preferences, age and educational level. In a small quantitative study (n=74) Timonen and Sihvonen (2000) found the main reasons patients did not participate in their nursing care were associated with tiredness, lack of encouragement and the esoteric language used by nurses. However as the study was undertaken in Sweden at a time when patient participation

was not high on the health care agenda and participation was only measured in relation to questioning, the empirical relevance of the study should be treated with caution.

Findings from a qualitative study by Biley (1992) found that the more seriously ill a patient was the less likely they were to participate in their care. Biley used a modified grounded theory approach to discover how patients felt about participation in decision making about their nursing care. Eight informants were interviewed informally following discharge from hospital for surgical intervention. Findings suggested that patients participated in decision making according to how well or how fit they were. "Being too ill" (p. 416) was regarded as a reason for not participating in care. However, on a methodological note, it is difficult to draw definitive conclusions from Biley's study. First, the small number of informants interviewed would not have enabled the researcher to capture the full range and variation in decision-making behaviour. Secondly, no attempt was made to examine the parameters of context. Since the nature of nursing practice and the organisational context of care on the wards where the informants underwent surgery could have influenced the way in which behaviour was evidenced context should have been considered in the analysis. Other potentially significant variables such as expectations regarding hospitalisation, educational background, diagnosis and previous health care experience were also not addressed. Therefore, to assume that acutely ill patients do not really 'want' to participate in their care may be erroneous.

More recently, Mansell et al. (2000) in a study of randomly selected patients responses to vignettes about cancer, acute myocardial infarction and diabetes found that clinical factors influenced clearly a patients desire to participate in decisions about illness. Patients reported wanting to participate in decisions about major interventions, more than decisions about minor interventions. It should however be noted that the range of illnesses and decisions in this study were restricted. For example, questions were asked about aspects of care such as the recording of vital signs and blood sugars as opposed to more significant interventions such as cardiac pacing and cardiac artery bypass grafting.

In another frequently cited qualitative study, which explored the degree to which patients desire to participate in their nursing care, Waterworth and Luker (1989) reported an entirely different picture. In a small-scale in-depth study involving a convenience sample of 12 patients from three medical wards and using informal interviews, patients' views regarding participation in decision-making were collected. The authors drew from their 12 interviews one theme, which they saw as throwing light on how patients view participation. They called this "toeing the line" (p. 972). The extent of participation was not dependent on variables

such as severity of illness or age but a preoccupation with "staying out of trouble" (p. 973). However, it is with extreme caution that one should draw inferences from Waterworth and Luker's study about the level of participation a patient desires as little information is provided by the authors about the way in which the interviews were conducted, where they were carried out or the patient and structural variables which may have been significant. Reference is made to grounded theory but given that a grounded theory study should continue until the categories are saturated, the small sample size makes acceptance of the findings difficult. A wider range of patients would have ensured that the researchers saw as much diversity as possible in responses. However, Avis (1994) in an exploratory study of patients' views about participation in decision making in a day surgery unit noted a similar vulnerability to that of Waterworth and Luker as patients "let them get on with it" so as not to undermine the skilled technicians (p. 294).

Owing to the complex nature of patient participation in care and the general failure to define and examine adequately the concept, it is inevitably difficult to evaluate the effectiveness of such an approach to care. While it would certainly appear from the literature that the consequences of patient participation are couched in arguments from a positive school of thought the research that has focused on outcome measures associated with participation is limited by its narrow focus. Research that has evaluated the impact of patient participation has essentially focused on discrete aspects of participation such as decision making (Entwhistle et al., 2004), question asking (Little et al., 2001), empathy (Elwyn et al., 2003; Mercer & Howie 2006), patient satisfaction (Poulton, 1996), building health literacy (De Walt et al., 2004), symptom control, functional ability, self-management of health and strengthening self-care (Coulter, 2011). It has also been undertaken mainly in the context of specific groups of patients; for example, chronic illness and specifically diabetes (Gillett et al, 2010), arthritis, asthma, heart disease and cancer care (Thompson, 2007). While most studies have measured the impact of patient participation through patients' reports of their experiences using well developed instruments such as standardised local and national survey questionnaires and/or generic and disease specific instruments to measure discrete activities few data gathering activities have explored the impact of participation beyond isolated patient activities. While the use of such self-reporting tools does not invalidate the insights gained there is a need to debate how and when it is best to measure the individual patient experience of participation and whether it is necessary to develop more nuanced and context-specific sets of measures. To obtain a complete picture of the patients' experience of participation throughout their hospital stay using only standardised measures that focus on isolated and discrete acts of participation is indeed not without difficulty. Standardised tools are less sensitive to variations in health status and the immediate, specific and general

context in which care is delivered and therefore do not measure accurately the impact of the process of patient participation from several perspectives. This view is supported by Elwyn et al. (2003; 2005) and Entwhistle et al. (2004) in reporting on the challenges of developing an instrument to evaluate the value or costs of participation beyond single acts of participation.

Despite the challenges associated with evaluating the impact of patient participation there is sound evidence to suggest that such an approach to care secures positive reports from patients. In one of the few studies undertaken within an acute care context, Hanucharurnkui and Vinya-nguag (1991) tested the effect of patient participation in care on postoperative recovery and satisfaction with care. Forty adult surgical patients who had undergone a pyelithotomy or nephrolithotomy were randomly assigned to either an experimental group (n=20) or a control group (n=20). To promote participation in the experimental group a specific intervention protocol was developed. There were two components to the intervention protocol, the content and the process. The content consisted of a description of the reasons for surgical procedures, postoperative discomfort and the purposes of pre and post activities. The process in the intervention protocol focused on the nurse investigator consciously attempting to influence the subject to implement actions beneficial to his or her welfare by creating an atmosphere in which the patient could verbalise feelings and concerns. Subjects in the control group received the usual care provided in the setting. Results indicated that patients in the experimental group had significantly less pain sensation and distress, used fewer analgesics, ambulated more, had fewer complications, and had a higher satisfaction with care than patients had in the control group. However, when contemplating the results there are a number of methodological issues that need to be considered. First, as the information given to the experimental group was not written or tape-recorded information giving may not have been constant for all experimental subjects. Secondly, the majority of indicators of postoperative recovery were self-reported therefore the findings might be an artefact of social desirability. Finally, little discussion was provided about how bias or context induced effects were reduced. There is no assurance that the control and the experimental group were kept separate to control the sharing of information between them.

Coulter and Ellins (2006) reported a proven association between the participation of patients in their health care and treatment and outcomes in relation to patient recall of information, knowledge, satisfaction and use of health care resources. Greater patient participation was also found to contribute to reduced symptom incidence and complaint (Taylor, 1979); stronger feelings of control (Eldh et al., 2004) and shorter hospital stays (Lott et al., 1992). Preliminary findings from a longitudinal study aiming to improve service and carer experience

of health care services found that patient participation is one of "the high five for quality of care" (Alimo-Metcalfe et al., 2011, p. 30). These early findings echo strongly the work of Coulter (2010; 2011) a recognised authority in the arena of patient participation who reports that engaging patients as participants in the business of healing, the promotion of health, and the management of healthcare resources has been found to contribute to a significantly improved patient experience and the delivery of high quality care.

The Picker Institute Europe (2010), in an extensive systematic review of the literature focusing primarily on consultations between the general practitioner and the patient, found that the impact of patient participation could generally be categorised into four main groups, impact on knowledge, experience, service utilisation and costs, and health behaviour and health status. Others while focusing on only discrete aspects of participation in the health care arena have reported how an active patient orientation has contributed to enrichment and an improved quality of care although only if sufficient resources such as knowledge and practical skills were at the disposal of the actual participants (Collins et al., 2007). On exploring the cost-effectiveness of patient participation, Coulter (2006) reported a reduction in hospital stays and better health outcomes. Similarly Wilson et al. (2007) in a grounded theory study conducted within the context of chronic illness found that participation in the form of self-care was a significant element in managing resource demand.

In examining the impact of patient participation a considerable body of literature also focuses on how an active patient orientation improves patient safety (Coulter, 2002; Hibbard et al., 2005; Davis et al., 2007; Entwhistle et al., 2005; Friedman, 2006). However, most of the literature reviewed was speculative and emanated from case reports or the viewpoint of professionals namely medical practitioners as opposed to patients themselves. There was a poverty of robust empirical evidence, which demonstrated improvements in patient outcomes, and patient perceptions of improvements in safety.

The exception is the work of Weingart et al. (2011) who in large acute hospitals in the United States of America found that most patients who participated in their care reduced the risk of experiencing an adverse event. They found that patients who participated in their care observed, identified and communicated potential problems before they resulted in medical injuries. Such heightened vigilance and effective communication was observed mostly among a few patients namely within the context of medicine administration. While the work of Weingart provided evidence of the capacity of hospital inpatients to participate in their care and added to understanding about the value of patient participation the researchers did not make explicit what participation activities offer the most promise for participation and

preventing adverse events. The study has several other limitations. Examination of adverse events was limited to data available by patient survey. Medical records were not reviewed therefore the prevalence of adverse events may have been inaccurate. Patients were also surveyed 6-12 months after discharge, which could have contributed to recall bias.

The Monash Institute of Health Service Research (2008) in an extensive systematic review of the literature also revealed that patients engaging in health care could make a significant contribution to patient safety. Participation was found to be associated strongly with favourable judgments about hospital quality and patient safety. More specifically the Institute championed that the risk of adverse events such as medication error could be avoided if patients were able to assume a challenging role. However although the review undertaken makes explicit that patient input can have a positive impact on patient safety synthesis of the findings revealed few articles or reports reviewed had conducted an evaluation of the impact of a patient's total experience of participation on patient safety. Principally most were also undertaken from the perspective of the medial practitioner. Patient insights or self-reporting estimates about adverse events were not considered. Furthermore, no study provided detailed description about the ways patients contributed to improving the safety of their care.

In examining the value of patient participation from the patient's frame of reference, it would appear that the consequences of patient participation are generally positive. However, the outcomes associated with patient participation are somewhat unpredictable as less favourable consequences such emotional trauma and stress may also arise (Berg, 1983; Biggs, 1993; Collins et al., 2007; Sahlsten et al., 2008).

Roter (1977) in a dated yet commonly cited study found that the dynamics of patient participation frequently resulted in patient dissatisfaction, anxiety and anger. In her study, Roter equated patient participation with increased question asking. Hypertensive patients (n=294) were randomly assigned to either a placebo condition and given general information about the clinic before meeting with their doctors, or to an experimental group in which they met with a health educator who assisted them in identifying and rehearsing questions they had about hypertension and its treatment. The clinical encounters were audio taped and followed by a 15-minute interview designed to assess satisfaction and health locus of control variables. Appointment keeping was also used as an outcome measure and monitored by inspecting records both retrospectively and prospectively. While Roter succeeded in increasing question asking from 1.21 questions per encounter in the placebo group to 2.12 questions in the experimental group, this change had negative consequences for the affective tone of the encounter. 'Activated' patient encounters displayed more tension,

anxiety and anger on the part of the participants than encounters involving patients who had been assigned to the placebo condition. Patients in the experimental group did, however, score higher in internal locus of control. Appointment keeping over a four-month follow up was also significantly increased.

Roter's study can however, be criticised on several points. The first is her assumption that participation is the patient's sole responsibility. No reference is made to the physician's role in the study and thus the question that emerges is whether different findings may be yielded from a study in which a physician is trained or coached to elicit increased patient questioning. Secondly, the outcome criteria were not entirely adequate. Satisfaction is a poor indicator of the quality of the doctor-patient relationship as it only provides partial insight into the perspectives of the patients studied. In a similar manner, appointment keeping particularly over a short period of time when other variables may intervene is a poor indicator of the effectiveness of patient participation in care. Furthermore, since the parameters of patient participation were narrowly confined to question asking during a 'one-off' encounter the conclusions that can be drawn are limited. Question asking by the patient is only one aspect of participation. Preparing patients for isolated encounters is not really supporting fully the concept of patient participation in care. The variability of a patient's disease trajectory needs to be considered. Arguably, it is also morally indefensible to empower patients for a one-off encounter and then abandon them. Finally, the study was undertaken at a time when patient participation was not in vogue therefore the currency of the findings is open to challenge.

Although there is some contemporary evidence to suggest that outcomes associated with patient participation in care present challenges to patients and health care professionals alike (Collins et al., 2007) gaps do exist in the understanding of the impact of patient participation and the observed effects of such an approach to care. A complete picture of the impact of patient participation is lacking. To uncover the specific consequences of patient participation further research is needed, research which according to S. Parsons et al. (2010) should involve securing patients' reports of their total experience of participation.

In summary, it is evident the patient's perspective of participation within the context of nursing practice and specifically the surgical care setting has not been explored sufficiently. The review of the literature reveals most researchers have focussed efforts on specific groups of patients and distinct components of patient participation. Most have also focussed on identifying and/or measuring the various features that comprise the concept of participation using fixed choice questionnaires and self-reporting measures. Most researchers have placed little attention on participation at the level of the individual at the

bedside. Most studies have also not given due consideration to the context in which participation is enacted. Prevailing examinations and conceptualisations of patient participation have failed to examine in-depth the nature of participation in nursing care and specifically within the context of a surgical care environment. This consequently illustrates that a fresh perspective of patient participation in surgical nursing care is needed. The challenge was to discover using naturalistic tools of enquiry, the meaning of patient participation in surgical nursing care from the perspective of the patient and the nurse. The power of such methods would ensure that an in-depth or holistic understanding of the concept is gained, that sense is made of participation in practice and that the impact of context on such an approach to care is given due consideration.

The intention of the present study was to explore the dynamic and multi-faceted nature of patient participation within the context of surgical nursing care practice in the U.K. More specifically, the intention was to explore in detail what roles actual patients want to assume in the acute surgical care setting, and the extent to which patients actually participate in all aspects of their nursing care throughout both the pre- and post-operative period. The aim was to expand the evidence available on patient participation in the acute surgical environment in order to give meaning to such an approach to care. Rich in-depth understanding of the process of patient participation in surgical nursing care was an objective.

2.3.6 The Professional's Perspective

Studies that have examined patient participation in care from the health care professionals' perspective have similar problems to the studies exploring patients' perceptions. They too are over simplistic and fail to explore attitudes and behaviour in practice and specifically nursing practice. Most studies seek professionals' views through self-completed structured questionnaires or attitudes scales and have focused on views on patient participation, either in general or on different facets of the same phenomenon, such as decision-making, making comparisons difficult. Emphasis has also been placed on the visible and quantifiable features of patient participation in care. Data rich in meaning have not been collected and practice has not been observed sufficiently. Furthermore, few empirical studies that have explored the practice of patient participation from the health care professional's frame of reference have been undertaken in the U.K. Most studies have been undertaken in the USA thus the findings may not generalise to other countries or cultures. Most were also undertaken at a time when patient participation was not especially fashionable; therefore, whether the findings can be applied to the prevailing health care climate is open to debate. The studies and anecdotal

accounts that have been reported do suggest that both nurses' and doctors' current practices and sentiments of the value and desire to promote patient participation as an approach to care are mixed. It would appear that despite the present Government's commitment to fostering patient participation in health care and the infusion of the concept into the nursing and medical profession, it is an approach to care that has neither been rejected nor welcomed as a panacea.

Linn and Lewis (1979) in a classic study, which operationalised patient participation in terms of self-care, sent Likert-type attitude scales to 520 Los Angeles physicians in family practice to describe the degree to which they favoured self-care. Physicians with the most favourable attitudes came from a Jewish background, were under 46 years old and had health beliefs that reflected an internal locus of control. They were also in a group practice or clinic. Physicians with the least favourable attitudes came from a Protestant background, were 46 to 63 years old, had externally controlled health beliefs and practised independently. While the study presents some information albeit limited that might be used by professionals or consumers who wish to identify primary health care physicians who might be most receptive to self-care innovations, care must be taken in interpreting the findings and assuming relevance to the modern day. The sampling procedure used, namely the selection of physicians from listings in the yellow pages, could have resulted in biased findings, as the sample obtained may not have been representative of practising physicians in family practice. The response rate achieved was also low. Only 36% (n=179) of the postal questionnaires were returned. Interestingly, no follow up procedure was employed. The Likert-format statements about self-care can also be criticised in terms of their lack of sensitivity. Response biases might have resulted from the general as opposed to personal wording of item statements. By using statements phrased in terms of people in general like '*very few people want to be self-reliant in making decisions about their health care*' it is unknown whether respondents perceived themselves or others as being less than willing to make independent decisions about personal health care. Furthermore, such a crude scaling method did not enable the researcher to determine and examine the complex interrelationship between variables such as religious background and preferences for self-care. Since patient participation is dependent on a whole variety of interacting variables and is context bound the use of scaling approaches to examine attitudes towards the complex phenomenon is indeed not without problem.

Within the context of general practice in the U.K. Woods and Metcalf (1980) equated patient participation in care with the practice of patient participation groups and sought to explore general practitioners' (GP's) attitudes towards this innovation. Two samples of general

practitioners were selected, one of general practitioners in whose practices groups were known to be operating and one of general practitioners who, according to available records, did not have any first-hand experience of them. Telephone interviews were conducted with all participating general practitioners to elicit full statements of opinion on patient participation groups.

Findings indicated that the idea of patient participation groups is an emotive one. General Practitioners who had formed patient participation groups did not conform to any stereotype in terms of their personal or background characteristics. However, most shared similar ideas about health and attitudes towards general practice. Overall, they adhered to the view that there was more to health than absence of illness, disability and stress. They were also of the opinion that patient participation groups increase general practitioners' understanding of their patients, make the practice more responsive to patients' needs, and reduce the number of complaints. No threat to autonomy and status was experienced. In contrast, general practitioners with little knowledge of patient participation groups were found to react negatively to the idea. They failed to see their relevance to professional objectives and feared that they would threaten general practitioners' autonomy and status. Some dismissed them as irrelevant and unnecessary in their practice. Woods and Metcalfe attributed this negative response to misconceptions about the origins and function of patient participation groups. While the findings of the study cannot be underestimated, the study can be criticised on methodological grounds. No detail is provided about the actual sample size or method of analysis employed. As the study was also limited to 15 practices in the north-western region of England, the population was small in relation to the total U.K population of general practitioners. Generalisations of results to other areas of the country would therefore not be valid. Indeed, given the differences between general practices within the UK it must be assumed, until proven otherwise, that the results of this study are specific to the sample group. Finally, as the study was undertaken at a time when the development of patient participation groups was at an experimental stage it could be argued that these findings would not apply to contemporary general practice.

Elwyn et al. (1996) in a qualitative study using focus group interviews found GP's have very positive attitudes towards patient participation with many of the view that participation as an implicit ethos should permeate medical practice in general. More recently, Collins et al. (2007) found many GP's supported greater participation in service delivery however, viewpoints differed between practices. Local variation in populations and the scarcity of resources and time were cited as the main reasons for differing practices in relation to patient participation.

A scale to measure nurses' attitudes towards patient participation in nursing care was developed by Pankratz and Pankratz (1979). They in a somewhat dated study administered a 69-item attitude scale to a diverse sample of 602 nurses representing nurse leaders, psychiatric, community and university hospitals. A principal components factor analysis revealed that the items tended to load on one of the three subscales of patient participation in nursing care: nursing autonomy and advocacy (factor 1); patients' rights (factor 2) and rejection of traditional role limitations (factor 3). The different nursing samples were scored on the three subscales. In all three subscales, more positive attitudes (or higher scores) were associated with education, specialisation, leadership and direct links with universities. While some light is shed on the profile of nurses who hold positive attitudes towards specific facets of patient participation in nursing care the method used in this study has the same limitations as other studies. There are many unanswered questions about how these attitudes are reflected in nurses' behaviour and why different nursing samples attach different degrees of importance to patient participation in nursing care. Given that health care professionals in this instance nurses, hold a unique and complex perspective of patient participation in nursing care, a survey is insufficient for the complexity of questions asked. From a research perspective, the process by which nurses develop their attitudes needs to be dissected. Research that is essentially descriptive will not enable accurate inferences to be made.

Brooking (1986) using a self-completed questionnaire to measure nurses' practices, opinions and attitudes towards the concept of patient participation in nursing care found nurses were more positive about patient participation than other health care professionals. However, this essentially descriptive study illustrates a number of the methodological pitfalls. The adoption of such a positivist approach inevitably led to a loss of expressiveness and information that could have been both valuable and relevant to the inquiry. More specifically the lack of opportunity to probe and assess the extremity and intensity of the nurses' attitudes resulted in only a superficial understanding of nurses' attitudes towards patient participation in nursing care being acquired. Furthermore, as only 'views' were obtained using a structured research instrument there is no indication as to whether the views were ultimately fed into practice, which would provide an evaluation of nurses' attitudes towards patient participation in nursing care. To capture a contemporary and more holistic and complete portrayal of nurses' current practices and attitudes further research using different methods of data collection would be needed. Indeed, Brooking herself concluded that observation and semi-structured interviews would have been useful adjuncts to the questionnaire, as richer and more meaningful data would have been obtained.

To elicit more meaningful and sophisticated expressions of attitude about patient participation in surgical nursing care a different methodology and perspective to the one used by Brooking and others is needed. While it is not possible to state unequivocally which particular methodological approach would work best to examine and fully understand the complexity of patient participation in nursing care from the frame of reference of the surgical nurse, a more qualitative approach that employs naturalistic interviews and participant observation would elicit richer data and ensure that sight is not lost of 'real world' complexity. It would also involve a shift away from 'idealistic' perspective and a move towards an attempt to understand nurses' attitudes and actions in terms of their own logic, knowledge and beliefs which are in turn closely tied to the social context and circumstances in which nursing care is delivered. To attempt to understand the complexities of patient participation in nursing care solely in quantifiable terms short circuits the potential for discovering the meaning of the whole phenomenon within the context of nursing practice. Indeed, the multifaceted nature of patient participation in nursing care could not be fully understood without an appreciation of what happens in the relationships that patients form and the experiences they encounter in the larger health care system.

A frequently cited study that attempts to examine health care professionals' practices and beliefs about patient participation in care in more depth is reported by Weiss (1986). A stratified sample of 72 nurses, physicians and members of the general public met together in small tripartite dialogue groups each month for 20 months, in order to identify existing norms or health care behaviours that effectively facilitated patient participation in care. Content analysis of 200 hours of verbatim transcripts from the dialogue sessions yielded 1245 behaviours that subjects regarded as being essential for patient participation in care. These behaviours were then spread across 13 scales: each scale reflecting one of the areas originally identified through the nominal group process by the tripartite group as being important to patient participation in health care. Each behaviour was then rated on a seven-point Likert-type response scale ranging 'should always be done' to 'should never be done'. Analysis revealed that, of the 1245 behaviours, 656 received scores identifying them as always being essential for effective patient participation in care. Further analysis of the 656 behaviours produced 44 clusters that were then systematically reduced to six key clusters or norms required to facilitate effective patient participation in care. The six salient norms centred on overt contracts in health relationships, egalitarian communication between patient and professional, patient access to broad-based information, the tailoring of treatment regimens and self-care and lifestyle modification. While the study generated a considerable amount of qualitative information, which may be used to elicit a more sophisticated understanding of patient participation in care from the frame of reference of the health care

professional, any inferences drawn should be treated with caution. The six key norms were essentially 'ideal' as opposed to 'real' as actual conduct within the health care relationship was not examined. Furthermore, wide generalisability of the study is limited as the study population was small and sample selection relied solely on interested volunteers. Finally, whether the contemporary health care system, which functions within an environment of reduced resources would allow such utopian norms or customary behaviours to be established, is open to question. Indeed Sahlston et al. (2007) in a grounded theory study involving 7 focus group interviews with registered nurses (n=31) from 7 different acute wards found that nurses explained participation as an interactional process dependent on not only intimacy, dynamic interaction and opportunities, but also resources. They reported that resources are considered crucial for patient participation within the context of nursing practice. However, while the study offers some clarity about the process of patient participation in care and the detail provided suggests the study was executed in a robust manner the study examined only one aspect of participation, that of physical care. Furthermore, as it was the perspectives of nurses that were the focus of the study, there is no guarantee that the descriptions provided reflect practice on the wards.

Interestingly, while the empirical data reported indicates that health care professionals hold positive attitudes towards patient participation or, more specifically, distinct component parts of the concept, there is little evidence that they translate such attitudes into practice. Indeed the apparent disparity between health care professionals' pro-participatory attitudes and the expression of these attitudes in behaviour highlights the difficulties associated with the use of attitude scales in measuring current practices, real attitudes or beliefs towards complex phenomena such as patient participation in nursing care.

Collins et al. (2007) reported that there is a general hesitation among health care professionals to engage patients in their care despite many anecdotal reports suggesting patient participation can result in increased job satisfaction (Lott et al., 1992; Timonen & Sihvonen, 2000); improved nurse-patient communication (Henderson, 2002), a rewarding relationship (Glenister, 1994) and raised self-esteem (Obeid, 2000). Patient participation in nursing care specifically is an elusive concept, which is hard to actualise in practice. It would appear that some nurses are only paying lip service to the concept, as there is little commitment to the concept in practice. According to Sahlston et al. (2007) the model that promotes dominance by professional caregivers still pervades the whole system. Hewison (1995) maintained that patient participation within the context of nursing practice is constrained by the pre-existing power relationship that exists between the nurse and patient. Furthermore, many nurses have been socialised within a hierarchical and bureaucratic

organisation where the associated emotional demands of nursing are not conducive to patient participation in nursing care. Indeed to forge an environment for patient participation, one of the main barriers to overcome is the potency of time-honoured tradition. The traditional hierarchy encourages a natural tendency towards a superior-subordinate mentality.

Entwhistle et al. (2006) and Thompson (2007) admitted that there is a reluctance to elicit patient participation in care among many clinicians, as many feel unable to relinquish any power or control over patients. In a grounded theory study, Cahill (1998a) found that in an attempt to maintain control and authority nurses consciously used superficial dialogue and professional terminology or jargon and limited the amount time spent at the bedside to prevent patients from participating in the bedside handover. Similarly, Eldh et al. (2010) reported that where some techniques have been adopted in the name of participation they have been assumed with the covert aim of legitimising or extending the already strong position of existing power holders. However, to provide evidence of expropriation would be difficult, as public justification for the execution of patient participation in care is usually couched in the argument of the enhancement or enriching schools of thought and little is said about the less positive elements.

Meyer (1995), in an action research study exploring the introduction of lay participation in care within the context of a general medical ward of a London teaching hospital, found that since such an approach to care constituted a radical change to practice, health care professionals preferred to maintain the status quo. Many health care professionals, although initially keen to promote lay participation in care, when probed held serious reservations about applying the concept in their own practice. Meyer attributed this to the transient nature of the workforce, the functional model of health care practice, the lack of multi-disciplinary team leadership, medical dominance and the lack of time, energy, resources and a supportive culture. Since much personal opinion and anecdotal experience (Sully 1996; Morse 1991) has indicated that patient participation in nursing care results in emotional strain, possible burnout and increased levels of stress, particularly among student nurses who have difficulty in understanding what the 'correct' level of participation should be, it might be that such reluctance to encourage patient participation is a defensive strategy employed to alleviate anxiety (Menzies, 1970). As Giloth (1990) asserted it might be that increased emphasis needs to be placed on developing educational, organisational and environmental strategies that support health care professionals in promoting patient participation in care.

On the contrary, Collins et al. (2007) found that many professionals frequently avoid involving patients in their care as they see it as a euphemism for cost cutting. Indeed the inclusion of patients in any form raises the notion of what Wilson (1987) referred to as "pawns in a cost cutting game" (p. 63) and begs the question of whether participation is being fostered for financial reasons. Higgins (1993) argued that a health care professional's aspiration to promote patient participation in care is tempered by the bureaucratic nature of the health care system. May (1991) reported that factors relating to structure exert powerful forces over the constitution of the professional-patient relationship and thus over individual clinicians' practices, preferences and attitudes towards patient participation in care. McMahon (1990) supported this premise as he found in a ward where primary nursing or a laterally managed system was employed, that a greater interest in patient participation was apparent in comparison to the interest expressed on a ward managed in a hierarchical fashion. According to Muetzel (1988) if effective patient participation is to occur, an environment that is emotionally secure is essential. Ashworth et al. (1992) maintained that to achieve a desired level of participation it is important that both patients and nurses possess a shared set of assumptions, have insight into each other's emotions and understanding of the situation and do not feel threatened. The personal attributes of nurses have also been reported to be critical (Vouzavli et al. 2011).

Henderson (2002) in a grounded theory study, which sought to establish what factors from the nurse's frame of reference, enhanced the practice of patient participation, reported similar findings. Using data collected through participant observation and in-depth interviews with 33 nurses from medical and surgical wards in four hospitals in Australia she found that one of the categories that emerged centred on the "nurses knowing the patients" (p.112). Nurses were of the opinion that it was only through knowing the patient that they were able to assess patient's needs and capabilities regarding patient participation. In getting to know the patient mutual trust and support, a positive nurse-patient attitude, sustained nurse-patient contact and meaningful interaction needed to be established. Henderson also reported that knowing the patient was essential for participation and frequently led to patients feeling in more control, being able to ask questions, being better informed and able to participate in decision making about activities of daily living. Factors such as lack of time, high patient load, negative nurse-patient attitude, task orientated nursing and early discharge were found to inhibit a participatory approach to care. Although Henderson's study went some way towards providing a detailed understanding of the factors that have an impact on patient participation in nursing care in practice inferences should be drawn with caution. Little detail is provided about the length of time spent in the field. The type of participant observation role and the unit of observation employed are also not discussed. Furthermore, no reference is made to

either the context in which the study took place or the system of work organisation employed in each of the four hospitals. Finally, as no indication is given that any attempt was made to clarify or verify the emergent category, the rigour of the study is drawn into question.

2. 4   Summary of Chapter

This chapter has reviewed the research and scholarly literature surrounding the nature of patient participation within the context of health and nursing care. Studies which have explored the meaning of patient participation from both patients' and professionals' perspectives of the concept, have been examined. The review has highlighted that patient participation has not been adequately articulated or clarified and remains one of the least understood practices in contemporary health care. It would appear that there is no consensus on what patient participation in nursing care means or how far it should extend. Given that a diversity of opinions exists in the way both patients and nurses view the concept there is an urgent need to open up the rhetoric of patient participation to scrutiny. While knowledge gleaned from positivist inquiries undertaken within the context of medical practice and chronic or long term illness has a significant role to play in a science based health service, for rich understanding of the process of patient participation within the context of surgical nursing practice more qualitative methodologies which have a close association with the applied environment need to employed. Against this backdrop, the present study sought to elicit more illuminative data, capture fresh insights and explore the meaning, value and processes underlying patient participation in nursing care in the surgical care context.

The following chapter presents the research method that was used for the present inquiry. The method will be critically appraised alongside the sampling strategy and methods of data collection employed. The chapter also provides a detailed view of how the research journey unfolded.

CHAPTER 3   THE RESEARCH DESIGN AND DATA COLLECTION

3.0   Overview of the Chapter

This chapter provides an account of the design of the study. Emphasis is placed on why the original grounded theory method as delineated by Glaser and Strauss (1967) and Glaser (1978) was selected as a tool for the facilitation of this inquiry. The philosophical foundations of the method and their relevance to the present study are detailed. The research setting and the study population are described alongside the process through which access and entrée was gained to the chosen setting. Specific reference will be made to the timeline associated with data collection and analysis. Examples of specific indicators in the data are used to illustrate how theoretical formulations guided data collection. The value of theoretical sampling and the challenges associated with the practical application of such a strategy are discussed. The chosen methods of data collection along with the strategies employed to promote the rigor of the study are also examined.

3.1   The Grounded Theory Method

Since the ultimate aim of the present study was to generate a grounded theory that would describe and explain the process of patient participation in nursing care within the context of acute surgical care, a qualitative research method was deemed most appropriate. On deciding to adopt a qualitative approach, I undertook a comparative analysis of the major qualitative traditions to ensure that the most appropriate form of qualitative research was selected for the intent of the study. Examination of the distinctions between the major approaches to qualitative research namely, phenomenology, ethnography, case study and grounded theory revealed that the approach that placed most emphasis on explicating complex social processes or evolving actions and interactions pertaining to a phenomenon as it evolved over time was that of grounded theory. Grounded theory as delineated by Glaser and Strauss (1967) and Glaser (1978) offered explicit systematic but eminently flexible procedures to achieve the broad aim of the study. I chose a research approach modelled on classic grounded theory as it was deemed that the theory generated through this method of analysis would be faithful to the empirical situation and thus everyday practice would be illuminated most clearly. It also had the potential to explain, interpret and guide practice.

As a strategy for theory development, classic grounded theory is potentially powerful in that it reaches beyond conjecture and preconception to exactly the underlying processes of what is going on in the substantive area. It generates a theory, which is firmly rooted in empirical

data. Glaser (1992) asserted that grounded theory, as first delineated by Glaser and Strauss (1967) offered "a rigorous, orderly guide to the development of theory that respects and reveals the perspectives of the subjects in the substantive area under study" (p. 17). Stern (1980) maintained that if followed carefully the rules and procedures of the original exposé of grounded theory could produce an analysis, which has both accuracy and applicability to the real world.

In contrast, grounded theory as described by Strauss and Corbin (1990a; 1990b; 1994) was rejected owing to its violation of the original premises of the method. Glaser (1992) asserted firmly that Strauss and Corbin's refinement of the strategies for handling data and developing theory is distinctly "not grounded theory" (p. 3). He maintained that the label that should be ascribed to the new method is that of "full conceptual description, a forced preconceived product" (p. 3). Strauss and Corbin in their quest to promote rigour and clarity overemphasised the research mechanics and introduced a rigidity that the originators never intended and which in essence does not rely for accuracy and truth on participants in the 'real world'. Their new coding process alongside the use of a coding paradigm involving conditions, context, action/interactional strategies and consequences brings to bear every possible contingency that could relate to the data whether it appears in the data or not. The importation of such rigid rules and the level of complexity introduced into the analytic process coupled with the tendency to put the direction of the research back in the hands of the researcher suggests that the concept of 'discovery' has been exploited. Indeed application of too inflexible rules could merely stifle what is essentially a creative endeavour.

Since classic grounded theory method is also dynamic and processual in nature in that it employs methodological strategies that can account for changes in human behaviour and conduct over time, it had appeal for a study that was to explore the intricacies of patient participation within the rapidly changing context of an acute surgical ward. The grounded theory format of continuous and simultaneous collecting, coding and analysing of data allowed a 'holistic' experiencing of the dynamics of patient participation action and interaction and an exploration of the concept in terms of current time, place and culture. With its emphasis upon process, grounded theory enabled the complexity and richness of everyday practice and variation in patient participation action and interaction to be captured. At the same time, the impact of both situational and contextual variables on patient participation could be understood. As Chenitz and Swanson (1986) and McCann and Clark (2003) asserted grounded theory is particularly useful for conceptualising human behaviour and

complex interactions in the real world and for the study of interpersonal activities between nurses, patients and others.

Justification for the selection of grounded theory was also derived from the assumption that grounded theory makes its greatest contribution in areas in which little research has been done (Stern, 1980; Chenitz & Swanson, 1986; Creswell, 1998). As made explicit in Chapter 2 many research endeavours offer an original perspective of patient participation however, they are limited by the angle of their scope, the precision of their focus and their neglect of the natural context in which patient participation occurs. Few studies have also been undertaken in the context of surgical care practice.

Through its rigorous method of analysis, grounded theory offered a way of constructing theory from data gained in the field. As in more traditional, logical-deductive approaches, research is not limited at the outset by rigid preconceived hypotheses. Theory is constructed from data obtained in the 'real world'. Indeed the 'groundedness' or inductive nature of grounded theory was a significant attraction as it had the capacity to allow patient participation action and interaction to be captured rather than preformed images.

Classic grounded theory was selected as an appropriate method also because of its methodological thoroughness and incisiveness of the analytic process. Charmaz (1994) asserted that the strategies of grounded theory foster a rigorous qualitative methodology that has its own integrity. The rigorous systematic process involved in generating grounded theory makes it possible to distinguish between one's own pre-understanding and genuinely new insights as revealed by the inductive research process.

Generally, qualitative research depends on an implicit method, the formulation of straightforward analytic categories and thus the researcher's intuition and talent. In contrast, grounded theory offers a set of analytical guidelines and procedures, which help to develop fruitful conceptualisations of data, and which are particularly helpful in developing knowledge about the research process. While the set of operations described by Glaser and Strauss (1967) and Glaser (1978) guide researchers through the process of generating grounded theory and meet the criteria for doing 'good science', the analytic process also allows for flexibility and a constantly changing environment such as that of the acute surgical care setting. Clearly, a major strength of classic grounded theory was its open-endedness and adaptability. Since analysis and data collection proceeds simultaneously, ideas can be followed up as they are created. Thus, the complex phenomenon of patient participation in

nursing care and the context in which it occurred could be examined in an intense and thorough manner.

Finally, the appeal of the classic grounded theory method was also influenced by the philosophical foundations of the method, which are anchored in the symbolic interactionist school of sociology, an approach designed to study reciprocal social relationships and "yield verifiable knowledge of human group life and conduct" (Blumer, 1969, p. 21). Essentially the notion of symbolic interactionism was founded on the work of Mead (1962) although subsequently to be associated with noted researchers such as Blumer (1969) and Goffman (1959). Within this perspective, considerable variation exists in the content of symbolic interactionism. No symbolic interactionist orthodoxy exists that commands universal acceptability. However, in spite of the significant differences in the thought of those who endorse a symbolic interactionist perspective Meltzer et al. (1975) asserted that all varieties of symbolic interactionists subscribe to the three basic premises proposed by Blumer (1969). Table 6 identifies these basic premises.

Table 6   The Three Basic Premises Proposed by Blumer (1969)
• Human beings interact and act towards physical objects and other beings on the basis of the meanings those things have for them. • Meanings emerge from experiences and social interactions between and among individuals. • Meanings are modified, constantly changed and dealt with through an interpretative process.

Given Blumer's three premises it would appear that within symbolic interactionist theory, human behaviour is not simply forced responses to stimuli but dynamic actions that emerge through reciprocal social interactions and from many significant symbols or elements such as innate nature and abilities, past knowledge and experience, communication, the interpretation of the current situation and larger social forces. Society's organisation and structure provides the framework within which social actions or interactions take place. However, behaviour appears not to be culturally or structurally prescribed but derived from the voluntary actions of individuals in interaction with others. As Manis and Meltzer (1978) pointed out symbolic interactionists recognise that while individuals are *shaped* by the social world in which they participate, the social world does not ultimately *cause* or *fully* determine human behaviour.

Accordingly, Blumer (1969) has described the aim of symbolic interactionism methodology as one, which develops a naturalistic approach where the researcher endeavours to see the world in the way that those he is studying perceive it, and to evolve a sympathetic and sensitive understanding of that world, in order to interpret it. Using a symbolic interactionist approach grounded theory provided the best opportunity for discovering the 'real' nature of patient participation action and interaction. With emphasis placed strongly on the empirical world, the actor's point of view, situational and contextual variables and an attempt to interpret and explain the reasons underlying behaviour, as distinct from the intention to discover cause and effect relationships, characteristics of positivist research, grounded theory provided a valuable perspective from which to study the complexities of patient participation within the context of an acute surgical care setting. As there is no rigid adherence to a predetermined research design with as Field and Morse (1985) pointed out, the consequent risk of imposing prior interpretations on the phenomena to be studied, grounded theory offered a flexible approach whereby research was directed by the emergent theory throughout the process of data collection and analysis.

3.2 Data Collection

3.2.1 The Research Setting

The setting for the present study was a National Health Service Trust Hospital of approximately 900 beds situated in an affluent residential area of North London. The Trust cares for a diverse ethnic population of which the age spectrum is broad. The three mixed-sex surgical wards, the only surgical wards in the Trust, which were chosen for data collection, were a colorectal and general surgery ward (Ward A), a vascular and general surgery ward (Ward B) and a genito-urinary and general surgery ward (Ward C). All wards are situated in a modern three-storey block. All have a similar geographical layout and comprise three six-bedded bays and six single rooms, which open on to a main corridor. The private room where the interviews were conducted is located off the main corridor. The location was chosen to minimise interruptions and external noise.

Figure 3 overleaf provides detail of the geographical layout of the three surgical wards used in the study.

Figure 3

Geographical Layout of each of the Surgical Wards Included in the Study

			Bed	**Bay**		Bed
			Bed			Bed
			Bed			Bed
			Single Room			Store Room
			Cloak Room			Toilet/Shower/ Bathroom
Bed	Bed	Bed	Doctors Room			Sluice
						Treatment Room
	Bay					Utility Room
Bed	Bed	Bed	Nurses' Station			
Bed	Bed	Bed				
	Bay					
Bed	Bed	Bed	Single Room			Linen Area
			Single Room			Toilet/Shower
			Single Room			Store Room
			Single Room			Patient Toilets
			Single Room			Staff Toilets
			Single Room			Cleaners Room
			Interview Room	Main Entrance		Office

During the study, each of the wards was managed by what is currently referred to as a ward manager (Band 7). Permanent staff consisted primarily of two junior sisters (Band 6), staff nurses of Band 4 and 5, health care support workers (Band 2) and pre-registration nursing students from the local University. There was some reliance on nurses from private nursing agencies but generally, staff had a permanent contract of employment with the Trust.

Formal weekly ward rounds with surgical consultants and their surgical teams were scheduled on each ward. The wards shared general surgical consultants and surgical team cover. Visits by other members of the multi-disciplinary team such as the dietician and stoma care nurse were ad-hoc or pre-arranged in accordance with the weekly ward round and patient need.

The system of care organisation that two of the three wards employed (Ward A and B) was that of team nursing. This system allowed a team of nurses to assume continuous responsibility for a small caseload of six patients throughout their hospital stay. Patients were allocated to a team on admission and were nursed by the same group of nurses throughout their stay. The team leader or most senior nurse on duty in each team was nominated as co-ordinator for the shift and was expected to retain an overview of the team's activities and to co-ordinate liaison between the team nurses and other members of the multi-disciplinary team. Management of care was devolved. The ward manager was concerned primarily with the overall running of the ward. The duty rotas where possible were organised to ensure that there was a minimum of one nurse from each team on duty.

The third ward, Ward C employed a system of work organisation commonly known as patient allocation. In this system, individual nurses were delegated responsibility for the care of a specific group of patients in a particular area of the ward. If a patient was moved to another part of the ward, perhaps to be near an oxygen point, then the nurse handed over responsibility to the nurse working in that area. The allocation was essentially for the duration of one shift only although sometimes it was possible to allocate for a period of days. The ward manager or most senior nurse on duty controlled the working patterns of all the nurses. There were fixed routines. Patient care was implemented as a series of tasks. A 'traditional' environment was preferred. Decision-making was centralised and the person 'in charge' usually the ward manager was the focus for communication with other disciplines and was, therefore, the gatekeeper to information.

The philosophy of each ward depicted that each patient's contribution to health care was valued. Nursing staff wanted to give patients 'a voice' in how health care was provided. The climate of each ward appeared to offer patients, carers and relatives the opportunity to participate in the health care process. Patient participation appeared to manifest in many ways. Participatory behaviour ranged from collaboration in the decision-making process to participation in the bedside handover and the care planning and health education process. All patients were asked during their hospital stay to partake in the Trust's patient satisfaction survey. Nursing was depicted as an alliance of experts in which nurses and patients on an individual basis actively worked together to achieve a beneficial outcome. However, it is of note that patient participation appeared to be significantly more embedded in nursing practice within the context of Ward A. The philosophy of Ward A was such that patient participation was reported as a priority in all elements of nursing work from the point of admission to discharge. This was not made explicit in the philosophy of Wards B and C.

3.2.2 The Study Population

In the present study, data were collected through theoretical sampling from a combination of sources. According to Glaser and Strauss (1967) theoretical sampling is a process whereby "the analyst jointly collects, codes and analyses data and decides what data to collect and where to find it in order to develop the theory as it emerges" (p. 45). The samples are chosen not under the structures of randomness but because they are the most fruitful avenues for the development of theory. In other words, sampling is about uniqueness not representativeness.

Figure 4 overleaf depicts the circular nature of data collection and analysis and illustrates how in the present study the interrelationship between informant selection, data collection, data analysis, theory formation and development evolved. It outlines how I executed the process of theoretical sampling and provides indication how theoretical sampling was implemented in response to emergent findings. As Draucker et al. (2010) and Breckenbridge (2009) reported, for a grounded theory study to be judged as credible it is necessary to demystify the theoretical sampling process and make explicit how theoretical insights emerged.

Figure 4   **Interrelationship between Informant Selection, Data Collection, Data Analysis, Theory Formation and Theory Development**

Initial Patient Interviews
(Purposeful Sample)

Data Analysis

Patient Interviews

Data Analysis

Literature

Observation

Interviews with Nurses

Theory Formation
Substantive coding
Theoretical coding

Theory Development
Selective Sampling of data
Selective Sampling of Literature

The Core Category: Engaging

Engaging in Nursing Care: A grounded theory of patient participation within the context of an acute surgical care setting

The timeline for the theoretical sampling process is depicted in Table 7. Phase 1 of the study was from January 1996 to February 2006. A necessary period of interruption unconnected with the study occurred during February 2006 to September 2009. Phase 2 was from September 2009 to July 2012.

Table 7 Timeline for Theoretical Sampling																
Research Activity	Phase 1										Period of Interruption			Phase 2		
	1996 (MSc/MPhil)	1997 (MPhil)	1998 (PhD)	1999	2000	2001	2002	2003	2004	2005/6	2006 Feb	2007	2008/9	2009 Sept	2010	2011	2012 July
Interviews with Patients	X	X	X	X	X			X	X	X				X	X		
Interviews with Nurses				X			X	X		X						X	
Participant Observation		X			X	X									X		
Data Analysis	X	X	X	X	X	X	X	X	X	X				X	X	X	X

Although data was collected and analysed in accordance with the tenets of theoretical sampling, I recruited initially, a purposeful sample of three patients from the operation list of one acute surgical ward (Ward A). Following consultation with the ward manager I selected three informants who had been afforded the opportunity to participate in their care in some way and who had been allowed sufficient time to reflect on their experience. The initial sample was chosen because they afforded an opportunity to develop theory. As Glaser (1978) acknowledged, in the initial stages of a study researchers "will talk to the most knowledgeable people to get a line on relevances and leads to track down more data and where and how to locate oneself for a rich supply of data" (p. 45). Undeniably, as the study progressed I utilised 'insider knowledge' constructively to inform the design of the research.

The goal of the initial sampling interviews was to provide data for the substantive coding process, the aim of which was to discover, name and categorise phenomena so as to uncover as many potential relevant codes and categories as possible. Consistent with the goal of studying situational reality there were minimal qualifying criteria for the initial study population. The criteria are listed in Table 8.

Table 8   Eligibility Criteria for Initial Study Population
• Willingness to participate in study.
• Completion of an informed consent form.
• Ability to speak English adequately enough to respond during interview.
• Sixteen years of age and over.
• Selection was to occur post operatively one day before discharge. This was to ensure the informants had undergone the experience of pre and postoperative care. Since meanings are devolved from shared interactions, it was felt that by the time of discharge patients would feel more able to process and articulate their views clearly.

It is acknowledged that selecting only English speaking patients had limitations for the study as the potential impact of culture on patients' experiences of participation could not be explored sufficiently. I excluded non-English speaking patients essentially because of the challenges that the recruitment and use of interpreters would present. Prolonged time would have been needed to train interpreters to conduct interviews. Recruiting personnel to translate and type the recorded interviews would also have been problematic in terms of time and resource. Furthermore, this along with the potential for misunderstanding would have affected adversely the rigor of the data collection process. However, in spite of this exclusion

many of the English-speaking informants did come from diverse cultural backgrounds (Table 11 page 73 refers).

Although somewhat haphazard, the initial sampling strategy provided the starting point for the identification of data-rich sources. As soon as data from the first interview were analysed, hunches and ideas emerged that yielded theoretical leads. However, in order to gain an in-depth understanding of the realities and issues at hand and prevent the amassing of general information, I delayed theoretical sampling until categories depicting the substantive area under study were defined loosely. Once categories were established, I asked questions of the informants and modified data according to the then current foci of the analysis or the emergent theory. Through theoretical sampling a change in focus was 'allowed', leads revealed by the on-going data analysis were pursued and data sources capable of informing the study were selected intentionally. Decisions about the study population were tailored continually to fit the data. No linear steps were followed. I selected the sample purely on the basis of need.

To illustrate how theoretical formulations guided the selection of the study population two specific examples or points of decision in the present study will be used. First, patients from Ward A spoke frequently during interviews of how the physical, psychological and social effect of their illness influenced their level of participation. An initial suggestion was that it was the complexity of the illness that influenced the level of patient participation. More information was therefore needed from as varied a range of individuals as possible. Accordingly, I sought a sample of informants who were experiencing different illnesses and who had undergone different surgical interventions to discover why, how and with what consequences the complexity of an illness influenced the level of participation. The sample was recruited from different wards (Ward B and C) to allow for possible variation or exception.

Another assumption tentatively proposed was that the level and amount of preparatory information a patient received before their surgery affected the extent to which they participated in their care in both the pre and postoperative period. To test this idea, I sought a sample of patients who received either the same or different amounts of preoperative teaching. The sampling plan drew on patients who had attended a pre-operative clinic prior to admission, received structured, informal teaching on the ward during the pre-operative period or no preoperative teaching at all as a consequence of being admitted for emergency surgery. Informants who had entered hospital at different stages before their surgery and

who had received expert education from a clinical specialist were also recruited to identify every possible variation in the group under study.

Despite the inherent value of this sampling strategy in terms of fruitful avenues of inquiry, it is not without problems. As theoretical sampling builds in criteria or characteristics, which help to develop and test theory and explanation, caution must be exercised so as not to simply select those sampling units, which will only support the analysed emergent theory. To maximise the opportunity to refute and refine the emerging theory, I modified continuously questions and sought negative or contradictory cases throughout the analytic process. As Denscombe (2002) asserted, the selection of negative cases to elicit variation is critical as the emergent theory needs to be "tested to destruction" by seeing if it works in the least likely circumstances (p. 200). If a theory is found to hold true under adverse circumstances there is more chance that it is a valid abstract rendition of the raw data and that it possesses explanatory power, an ability to explain what might happen in given circumstances.

In practice, the complex process of theoretical sampling as described by Glaser and Strauss (1967) was both challenging and difficult to accomplish. Glaser and Strauss (1967) in their original work failed to explain how theoretical sampling proceeds throughout the research process. The principles and logic of theoretical sampling are articulated yet little methodological help is provided for the neophyte researcher. In contrast, Strauss and Corbin (1990a; 1990b; 1994) and Draucker et al. (2010) offered rigorous guidance for theoretical sampling according to the type of coding the researcher is engaged in. However, while their theoretical sampling procedures or instructions provide valuable insights into the mechanics and complexities of theoretical sampling their approach is rather formulaic and tends to divert attention from data towards the operational steps, prescribed by the procedures. (Schatzman, 1991; Robrecht, 1995; Melia, 1996; Breckenbridge, 2009; Glaser, 1978; Holton, 2007). Boychuk-Duchscher and Morgan (2004) captured aptly this concern in writing; "...by focusing the researcher's energies on the perfect approach to finding data, the true nature of the data may be lost" (p. 611). Certainly, it could be argued that Strauss and Corbin's rigid rules for each step of theoretical sampling disregarded the original premises of the grounded theory method in which theory comes from data.

In the present study, the continuous interplay of inductive and deductive reasoning was often difficult to sustain. Variables such as severity of illness, post-operative complications, unannounced consultant ward rounds, early discharge, imposed pre-set times for data collection and delays in gaining access to different types of data had a cumulative effect on informant recruitment and the process of theoretical sampling. It became evident in the early

stages of the research that a planned protocol for theoretical sampling could not always be controlled. Continuous revisions had to be made particularly as it was not always possible to retreat to field data to undertake an in-depth analysis prior to the collection of further data. However, in an attempt to adopt a 'purist' approach and diminish the pursuit of theoretical 'flights of fancy' which had little connection to the data, I always undertook an overview analysis of the transcribed data so as to permit the pursuit of hunches, ideas and emergent codes from the raw data.

Since a concerted attempt was made to employ theoretical sampling in its purist sense, no sample was predetermined numerically. I continued with data collection until it became apparent that the emergent categories had saturated. According to Glaser and Strauss (1967) saturation is a term that depicts a time when no new information can be added to the understanding of a category. It refers to the repetition of discovered information and confirmation of previously discovered data and is heralded as a key to excellent qualitative research. Morse (2010) asserted that failure to achieve a sense of saturation will impede the exploration of the identified phenomenon, the generation of theory and inevitably the quality of the research and result in "cherry picking ", a style of analysis used when the researcher has terminated data collection with a minimal data set (p. 3). Strauss and Corbin (1990) report that unless saturation is achieved the theory generated will be conceptually inadequate. Sandelowski (1995) affirmed that samples must be large enough to enable the researcher to identify and validate theoretical variations discerned in the data and achieve "informational redundancy" (p. 179). Morse (1994) recommended that for a grounded theory study the minimum sample size is about 20 - 40 interviews. She maintained that such numbers are sufficient normally to elicit key characteristics of a phenomenon.

In the present study, category development was dense, all variations in categories could be explained and relationships between categories were well established and validated after analysing 46 interviews (37 with patients and nine with nurses) and 48 hours of participant observation (the end of Phase 1 of the study). Although there are no specific guidelines for the *a priori* estimation of the amount of data required for each category to achieve a state of saturation and reaching this position is essentially a matter of subjective judgment, it was at this conceptual point in the study that new data yielded only redundant information and a consistent level of repetition. Categories appeared to be saturated as during analysis no new properties or dimensions of categories or relationships among categories were seen in the data. The established theoretical scheme appeared to account for and predict variation in the course of patient participation. The collection of additional data at this point seemed counterproductive, as 'new data' did not add more to the overarching theoretical scheme.

However, owing to the interruption in the study and thus the need to ensure currency and relevance and more specially achieve the objectives identified earlier in Table 3 (page 8 refers) the original theory was challenged through the remainder of the data set namely ten interviews with patients, five with nurses and a further 24 hour period of participant observation (Phase 2 of the study).

On returning to the field and undertaking further analysis and an up-to-date critical review of the literature, the original theory was challenged to ensure it provided a reasonable explanation of the manner in which patient participation was initiated, developed, maintained and evaluated in modern surgical care practice and that it was sufficiently adaptable and modifiable to stand the passage of time. Variation in patient participation action and interaction within the context of contemporary surgical care practice was also confirmed. Rather than trying to prove the theory right, I made a concerted effort to seek exception, challenge and refute the originality of the theoretical scheme. Because of the human cognitive bias towards confirmation (Mahoney, 1991; Raymond, 1998), I undertook an active search for disconfirming evidence in an attempt to achieve rigor in the study. I focused particularly on exploring whether contextual conditions such as changes in national and/or local health care regulation, policy and practice, societal values and expectations and professional values and standards had a bearing on the theory.

Ultimately the further period of data collection and analysis combined with the review of the literature facilitated critical engagement and allowed me to ask targeted questions of the informants to ascertain whether the original theory confirmed, was comparable or incompatible with their experience of participating in contemporary surgical nursing practice. The theory was also examined for what Glaser and Strauss (1967) defined as "a good fit" (p. 238), that is that the theory was faithful to current practice and was meaningful, understood and recognisable by patients and nurses in surgical care environment. The unusual opportunity of returning to the field after a period of interruption was invaluable in that the theory could be located contextually and its direct relevance to current surgical care practice could be ensured.

3.2.3   Profile of Patient Informants

Ultimately, the study population comprised of a group of 47 patients undergoing planned or emergency surgery and a group of 14 nurses, both qualified and unqualified. Figures 5 and 6 overleaf depict how the study population evolved through the process of theoretical sampling and more specifically in Phase 1 and 2 of the study respectively.

Figure 5   The Evolution of the Study Population in the Phase 1 of the Study
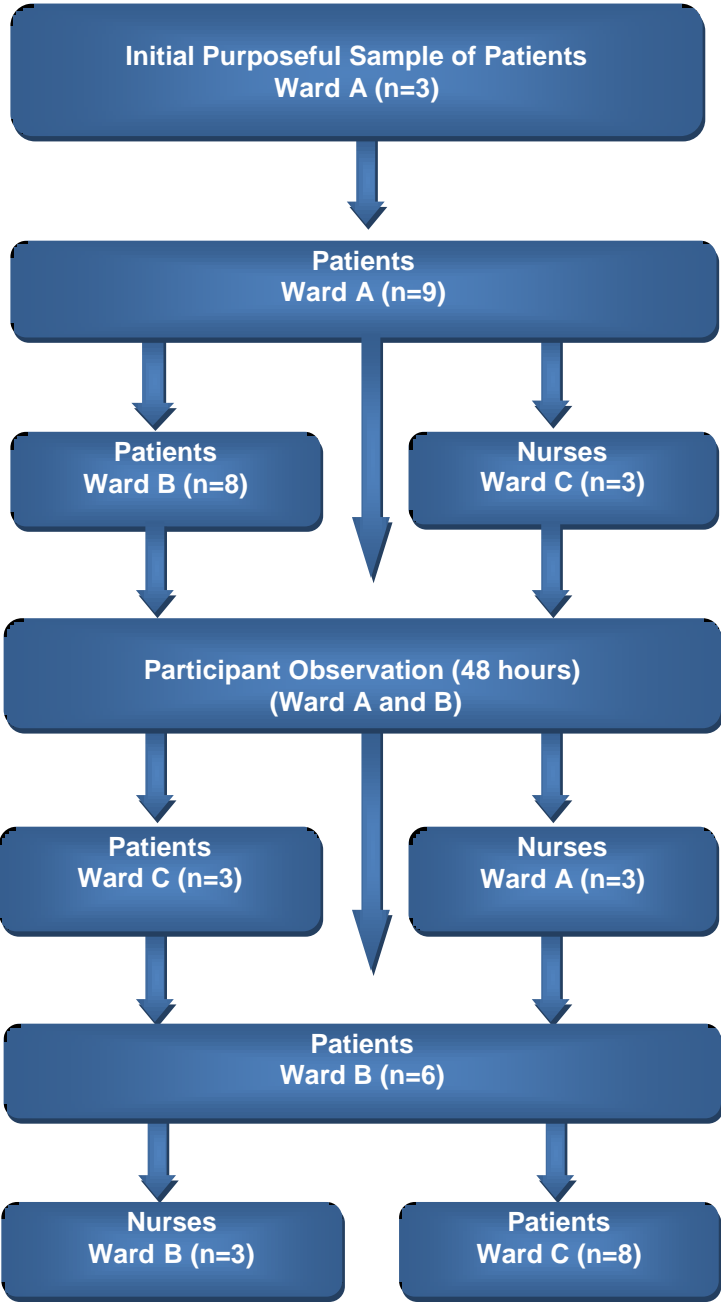
Figure 6   The Evolution of the Study Population in the Phase 2 of the Study
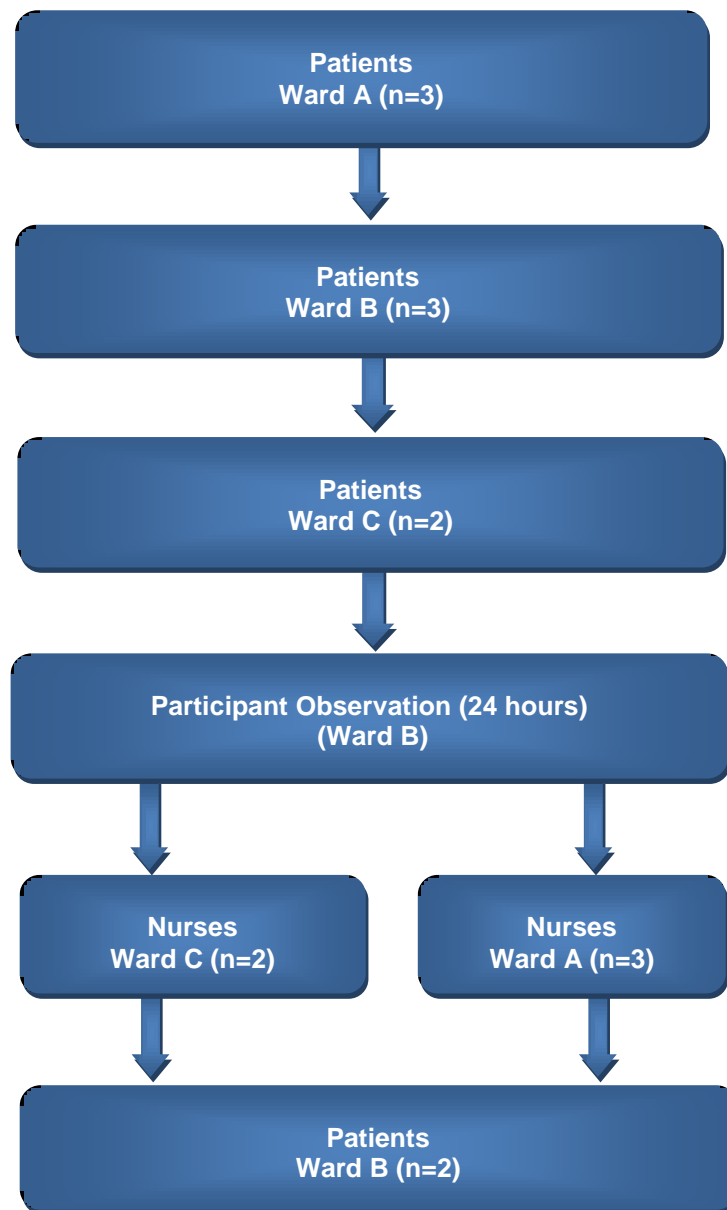
Table 9 indicates specifically where the 47 patients in the study were recruited from.

Table 9 Wards where Patient Informants were Recruited from							
Patients in Phase 1 of the Study				Patients in Phase 2 of the Study			
Ward				Ward			
A	B	C	Total	A	B	C	Total
12	14	11	37	3	5	2	10

With the exception of 14 patients admitted via the Accident and Emergency Department, all patients were planned admissions, admitted by the waiting list.

Table 10 identifies the nature of the surgery experienced by the patients in the study population.

(e) = Emergency Admission

Table 10 Nature of Surgery Experienced by Patient Population	
Nature of Surgery	Number of Patients
Laparoscopic Cholecystectomy	1
Bowel Resection for Carcinoma of the Bowel(with stoma formation)	6
Total Hip Replacement	3
Thrombectomy for limb ischaemia (e)	1
Nephrectomy	1
Oesophagectomy and gastric tube reconstruction	1
Thyroidectomy	1
Intestinal Obstruction (e)	3
Cystectomy and formation of an Ileal Conduit	3
Aortic Aneurysm Repair (e)	2
Investigative Laparotomy	6
Partial Gastrectomy (for peptic ulceration) (e)	2
Drainage of Pilonidal Sinus (e)	2
Dental Extraction	1
Appendicectomy (e)	4
Inguinal Hernia Repair	2
Radical Mastectomy for Carcinoma of the Breast	3
Transurethral Resection of Prostate	4
Amputation (above knee)	1

Seven patients entered hospital two days before their surgery, 13 patients entered hospital one day before surgery and 13 patients entered hospital on the day of surgery. The remaining 14 patients who were admitted as emergency admissions had surgery on the day they entered hospital.

The time spent in hospital varied from two to 24 days. Three patients had been discharged by the second postoperative day, 14 by the fifth; another 27 had been discharged home within ten days. Only three patients were hospitalised for more than 15 days. The number of previous admissions to hospital varied. Fifteen patients were first time admissions, 27 patients had been in hospital between two and five times and five patients had been in hospital between six and ten times. Although patients were selected from three wards in one NHS Trust, 16 patients had experienced hospitalisation in other NHS Trusts within the U.K. and four had experienced hospitalisation outside of the U.K. namely in Ireland or the Caribbean. Interviews were conducted at a time selected by the patient and were normally held in the morning between 10.00 and 11.00 hours or in the afternoon between 13.30 and 16.00 hours within three days of discharge.

Table 11 summarises the demographical characteristics of the total patient population. Consistent with theoretical sampling the intention was not to select the initial sample to reflect specific characteristics.

Table 11 Demographic Characteristics of the Patient Informants		
Total No: 47		
Gender: Men 28 Women 19		
Ethnic Origin		**Marital Status**
White British:	22	Married/Partners 24
White Irish:	5	Single 11
Black British:	4	Widowed 4
Black Caribbean:	5	Divorced 8
Asian-Indian:	2	
Chinese – Singapore:	2	**Age**
Mixed Black Asian	3	Under 20 3
Black African:	4	20-39 10
		40-59 15
		60-79 19
Occupation:		
Cafeteria Assistant	Policeman (2)	Chief Operating Officer
Plumber	Shop Assistant	Company Director - Baker
Head Storeman	Senior Sales Representative	Interior Decorator
Housewife (4)	Nurse (3)	Head of Portering
Student (3)	Taxi Driver	Estate Agent
Minister	Electrician	Pilot
Receptionist	Real Estate Salesman	Secretary (4)
Director (2)	Draftsman	Personnel Officer (2)
Accountant	Self Employed (4)	Teacher (2)
Store Manager	Engineer	Builder

3.2.4 Profile of Nurse Informants

The nurses in the study population were recruited from Ward A (n=6), B (n=3) and C (n=5). The demographic data of the nurses who were interviewed is summarised in Table 12.

Table 12 Demographic Characteristics of Nurse Informants	
Total No:	14
Designation:	
Pre-registration Nursing Students	3
Ward Manager Band 7	3
Staff Nurses Band 4	3
Staff Nurse Band 5	2
Junior Ward Sisters Band 6	1
Health Care Support Workers Band 2	2
Gender:	
Female	11
Male	3
Training/Education Institute:	
Local University	
(Diploma of Higher Education in Nursing/BSc (Hons) Nursing)	6
Local Hospital (Registered General Nurse)	5
Local Hospital (NVQ)	3
Age:	
Under 20	5
20-39	3
40-59	6
Ethnic Origin:	
White British:	8
White Irish:	2
Black British:	4

In keeping with the tenets of theoretical sampling, the sample of nurses was not selected from the population based on certain variables prior to the study. Rather, I selected the sample on the basis that they could contribute to the emergent theory. Nursing experience varied from six months to 22 years with the mean being 6.75 years. Eight nurses in the sample had five years or less nursing experience, four nurses had between five and ten years of experience, one nurse had between 11 and 20 years' experience and one had over 20 years experience.

With the exception of the three students, two staff nurses of Band 4 and one health care support worker of Band 2 the entire nursing population were permanent full or part time

employees of the Trust where the study was undertaken. One of the student nurses was in their first year of study and the remaining two in their final third year. The remaining three nurses who were not permanent employees of the Trust were contracted by a local private nursing agency to work anywhere within the surgical unit of the hospital. The apparent bias towards female nurses was not intentional. It simply reflected the staffing demographics at the time of data collection.

Nine of the nurses in the sample worked only morning (07.00 to 15.30 hours) and afternoon shifts (13.00 to 21.00 hours). Two of the nurses worked all shifts, which included morning, afternoon and night shifts (21.30 to 07.30 hours), and three nurses worked permanent night shifts on a full time basis. All interviews were held at a time convenient to the nurse and patient and were normally held in the morning between 10.00 and 11.00 hours or in the afternoon between 14.30 and 16.00 hours. Two interviews with nurses were held at night between 11.30 and 02.00 hours.

3.2.5 Entry to the Field: Negotiating Access and Ethical Issues

3.2.5.1 Ethical Approval

Before data collection in Phase 1 of the study began, I obtained verbal permission to undertake the unstructured interviews with patients from the Lead Consultant for Surgery in the Trust and the relevant Ward Sisters. With their support, the proposal was forwarded to, and approved by, the Trust's Nursing Ethics Committee (Appendix 1 page 260 refers). In accordance with the tenets of theoretical sampling, some modifications had to be made to the original proposal when the analytic process revealed that a period of observation and unstructured interviews with a sample of nurses from diverse surgical wards would be needed to capture the complexity of patient participation in everyday practice. The changes were permitted and approved by the Trust's Nursing Ethics Committee at the time (Appendix 2, 3 and 4 pages 261-63 refer).

Following the period of interruption and prior to the commencement of Phase 2 of the study, I approached formally the newly established National Research Ethics Service explaining that a period of interruption had occurred and that further data collection with patients and nurses and a period of observation would be needed to complete the study. Permission was granted by the Committee to proceed with the study provided that it did not affect the approval of the research given by the Research and Development Office for the Trust (Appendix 5 page 264 refers). Formal application to continue with the study was therefore made to the Department

of Clinical Governance and Risk at the National Health Service Trust, namely the Trust Lead for Research where the study was being pursued. Permission to continue with the study and to undertake a further period of data collection was granted in writing prior to returning to the field (Appendix 6 page 265 refers). In Phase 1 of the study formal permission to undertake the study was received from the leading surgeon (Appendix 7 page 266 refers). Such permission was not deemed necessary for Phase 2 of the study as the Trust Lead for Research advised that the same surgical lead would be advised formally of the extension by the Department of Clinical Governance and Risk.

3.2.5.2   Informed Consent for Patient Informant Interviews

Before all interviews with individual patients, I discussed the study with the Ward Manager, the nursing staff and other members of the ward team namely the dietician, physiotherapist, the stoma nurse, community liaison nurse and ancillary staff on each of the wards concerned. Staff were addressed informally at prearranged meetings. Nurses or other members of the ward team who were not present at that meeting received a personal explanation if they were assigned to nurse or visit a patient involved the study. Staff showed variable amounts of enthusiasm and interest, although no overt opposition was encountered. The last step before making an appointment to meet each patient was to discuss the study with the informant's surgeon. No difficulties were encountered in gaining the support of the eight surgeons, although the qualitative methodology provided a little difficulty for them, providing a real-life reminder of the qualitative-quantitative controversy.

During a meeting held between 1 and 4 days prior to a patients discharge individual patients were asked about their desire to participate in the present study. I explained fully the study to each patient and all were given the opportunity to reflect in private on whether they wished to take part. I did not attempt to conceal the nature and purpose of the research. Once verbal agreement was obtained, I scheduled an interview with the patient in consultation with nursing staff. All questions raised by patients were answered before agreement to participate was obtained in writing (Appendix 8 page 267 refers). A statement was made concerning the anonymity and the confidential nature of the data collected. Since Chenitz and Swanson (1986) argued that those who choose to participate in research may believe that they may be offered a better treatment deal, I gave an assurance that a decision to withdraw from the study at any time would not jeopardise treatment or nursing care in any way. Finally since a patient's condition influenced whether they were well enough to participate in an interview the nurse assuming responsibility for the patient on the shift when the interview was scheduled was consulted prior to approaching the patient to ensure the patient was fit for

purpose. I obtained brief demographic data from every patient at the conclusion of each interview. Detail of the baseline demographic data collected can be seen in Table 11 (Page 73 refers).

At the outset of each interview I explained the agenda for each patient interview. However, I indicated that there was no requirement to cover all the issues or to cover the issues in any particular order. Patient informants at all times were invited to raise issues they felt were relevant. Although the agenda was primarily used to guide the duration and scope of the interviews, the major determinant was the patient's condition.

3.2.5.3   Informed Consent for Nurse Informant Interviews

Before the commencement of all interviews with individual nursing staff, I arranged a meeting to explain the purpose of the interviews and asked for volunteers. I explained that, having examined the patient's perspective of patient participation in nursing care there was a need to explore nurses' perceptions of the concept. In this way, a more comprehensive view could be obtained. I assured the nurses that although the interviews would be tape-recorded, all information would be treated as confidential and no record would be made of the nurse's name. However, at this point I stressed to the nursing staff that should any informant raise examples of poor practice or practice that contravened the Code of Professional Conduct (United Kingdom Central Council for Nursing, Midwifery and Health Visiting, 1992; Nursing and Midwifery Council, 2008) there would be a need to explore this further at the conclusion of any interview. Following an opportunity to consider in private whether they wished to participate in the study written consent from all the nurses who volunteered to participate in the study was obtained (Appendix 9 page 268 refers). As with the patient interviews, the interviews with nurses began with a discussion of the topics that were to shape the interview. However, while there was a need to guide the interview process sight was not lost of the major purpose of the interview, to learn to see the world from the eyes of the person being interviewed. I obtained brief demographic data from every nurse at the conclusion of each interview. Detail of the data collected can be seen in Table 12 (Page 74 refers).

3.2.5.4   Informed Consent for Period of Observation – Patient Informants

Before commencing each period of participant observation, during a meeting with individual patients I explained the purpose of the observation to all patients. Each patient was given the opportunity to reflect in private on whether they wished to participate in the period of observation. Once verbal agreement was obtained, I planned the period of observation with the patients in consultation with nursing staff. All questions raised by patients were answered

before agreement to participate was obtained in writing (Appendix 10 page 269 refers). No patient refused to be included in the period of observation.

3.2.5.5 Informed Consent for Period of Observation – Nurse Informants

Prior to the period of observation Ward staff (nursing, medical, paramedical and ancillary) were informed of the participant observation at a further pre-arranged staff meeting. Ward staff not present received a personal explanation. I explained the purpose of the observation to all staff. Each member of staff was given the opportunity to reflect in private on whether they wished to participate in the period of observation. Once verbal agreement was obtained written consent was acquired from all the nurses who would be involved in the unit of observation to be employed (Appendix 11 page 270 refers). No member of staff declined me the opportunity to observe their practice. It was again stressed to all nursing staff that should I observe any examples of poor practice or practice that contravened the Code of Professional Conduct (United Kingdom Central Council for Nursing, Midwifery and Health Visiting, 1992; Nursing and Midwifery Council, 2008) there would be a need to explore this further at the conclusion of the period of observation.

During the time in the field, I made every effort to announce my presence as a participant observer in advance. However, owing to the unstable workforce and an inability to control those who entered and left the field of study I soon realised the complexity associated with seeking consent in relation to participant observation. Informed consent was not a single event but an on-going process. On six occasions, I had to announce my presence as newcomers joined the 'unit of observation'. I sought both verbal and written consent from all the patients and nursing staff who were involved in the period of observation. However, owing to the nature of theoretical sampling informed consent was not definitive. It was difficult to tell informants exactly what they were consenting to. As a way of dealing with this, openness and honesty was key. I advised all informants that as the study progressed questions or issues not previously thought of may arise and that these would then influence further observation and conversation.

3.2.5.6 The Challenges of a Joint Role

As the clinical link lecturer for the Surgical Unit where the study was undertaken I had a degree of sensitisation to the general parameters and nature of patient participation in nursing care in the surgical care setting. However, the clinical area was not known so intimately to risk the data being analysed from personal experience and my own categories

of analysis being imposed. For as Blumer (1969) remarked the study has to be conducted from the position of the actor in order to see the way in which actors perceive situations.

Arguments are presented against 'going native', the most important one being that such research is inherently biased (Aguilar, 1981). However, Aamodt (1983) pointed out that while there is some evidence in a few studies of bias in relation to selection of data and formulation of conclusions, the examples are few. Since one cannot claim the role of privileged stranger in one's own culture, the inherent risk of being seen as a nurse or clinical link lecturer, as opposed to a researcher, by one of the informants was considered. With patients and staff alike, rather than presenting myself as a nurse or clinical link lecturer, the role of research student was emphasized in order to encourage both patients and nurses to view the role as that of a detached observer. To adopt the role of nurse may have meant that patients would be reluctant to be critical of any part of their care for fear of causing offence. Similarly, if the role of link lecturer had been adopted nurses may have viewed the role with suspicion. So as not to underestimate the difficulties associated with role separation, prior to starting each period of fieldwork I explained the role to be adopted and agreed that clinical consultation would not be allowed. For these reasons, throughout the period of data collection, I wore smart casual clothing, rather than a uniform or white coat.

Despite the difficulties associated with role separation there are obvious advantages of doing fieldwork in one's own setting. Being an 'insider' is a useful means of creating an informal atmosphere and rapport with the informants. Interactions are intimate and the information more valid and meaningful. The nurse researcher may avoid the 'culture shock' experienced by a non-nurse on entry to the nursing field and may be sensitive to certain aspects of nurses' and patients' behaviour, which a non-nurse may not notice. Acknowledgement of the value of the joint role and use of it to enhance the quality of the research has been identified by many (Fagerhaugh & Strauss, 1977; Morse, 1994). However, awareness of the potential risk of bias is critical as the success or failure of the study depends on it. Nursing knowledge was concealed as far as was ethically possible. As suggested by Reed and Proctor (1995) I attempted to dispose of any cultural baggage that may have coloured interpretations of behaviour and responses during the period of fieldwork. As Sapsford and Abbott (1992) suggested the role adopted should be that of the "amiable incompetent - someone friendly and who has to be told things" (p. 12). In an attempt to avoid influencing both the collection and interpretation of data and thus the inductive generation of theory, bracketing was used. Swanson-Kauffman and Schonbald (1988) and Beck (1992) claimed the use of bracketing, which involves the deliberate examination and temporary suspension of one's beliefs, enables empirical reality to be captured and concentration to be placed on the informant's

experience. To achieve neutrality (Guba & Lincoln, 1985) or increase the objectivity of the data, biases, sensitivities, inner conflicts and 'grabbing effects' from the initial broad review of extant literature were acknowledged formally and committed to field notes and ultimately self-reflective memos. This activity led to an awareness of personal feelings aroused by observations, interviews, published literature and personal or professional experience and increasing reflexivity which is defined by Robson (2002) as "an awareness of the ways in which the researcher as an individual with a particular social identity and background can have an impact on the research process" (p. 22). Indeed my joint role or dual identity stimulated an increased desire to interrogate my own feelings and beliefs and led to me openly acknowledging in self-reflective memos the influence of prior work and experience on patient participation. Reflexivity characterised by the on-going analysis of personal involvement, openness and transparency of potential influence was seen as critical to the credibility of the present study. It was seen as paramount to the emergence of an unbiased in-depth understanding of patient participation in care. As Jooten et al. (2009) affirms the continuous process of reflection on the researcher's own values, preconceptions, behaviour or presence enhances the rigor of the research process and should be part of any qualitative enquiry. According to Arber (2006) when undertaking demanding fieldwork in the health care context where a researcher has a practitioner background such as in the present study a reflexive approach is critical to the credibility of any such study.

3.2.6   The Unstructured Interview

Since the aim of the present study was to elicit an inductively derived theory that would explain the process by which patients participate in their nursing care within an acute surgical care setting, data would be best collected by naturalistic field methods. Although Glaser and Strauss (1967) can be criticised for not attending to data collection in a rigorous or careful manner, to develop dense, useful grounded theory, data must be rich and provide a variety of complete accounts of the major issues and processes involved in the area under study. In an attempt to be faithful to the form and logic of the original grounded theory method, use of the unstructured interview was deemed most appropriate, as it would enable reality to be captured and transactions with informants to be entered as naturally as possible. A theory would also be generated that was neither forced nor redefined but emergent in nature. In an attempt not to naturally lead or guide conversation each interview started with the initiating question: *'I would like to learn something about patient participation in nursing care. Could you tell me what you think about patients participating in their care?'* As Guba and Lincoln (1985) asserted, "the unstructured interview is the backbone of field and naturalistic research" (p. 154). They maintained that to understand and interpret meanings that

individuals give to objects or things, face to face verbal interaction, which resembles natural conversation as far as possible, is essential. According to Sapsford and Abbott (1992) when the prime concern is for interviewees' perceptions in a particular context interviews should inevitably be unstructured. No preconceived ideas about the content and flow of discussion should be imposed on the conduct of the interviews, as the aim is to elicit the informants' views in their terms. However, as Blumer (1969) pointed out human behaviour, interaction and conduct is continually influenced and shaped by the social world in which humans live, therefore no interviewer can enter an interview with a *tabula rasa* view.

The emphasis on the need for first hand immersion in the sphere of patient participation coupled with the requirement to elicit a wide and diverse range of information on the unique and multifaceted nature of the concept emphasised a need to select a method of data collection that imposed minimum structure. Flexibility was the major appeal of the unstructured interview. The adaptability of this style of interview enabled certain responses to be probed and thus rich detailed data could be obtained. Two types of probing were of particular value at different times during the interview process; the recapitulation and the silence probe (Gordon, 1980). The recapitulation probe took the informant back to the beginning of different experiences described and often resulted in new details being recounted. The value of the recapitulation probe is depicted in an excerpt of raw data. The exemplar is taken from an interview in which an informant had earlier mentioned that the non-verbal behaviour of the nurse during the bedside handover affected his level of participation in the activity. The informant alluded to the fact that a nurse's lack of eye contact resulted in a degree of detachment rather than a degree of participation:

Researcher	You mentioned earlier in our conversation that the body language of Nurse X or more specifically her lack of eye contact during the inter-shift handover left you feeling…. I think you said feeling as if you should not participate in the handover. Could you tell me more about that?
Informant	Oh yes, she, she avoided looking at me…It's almost as if you are being talked about and not there. You know this is Mrs X I'M HERE (raised tone). She deliberately set limits on the contact she had with me. She not only avoided looking at me; her encounters with me were brief and very what I would call…superficial or even insincere. You know conversation focused on the weather, sport or the soaps. She certainly made sure that no permanent relationship was established. She certainly didn't want me to take part in the duty report. (P 13)

Clearly, this extract of data illustrates that the recapitulation probe not only provided a signal to describe and develop views further, it too encouraged the informant to speak about issues that might not have been mentioned spontaneously. More interactive opportunities were also established as the informant seemed to interpret that the recapping of experience was a means by which substantial interest was expressed.

However, in contrast there is a risk associated with the deliberate use of a recapitulation probe. The following extract of data illustrates the point:

Researcher	If you don't mind I'd like to go back to something you brought to my attention a little earlier on. You said a few minutes ago before we got onto the conversation about your ability to use the controlled analgesia that you couldn't do much because you needed more information and were reluctant to ask.
Informant	(Interrupting) yes that's right that is what I said…Did, did you not believe me? I was telling the truth you know. I have no reason to tell you anything that is not true (sharp tone – facial expression became very stern) I'm not prepared to get into all that anyway because it just angers me…. I am sure I was deliberately kept in the dark for some reason…this resulted in me getting a lot of pain. I was not shown how to use the pump you see. I'd rather not talk about it though. I do intend however to do something about it – I intend to do something more formal yes I don't want to talk about it. I hope you respect that. Let us go on with something else shall we. (P 7)

By repeating back to the informant a part of what had been said an air of anger resulted. A few minutes had to be taken to soothe the informant in order to defuse the tension that had built up and make the informant feel more comfortable.

The silent probe although valuable in the sense that it established a comfortable pace for the interview frequently constrained dialogue especially when used during the initial stages of an interview. The following sixth minute extract of data from an early interview with a patient provides the most striking example of how discourse was constrained by using silence.

Researcher	You were told to fill in your own chart as opposed to being asked to.
Informant	Yes. (With the intention of getting the informant to expand on the response a 6-second period of silence and an enquiring glance followed. As no dialogue was forthcoming, the interview was continued).

Researcher	Can you elaborate on this a little more – Tell me about the filling in of your chart.
Informant	Sorry what were we talking about; I think I wandered a bit…Sorry.
Researcher	You mentioned about being told to fill in your chart.
Informant	Did I? So I did…Let's see oh yes what was I going to tell you (laughing). (P 3)

The silence, albeit short, contributed to a lack of concentration or memory decay, which in turn stifled the free exchange of information. However, in later exchanges when interaction was more intimate and the informant was feeling less vulnerable and more comfortable with a 'questioning asking/answering' mode, naturally occurring periods of silence frequently produced small floods of spontaneous information from the same informant.

The flexibility inherent in unstructured interviewing also permitted issues to be clarified and a search for negative cases (Glaser & Strauss, 1967), cases that do not fit or support earlier categories. In this way, the unstructured interview served as a means of guarantee for the rigour of the emerging theory. It too enabled topics that had conceptual promise to be pursued. To illustrate the point, early interviews revealed that many informants felt the ethnic orientation or culture of the nurse had a significant impact on patient role preference and behaviour. Analytical memos or written records of emerging hypotheses, analytical schemes, hunches and abstractions stated that:

> Some patients seem to be suggesting that the ethnic origin of the nurse is important. They keep saying that Nurse X always encourages them to participate more, that she really cares and encourages patient activity. Interestingly Nurse X is of Afro-Caribbean descent. Patients are saying it is her innate caring ability that promotes this sort of approach to care. Are all patients experiencing this I need to explore how common these thoughts are and how they are connected with participation? I will add a direct question in the next 3-4 interviews regarding this experience. I also need to speak to some patients who are being nursed by nurses of a different ethnic origin. (AM 77)

In essence, the flexibility of the unstructured interview enabled me to pursue questions that would develop further the proposed idea and sharpen the focus of the study. However, as more data accumulated through more direct questioning in subsequent interviews the analytic process disclosed that it was not the ethnic background of the nurse *per sé* that impacted on patient participation behaviour and interaction but the demeanour, linguistic and non-linguistic behaviour of the nurse. The openness of the unstructured interview enabled

me to refine and develop interview questions to explore the links between patient participation and nurses' interpersonal ability and conduct.

Finally, the selection of the unstructured interview as a method of data collection for the present study was guided by the ontological and epistemological positions of grounded theory. Since the original enterprise of grounded theory (Glaser & Strauss, 1967) is anchored somewhat in the symbolic interactionist school of sociology, it follows that grounded theorists and symbolic interactionists have a shared set of ontological and epistemological assumptions. The symbolic interactionist ontology or belief about the nature of social reality delineates that social life is characterised by a multiplicity of viewpoints and that no single social reality exists (Blumer, 1969). Value is placed on soliciting emic viewpoints or multiple social realities that are faithful to the empirical situation. In symbolic interactionist epistemology, priority is given to objectivity and the maintenance of a degree of detachment between the knower and what can be known in order to capture experiences as they are lived and defined by the actors in the substantive area. Accordingly, application of a symbolic interactionist or grounded theory ontology and epistemology requires undertaking inquiry in natural settings, soliciting viewpoints from the participants in the substantive area, researcher passivity and the inductive generation of theory. Such accentuation on emergence and discovery firmly suggests a qualitative methodological stance is preferable.

The primary assumption derived from the symbolic interactionism perspective was that in order to understand the process of patient participation in nursing care, it was essential to understand the perspectives of the 'actors' – the patients and the nurses – who were engaged, by their presence in the ward, in that social world. The symbolic interactionist perspective would not regard as valid any attempts to explain actions and interactions of patients, for example, without reference to their perceptions of their role, their perceptions of nurses, their interpretation of both their own actions and those of other participants and their experience and expectations of being a patient. Similarly, interpretations of nurses' behaviour must take account of their perceptions of patient participation and their experience and expectations of being a nurse. Thus, to achieve depth of understanding and generate data on patient participation there is a need to interact with the patients and nurses, to talk to them, to listen to them, to gain access to their accounts and interpretations. The unstructured interview allowed this to happen.

Since the unstructured interview is characterised by natural speech and everyday conversation and is essentially non-directive in nature it was assumed that discovery of a theory relevant to patient participation action and interaction would be best inferred from

listening to what the informants had to say about the substantive area under study. Indeed, the unstructured interview enabled insight into the natural world as the informants see it to be gained and theory that is faithful to the empirical situation to be developed. However, it must be noted that as the study progressed the degree of interview structure altered. It was not possible to generate data in a wholly unstructured way throughout the study as the decisions and judgements made gave some form of structure and purpose to the data generation process. The first three interviews tended to be the least structured however, as the analytic process commenced and fruitful avenues of inquiry needed to be pursued, the interviews became more structured but not to the extent that they inhibited informants' freedom of expression. To minimise the imposition of predetermined responses or ideological expressions both open and closed questioning were used.

As a grounded theory study is integrally dependent upon the accuracy of source data, the 61 unstructured interviews, which ranged from 20 to 95 minutes, were audio taped using a digital voice recorder, which incorporated a built in microphone. A total of 43.08 hours of audiotaped interview data were collected during the period of study. The use of a tape recorder removed the necessity of arduous writing during each interview and prevented what Deatrick and Faux (1991, p. 217) termed "filtering of data" due to investigator recall or summarisation. The nuances of the interaction, namely the pauses and intonations that were captured by the use of the audiotape, helped to validate the accuracy and completeness of the information collected. I recorded only brief jotted notes (Lofland & Lofland, 1984) during the interviews to capture the emotional context of the interview and any non-verbal exchanges, which occurred. According to Silverman (2005), it is essential to capture non-verbal communication during an interview, as it can be *5* times more effective than verbal.

The tape-recorded interviews were also used as a means of self-monitoring whereby questions that may have shaped data could be reflected on constantly. Rogers and Cowles (1993) point out that an audio taped interview is of much value in qualitative inquiry as it provides a complete audit trail in that data faithful to the interview can be produced for inspection. On the contrary, there are limitations associated with the audiotaped method of data collection. Loss of data due to failure to capture the context of the interview, lack of familiarity with the equipment and unknown invasive effects on the interactional process is common (Douglas, 1976). To prevent such difficulties arising there was a need to become familiar with the equipment before the collection of any data. To reduce the voice recorder's intrusiveness and increase its acceptability to the informants, I placed the recording equipment out of sight. I used a voice recorder with an in-built microphone with sufficient magnitude to record conversations to reduce what Field and Morse (1985) referred to as

stage fright. Any self-consciousness, which was felt by the patients or nurses because of the voice recorder, was soon dispelled. To maintain confidentiality and anonymity I coded all voice-recorded files and associated transcripts and stored them in a safe locked cabinet accessible to only myself.

Since a qualitative research study demands that the researcher acts in the place of a research instrument the researcher's skill, ability and sensitivity are critical. Accordingly, as much attention needs to be afforded to developing the skill and sensitivity of the researcher as would be paid to the development of any research instrument or tool in conventional research.

In the present study, I conducted pilot interviews with two individual patients from Ward A before the collection of data for use in the study. The 'pre-test' interviews facilitated an increase in self-confidence and the development of interview competence. The analysis of these recordings for common pitfalls in interviewing such as the use of loaded questions and inappropriate probing ensured this interview experience was capitalised on. Reflective analysis revealed that loaded questions were often used subconsciously. For example, asking 'how *did you decide to participate in your care?'* assumed that the informant decided. In contrast, the question *'how did you come to participate in your care?'* leaves things open. Clearly, the pilot interviews were a valuable self-evaluation tool in relation to the skill of question wording. The self-assessment allowed the phrasing of topics to be practised in a variety of ways so as to facilitate the generation of informal, relevant discussion and avoid the over directing of conversation, a practice common to practitioner interviews (Reed and Proctor 1995). Indeed, the initial and subsequent attention that was afforded to interview skill development was crucial to the rigour of the study. According to Sandelowski (1985), such care with data collection is paramount to ensure a degree of credibility. The transcribed data from these initial interviews also enabled an informed judgment to be made regarding the use of a computer software programme to facilitate the analysis of qualitative material. This will be discussed further in Chapter 4 (Section 4.2. page 109 refers).

In addition to developing verbal technique, the pilot interviews also confirmed that no more than one interview should be scheduled in one day, a practice supported by Patton (1990). Conducting two pilot interviews in one day stretched my concentration and did not allow for reflection on the preceding interview, a pre-requisite of theoretical sampling. Finally, the pilot interviews enabled me to practice and develop my skills of analysis. Initially I thought that some 'magical ability' was necessary to create substantive codes and categories. However, with much patience, rigorous examination of the data and assiduous practice in using the art

of questioning, I soon began to develop self-confidence, creative imagination and analytical skills as it became apparent that data could be turned into effective theoretical leads.

For each of the 61 interviews conducted, I typed within 24 hours of the interview a verbatim transcript. Transcription was undertaken as soon after the interview as possible to ensure that memories of the completed interview were still fresh and that ideas, personal feelings, relevant responses, non-linguistic features and the emotional context of the interview that had not been recorded in the jotted field notes could be readily documented. As Atkinson and Heritage (1984) pointed out, the production of detailed transcripts is a crucial research activity, which demands time and rigorous attention. Although the whole transcription process occupied 297 hours and at times resulted in feelings of being overwhelmed by data, self-transcription was of enormous value as it facilitated close contact with the patient's and nurse's world and developed a sensitivity that was necessary for the discovery of theory. In essence, it also led to in-depth thinking and intimate understanding.

To ensure accuracy and improve transcription quality before the analysis of textual data commenced, as soon as each audiotape was transcribed, I listened to the tape and read the transcript concurrently. While it could be argued that the most reliable method for improving the accuracy and adequacy of a transcript is to return it to the informant, I made a conscious decision not employ this strategy as it had the potential to create many methodological problems. Sandelowski (1993) asserted that it is a great imposition when informants have already given their time freely. She further maintained that stories are remembrances about the past and asking respondents to relive these moments has unknown consequences. Owing to memory decay, many members may also simply not be a position to test accuracy. Furthermore, testimonies may be altered on further reflection or later in time, for the ethical purpose of ensuring that ultimate control over how stories are reported is retained.

3.2.7   Observation in the Field

As decisions in grounded theory about how and what data should be collected are made according to the dictates of the emerging theory it was impossible to predict at the beginning of the study that a period of observation would add breadth to the study and provide rich data and answers to contextual questions that the interviews could not address. The decision for choosing to sample for observational data was based specifically on theoretical grounds. Microscopic analysis of the interview data suggested that a period of observation could yield important dividends. The audit trail for this additional methodological approach is depicted in an excerpt of raw interview data. The exemplar, which is taken from one of the early patient

interviews, follows a discussion wherein the informant disclosed that different levels of participation occurred on a shift-by-shift or day-to-day basis.

Researcher	You said you participated in your care - To what extent did you actually participate in it on a day-to-day basis?
Informant	Well it varied.
Researcher	Varied - what do you mean?
Informant	Well it was very much up to the individual nurse. Sometimes you would actually be asked to do specific things like recording all your drinks and preparing all the equipment for a bag [stoma] change. On another day, you just knew that you shouldn't do anything.
Researcher	You just knew ...could you explain what you mean?
Informant	Well you could just tell instinctively. The general manner of the nurse just told you. If the nurse was walking around the bay in a hasty manner looking stressed out, you knew she didn't have the time to wait for you to do things. Sometimes her air just warned you off doing anything. Take my bag (stoma) for instance. When I was first learning to change it I took a long time, I could see from the nurse's face or her frowning..., and occasional sighs to be exact that I was hindering her. In fact, she kept trying to reposition my hands and intervene to speed up the process. It was very off putting you know and I retreated from changing my own bag for a while. She did not have to say anything I just knew by looking at her that I should let her do it. One day the same nurse after the shift report came over and stood at the end of my bed. She then greeted me and asked me how I was getting on. My response was somewhat slow but before I had time to say anything she saw my paper on the bed and asked what the headlines were. She didn't want to hear how I felt I was getting on. On the other hand, I had a nurse look after me whose conversation centred on remarks like - 'would you like to try this?' or 'see if you can do it when you are ready'. This kind of talk encouraged me to participate in my care plan. You basically make a judgement about what you do depending on who is looking after you. You learn to read the signs (laughing). (P 9)

This extract of data illuminated that there was a hidden dimension to patient participation that could not be wholly grasped or articulated by interview alone. The data seemed to suggest that there was interconnectedness between the environment in which participation occurred and how it was perceived and experienced. It appeared that the explicit or even covert behaviour of the nurse (or even the patient) during the provision of routine care imposed limitations on the extent of patient behaviour. However, to account for, appreciate the nuances of what was discussed in the interview, and test the generality and boundaries of

this idea or hypothesis different slices of data (Glaser, 1994) were needed. Since observation is fundamentally naturalistic in nature and there is an acute sensitivity to facial expressions, body language, patterns of activities or actions and contextual elements (Morse & Field, 1996) a decision was made to seek direct observations in the clinical setting. Robson (2002) reported observation is frequently used by the naturalistic investigator to supplement or support data collected by interview and thereby contributes to a holistic understanding of the phenomenon under study.

In the present study, the use of observation data not only confirmed that the verbal accounts reflected real experience it also uncovered some of the otherwise invisible aspects of patient participation behaviour and stimulated lateral thinking and further critical examination of the data. Undeniably, such a methodological approach enabled full immersion into the real world of the patients and thereby enabled a direct and comprehensive view of the complex and dynamic nature of patient participation behaviour and interaction to be obtained. It revealed how nurses used different types of non-verbal communication such as interpersonal space and variation in volume, pitch and quality of voice to *direct* patient participation in nursing care.

Like the selection of interviews, the decision to generate data using observation was also guided by the ontological assumptions under-pinning grounded theory. As grounded theory or symbolic interactionist ontology encapsulates the idea that human behaviour or conduct rather than being a fixed entity, is continually being reacted by the meaningful actions and interactions of social actors it would seem that data gathered through direct observation would provide in-depth insight into the intricacies and dynamic nature of patient participation in the real world. Much information can be elucidated from observing mundane events which social actors may not even be consciously aware of, and therefore unable to recount in an interview (Strong, 1979). Furthermore, as the epistemological position of grounded theory inclines towards the belief that knowledge or evidence of the social world can be generated by observing, or participating in, or experiencing natural or real life settings, it follows that a period of observation would be crucial to the achievement of the ultimate aim of this study, namely the development of a theory that explains the nature of the patient participation within practice.

In prospect, observation seemed very straightforward, but the experience of being in a situation with the directive to observe was extremely daunting and required considerable thought. Since a key feature of observation is that the observer seeks to become some kind of member of the observed group it was necessary to establish not only some role within the

group and whether it would be physically as well as emotionally possible but also what, how and when to observe. Schatzman and Strauss (1973) asserted that these beginning steps in the field are called 'mapping' (p 34).

As part of the 'mapping' process, I made a decision to undertake an exploratory period in the field in preparation for the first 48 hour period of observation during which data would not be collected for inclusion in the study. Although Glaser (1978, p. 8) maintained that a basic tenet of grounded theory is that "all is data", in the present study an explicit decision was made not to collect formally and analyse data during the exploratory period of fieldwork. It was felt that it was necessary to first acquire the skill of being present and being trusted or as Morse (1994) asserted, demonstrate a degree of institutional, political, personal and professional neutrality. However, while data were not formally collected, recorded and analysed during the exploratory period in the field it did facilitate immersion in the world of the acute surgical ward and thus stimulated creative and critical thinking. Ideas, hunches, assumptions and abstractions generated during the exploratory period were later woven into the analytic process.

Essentially, the exploratory period of 28 hours enabled me to establish ground rules for the observation. It also gave staff and patients time to acclimatise to an observer's presence and thus reduce the potency of observer effect. Although no single view as to how much work should be done in the field before starting observation commands universal acceptability, in the present study, several indicators provided some reassurance that following either the acclimatisation or exploratory period the role assumed was not too obtrusive. Patients, nurses, doctors and other health care professionals appeared to accept the presence of an observer to the extent that they did not seek interaction. Furthermore, the informal discussions with both patients and nurses at the end of each field session revealed that minimal disturbance on actions and interactions had occurred. Frequently patients commented that little variation occurred in their behaviour and that of the nurse. On the contrary, many nurses reported temporary self-consciousness but this feeling appeared to diminish or disappear after the exploratory field observation or each period of acclimatisation. As Reed and Proctor (1995) pointed out people cannot for long maintain a special kind of behaviour for the benefit of an observer. In the surgical wards where the observation was undertaken, this appeared to hold true. The wards were frequently busy and nurses inevitably had to concentrate on the demands of their work, the presence of an observer becoming a secondary concern. A further factor, which Strong (1979) described, is that in most medical settings the presence of an observer is not unusual to staff or patients as there

is a constant mix of new and different people and group members become accustomed to a fluctuating presence of strangers.

A further intention of the exploratory fieldwork in Phase 1 of the study was to ascertain not only what degree of concealment would be adopted but also what unit of observation, what positioning and what method of recording would be employed. In deciding to use participant observation as a means of obtaining data about patients and nurses in their natural setting a role had to be selected that would maximise opportunities for gaining understanding and insight into patient participation action and interaction. Gold (1958) described the participant observer's role according to a continuum of:

- Complete participant
- Participant as observer
- Observer as participant
- Complete observer

The role of complete observer role where the researcher remains passive and outside the observed interaction was rejected because it is an almost impossible role. To attempt to maintain such researcher distance or neutrality also defeats the epistemological purpose of immersing oneself in the natural setting. Although similar to the complete observer, the observer as participant role differs significantly in that both field worker and informants are aware that theirs is a field relationship. Work roles and time for writing field notes are negotiated and well defined on entry to the setting. This status, although suitable if the type of phenomenon is not constantly present in the setting, is inappropriate for the present study as patient participation behaviour is constantly shaped and modified in accordance with social interactions. The complete participant, a role whereby the observer enters the setting as a member of the group and conceals the research role was also considered inappropriate. Firstly, the role pretence or degree of concealment is rarely defensible on ethical grounds. Secondly, it is with extreme difficulty that one immersed in a work role can gain epistemological privilege or objectively observe at the same time. Even Gold (1958) noted that the balancing between the demands of the role and self is exceedingly delicate and difficult to manage.

In the present study, it was the role of participant as observer that I adopted for the period of observation in Phase 1 and Phase 2 of the study. This role enabled what Hammersley and Atkinson (1985) referred to as marginality that is a role, which is sufficiently that of an outsider to allow objectivity, yet sufficiently that of an insider to allow insight and understanding to be managed. The role involved minimal participation in the work role,

informing those involved about the purposes of observation and gaining their written consent before each period of observation. The exploratory period in field indicated that the observer as participant role was the most suitable approach for recording data.

Minimal participation in the work role was considered essential so as not to interfere with the nurse - patient relationship and any naturalistic participation action or interaction. Interaction was casual and non-direct during the observational pursuit. I made no attempt to participate in the setting's core activities although on occasions nurses would sometimes request assistance with simple tasks such as bed making, which was always given.

In order to maximise opportunities for observing and understanding role behaviour, it was important to establish good relationships with staff members although every effort was made to balance participation with detachment, familiarity with strangeness and closeness with distance. On occasion however, it was difficult to sustain an essentially inert role. Patients and nurses alike sometimes wanted to share their concerns and annoyances as quiet asides. Nurses in particular attempted to use me as an object of catharsis. Sometimes this created some discomfort and occasionally resulted in a struggle between the human inclination to be friendly and the symbolic interactionist guidelines for observing, that is the need to maintain a degree of detachment between the researcher and the actors in order to ensure the world is seen from the actors' viewpoint (Blumer, 1969). To overcome this challenge I took short breaks when such inner discomfort in observing interfered with the observer as participant role. Details of what contributed to the break were recorded in field notes in order to permit examination and careful scrutiny of the complexity of nursing in action in its natural setting. In total excluding the exploratory and/or acclimatisation period, I spent 72 hours assuming the role of observer as participant in the field.

The unit of observation employed during both periods when data were collected for inclusion in the study was a small group of 4 to 5 patients in close geographical proximity to each other. I found during the exploratory period that such a group of patients interacted with no more than one or two nurses during a span of duty and were hence, a manageable unit, which generated sufficient activity for meaningful conclusions to be drawn. It proved impossible to focus on a larger group due to the number of interactions and activities that occurred simultaneously. Carr (1991) warned that errors of omission are frequently made if too many variables are observed at any one time. In addition, audibility of conversations was considered a problem with a larger observation unit. Where possible particular patients and nurses responsible for their care were followed longitudinally during their hospitalisation in order that aspects of continuity and discontinuity of patient participation could be observed as

they occurred. However, the group being observed did not always remain static. Frequent tactical decisions in relation to participant observation according to situational limitations and opportunities had to be made.

A variety of positional approaches were appraised during the exploratory period to determine which vantage point would yield the most rich, meaningful and reliable data. I ultimately made a decision to adopt a combination of positioning approaches; that of single, multiple and mobile positioning. The flexibility and freedom that such an approach allowed meant that either a static or a mobile position, to observe in sufficient detail all behaviours in different locations could be assumed.

A further decision that needed to be made during the exploratory observation period involved whether to make 'live' observations or whether the observations should be made by studying video-recordings of the research situation. While it is acknowledged that the video-recording of behaviour minimises errors of omission and commission (Carr 1991) and provides a permanent record that can be reviewed repeatedly, it was felt that the limitations of video-recordings far outweighed the advantages. Costello (1973) compared the angle of a camera lens with that of the human eye and reported that a videotape frequently defined some observed behaviour ambiguously. Lighting was also found to impair the quality of recordings (Weick, 1978). Indeed, this would have been a particular problem for the present study, as light streaming in from windows at the end of each bay would have cast half of the patients into shadow, making subtle actions or interactions imperceptible. Furthermore, it was considered that the use of a camera would not be conducive with the epistemological basis of grounded theory, as it was felt that the presence of a camera would be more intrusive in a six-bedded bay than that of an observer. Since the intent of the observation was to study the dynamic and complete nature of patient participation, audio-visual recordings would not capture all the aspects of behaviour and interaction with as much detail as the analysis required. Ultimately, I made a decision to observe live behaviour.

The method of recording essentially followed an unstructured format in contrast to the use of pre-determined activity checklists or rating scales. Such a style was deemed conducive to the inductive generation of theory as it permitted freedom and flexibility in the recording of observation data. Ely et al. (1993) pointed out that unstructured observational methods can be extremely profitable for in-depth research in which the investigator wishes to establish an adequate conceptualisation of an important phenomenon in a social setting.

Structured observational schedules, because they are based upon a given set of categories, furnish a powerful conceptual grid from which it is difficult to escape. While such categorisation is helpful in organising both data collection and analysis, it can also deflect attention away from uncategorised activities (Atkinson, 1992). By using a structured approach, a wealth of data would be lost by reducing the complex and multifaceted nature of patient participation to sets of numbers or categories. However, in the present study as the emergent theory developed, observations became more structured and focused in accordance with the tenets of theoretical sampling. Initial observations were primarily descriptive in nature, unfocused and general in scope. As suggested by Spradley (1980), nine major dimensions of social situations (space, actors, activities, objects, acts, events, time, goals and feelings) were used to guide observations at the outset: As the key processes in operation were grasped observations became more focused and selective and attention was directed towards a deeper and narrower portion of the nurses' and patients' actions and interactions. For example as earlier patient interviews revealed that nurses' general demeanour had an impact on patient participation in nursing care initially, nurses' styles of behaviour or actions were observed. Following a period of observation and analysis, it was apparent that specific micro-behaviours such as raised eyebrows, head nods and language and voice tone had a significant impact on patient participation activity. Thus, a situated yet strategic decision to observe for particular styles of verbal and non-verbal behaviour employed by nurses at different times during the pre and post-operative period was made. In addition, increased attention was placed on the nurse-patient dyad as opposed to the individual nurse in order to observe in a more rigorous manner the impact of nurses' behaviour. In this way, future observations were shaped by the developing theory and thus became more structured.

The developing theoretical formulations also led to the selection of a new data source. Following the first period of observation, the focus of the sampling changed to include individual interviews with a diverse range of nurses. The interviews with nurses were used to substantiate the validity of the data obtained during the period of observation and to further expand and bring clarification to the data. They were also undertaken to clarify variability. As an example, the analysis of the patient interviews and observation data gave rise to the idea that a nurse's level of experience or competence affected the extent to which patients participated in their care. It appeared that nurses consciously or unconsciously used specifically developed verbal and non-verbal strategies to either encourage or inhibit patient action and interaction. However, the validity of this supposition needed to be challenged by interviewing a diverse sample of nurses, both unqualified and qualified.

The following extract of data taken from an observational field note provides evidence for why the focus of sampling changed to include individual interviews with nurses:

> I have just observed two very interesting scenarios. One involved a 3rd year student nurse and a patient who had surgery two days ago. The other a staff nurse (Band 5) and a patient who had undergone surgery the day before. In the situation with the student, I observed that the student approached the patient's bedside saying 'it's time to get up'. She exerted authority over the patient by controlling the agenda. The nurse chivvied the patient out of bed and used request phrases like 'do this', 'keep that flat' and 'put your hand here'. The encounter was crisp. The interaction was in the form of instructions and admonitions. The nurse was in charge and set the parameters of what and what was not acceptable. The power base was certainly unequal. Between instructions, there were periods of silence. There was no courtesy talk to ascertain what the patient wanted to do. Cues, such as negative nodding and frowning, which suggested that the patient did not want to get up or was having some difficulty were missed or even dismissed
>
> The encounter between the staff nurse was different. Communication was such that there was an element of reciprocity and intercourse between the players, epitomising what was perhaps a degree of interpersonal competence. The nurse's discourse was such that she was promoting or even encouraging participation. The nurse had just helped a patient put on a shoe and proceeded to ask the patient if he wanted to try to put on the second shoe and tie the lace himself. Dialogue was peppered with encouraging remarks such as 'you did that very well' and 'that's very good'. Furthermore, on seeing the patient struggling, the nurse offered the use of a shoehorn. No attempt was made to assume control. Emphasis was placed on 'doing with' not 'doing for'. Courtesy talk was used throughout the encounter but conversation essentially focused on the purpose of the patient performing the activity. The patient was definitely responsive and happily attempted to put his shoe on. (FN 94)

The observational data suggested there was an association between the type of interaction or discourse consciously or unconsciously employed and the degree of patient participation that developed. Interactional patterns among nurses appeared to have a significant impact on patient action and interaction. It appeared that through the use of language nurses' exerted control over patient actions and interactions. However, for conceptual and ontological clarity and to determine the extent to which the observational data was translated into meaningful and relevant epistemology it was necessary to employ different slices of data. In this instance a series of interviews with a sample of nurses were conducted to enable an understanding of the nurse-patient encounter from the nurses' perspective and an account of the nuances in therapeutic interaction to be gained. Since the emergent theory also indicated that variables such as the ward climate or more specifically the type of work organisation also had an impact on how patient participation was established, developed or

maintained it was apparent that additional conceptual detail might be obtained by interviewing a diverse sample of nurses from different clinical settings. I thus selected the sample from two wards one of which had adopted a lateral management structure, that of team nursing (Ward A) and the other a more hierarchic structure (Ward C). The wards were chosen on the basis of an informal discussion with the Senior Nurse for surgery and the Ward Sisters to ascertain that the wards exhibited the characteristics of their professed management system.

Indeed, many follow-up interviews with nurses confirmed truth in the observational data. As the following account reveals nurses employ specific verbal and non-verbal strategies to promote or impede patient participation:

Researcher: Picking up on what I have observed over the last few days and what you said earlier about being able to control the level of patient participation – Could you expand on this? Perhaps give me some examples of what you mean.

Informant: Well a lot is down to how you talk to the patient. If you are very prescriptive or direct, the behaviour of the patient the patient will feel reluctant to take part in any care activity. On the other hand, if you seek to impart knowledge or information to the patient and then affirm the worth and value of their actions you are able to facilitate participation. You use a number of cues to encourage patients to participate in their care. Patients then learn to pick up our deliberate pensive….or feeling cues. Nurses are very powerful in this respect and I think most but not all know that. The more experienced you are the more skilled you are at conveying what is essentially I suppose a hidden agenda. (N 13)

During both periods of observation in the study where possible I made on-the-spot records or jotted notes. No definite answer to the question of whether or not to take notes in the field was found. At times, it was a chore that seemed to interfere with observing. At other times it ensured that the task at hand remained the focus and other times, when patients or nurses tried to engage in intensive dialogue, which impacted on the 'observer as participant' role, note taking was a useful escape. The solution was to remain flexible and achieve a delicate balance between the taking of mental, jotted and full field notes. As suggested by Lofland and Lofland (1984) five types of material were included in the field records: a running description of the events that occurred during the period of observation; recalls of forgotten material, interpretative ideas, personal biases, impressions and feelings and reminders to look for additional information.

To give form and precision to the observational data endeavours were made to have, where appropriate opportunistic on-the-spot discussions about events, activities and interactions with the patients and nurses observed during each field session. This kind of dialogue was short in duration and lasted between 3 and 10 minutes. The main focus of this dialogue was to seek explanation from informants about their behaviour during observation. Information gleaned during these conversations also shaped future interviews. To minimise the risk of memory decay and inaccuracy I attempted to typewrite the field notes into a full narrative account at the latest within 24 hours of the field session.

Finally, since an interactionist view of patient participation presupposes a diversity of participation behaviours and diversity in situational and contextual conditions that affect the enactment of such behaviour, observation periods were designed to cover all shift patterns. Although prolonged observation would be of value in observing patient participation action and interaction, during the exploratory period, to maintain sufficient concentration during a recording period and to be able to record voluminous field notes, observation needed to be carried out for a set time of 2 hours at predetermined intervals. While it can be argued that such time sampling can impose a threat to the credibility of observational data (Deatrick & Faux, 1991), measures can be taken to overcome this criticism. In the present study, I held informal discussions with patients and nurses on return to the field, to ascertain what had occurred during periods of absence. In this way, I obtained a complete picture of the substantive area.

3.3   Summary of Chapter

This chapter has described and analysed the design of the present study and the strategies employed for the purpose of data collection and informant selection. Commentary has illuminated that grounded theory and the use of a combination of naturalistic methods of data collection were well suited to the ultimate purpose of the study. The use of grounded theory, interviews with patients and nurses and a period of participant observation in the field of acute surgical care enabled rich data to be gathered and the reality of patient participation to be captured.

The next chapter proceeds to discuss the constant comparative method of data analysis. How the core analytic tasks of description, comparison, categorisation, conceptualisation and theory development were conducted is made explicit. The challenges associated with the analytic cycle are also discussed. The audit trail of proceedings will be made explicit throughout.

CHAPTER 4   DATA ANALYSIS: CODING AND CONSTANT COMPARATIVE METHOD

4.0   Overview of the Chapter

This chapter describes coding and the constant comparative method of analysis used in grounded theory and seeks to explain how it was operationalised in the present study. The challenges that were encountered with this method of analysis are discussed. As grounded theory does not proceed according to a prescribed process with distinct stages, it is difficult to explicate the simultaneous or circular fashion of data collection and analytic activities and the constant dynamic interactional relationships between the researcher and the data. Linearity in the analytic process is therefore deliberately presented for the sake of illustration. To make explicit the actual cognitive and inductive processes, the emergence of one of the three major conceptual categories, which form the basis of the substantive theory that of *Establishing Readiness* is described. Segments of raw data and extracts from theoretical notes and memos are used for explanatory power. Finally, the value of using software to assist in the analysis of qualitative data is examined. Argument is presented as to why a computer-assisted software programme was not employed for the archiving and retrieval of coded data, notes and memos.

4.1   Constant Comparative Method

Constant comparative analysis is the cornerstone of the grounded theory method. It is an intricate process whereby the research is continually redesigned in the light of emerging concepts and interrelationships among variables. Raw data are initially reduced, through the constant comparison of incidents, to concepts that are designated to stand for categories. The process then progresses to a comparison of incident with category, a strategy that allows the properties of categories to be developed. Comparison of category with category follows. Categories are developed and refined until they crystallise and a point of saturation is reached whereby no new information is identified which would indicate that new categories are emerging or that old ones need expanding (Glaser & Strauss, 1967). Theoretical codes are then identified in an attempt to interweave the component parts of various categories. The emergence of hypothetical relationships represents the beginning of theory emanation. As the interrelationships become more apparent one, and occasionally more, core categories evolve. At this stage, it is likely that a theory can be written that is dense and capable of describing the maximum amount of variation in behaviour in the substantive area under study, in this study patient participation behaviour within the context of the surgical care environment.

According to Glaser and Strauss (1967), the purpose of comparative analysis is to generate accurate evidence about what is going on in the area under study, establish generalisations, verify, and generate new theory that encompasses as much behavioural variation as possible. Although the original explication of the constant comparative method (Glaser & Strauss, 1967) offers a valuable, orderly guide to theory development, the processes inherent in the analysis of data are somewhat unclear and poorly articulated (Schatzman, 1991; Turner, 1981; Morse, 1994; Melia, 1996; Holton, 2007). To shed light on the discourse and the mysterious passages of 'Discovery', Glaser (1978) usefully redefined the essence of the constant comparative analysis. As Turner (1981) asserted Glaser's (1978) manual is perhaps best thought of as a guide to the finer points of grounded theory generation. In his complementary book, Glaser (1978) elaborated on the intricacies of the analytic process particularly the nature of coding.

According to Glaser, there are two types of coding: substantive and theoretical. Substantive coding conceptualises the empirical substance of the area under study. It comprises two steps, open coding followed by selective coding. In open coding, the researcher codes for as many categories as possible, which in turn initiate and guide the theoretical sampling process. Codes at this time proliferate fast and begin to slow down once visible patterns begin to emerge. Open coding continues until the data can be subsumed into an emergent set of categories, which are relevant for integrating into a theory (Glaser, 2003). Ultimately, open coding results in the emergence of a potential core category, which put simply is the variable, which accounts for the most variation in the action scene. Open coding is undertaken on two levels: an *overview* and *microscopic* level. During both levels, questions are asked of the data. Glaser (1998, p. 140) proposed a set of questions be asked namely:

- What is this data the study of?
- What category does this incident indicate?
- What is actually happening in the data?
- What is the main concern being faced by the participants?
- What accounts for the continual resolving of this concern?

Selective coding begins following the emergence of a core category and involves a delimiting of data collection and analysis to saturate theoretically the core category and related categories. The core category then becomes the guide for further data collection and theoretical sampling.

In theoretical coding, the analyst conceptualises how the substantive codes and categories may relate to each other as hypotheses to be inserted into the theory. Theoretical codes like

substantive codes are emergent but more abstract in nature and result in an integrated theoretical framework for the overall grounded theory (Holton, 2007). Glaser (1978) provided many examples of coding families that may be used as a guiding force for the identification of theoretical codes. In using a theoretical coding family, Glaser asserts that the fullest range of theoretical coding possibilities and a myriad of implicit integrative possibilities in the data can be captured. However, in an attempt to remain faithful to the concept of emergence Glaser (2005) warned that flexibility in their use is essential. He forcefully reminds the analyst "to stay open to the emergent, earned relevance of theoretical codes" (p. 2).

Strauss and Corbin (1990a; 1990b; 1994) in an attempt to enhance the understanding and the effectiveness of the original enterprise of grounded theory developed an increasingly complex set of operations and procedures to guide researchers through the analytic process. Three explicit types of coding were proposed:

Open Coding
The process of breaking down, examining, comparing, conceptualising and categorising data.

Axial Coding
A process whereby data are put back together in new ways after open coding. Comparisons between and interrelationships of categories are explored using a coding paradigm.

Selective Coding
The process of selecting the core category, systematically relating it to other categories, validating those relationships and filling categories that need further refinement and development.

Although it might appear on first inspection that the descriptions of the three types of coding advanced by Strauss and Corbin are essentially the same as those reported by Glaser and Strauss (1967) and Glaser (1978), the mechanics of the analytic process are quite different. Elaborate instructions, which do not permeate the classical constant comparative method, guide each of the three coding operations in an exceedingly stringent and inflexible manner. The original discussion of theoretical sampling has also been advanced. Complex, intricate rules, instructions and models for the theoretical sampling process have been introduced with the type of theoretical sampling (Open, Relational or Variational) being dependent on the type of coding with which the researcher is engaged. Strauss and Corbin also imposed on the analytic process a conditional matrix or analytical tool for capturing the many conditions and consequences bearing upon a given phenomenon.

While it could be argued that the guide to theory development and the operations of the constant comparative method explicated by Strauss and Corbin offered some level of clarity, the analytic process they described imposes on grounded theory a rigidity that Glaser claims the originators never intended. As Stern (1985) pointed out Strauss and Corbin's interpretation of the method "bears only faint resemblance to the original work" (p. 149). Clearly, the original premises of the method have been violated. A paradigm shift has occurred, as the refinement of the strategies for handling data and developing theory do not rely for accuracy and truth on the participants in the real world. Rigid rules and major transformations such as the multiple coding instructions, the techniques of comparison, the coding paradigm and the conditional matrix used to advance the analysis appear to manipulate intentionally data and thus abuse the concept of emergence, which comes from constant comparative analysis. The focus on the application of technique has diverted the researcher from generating theory directly from data obtained in the real world. The modified objectivist approach (Guba & Lincoln, 1985) is no longer sustainable as the new analytic procedures have the potential to impose the biases and perspectives of the researcher and produce what may be judged as an unfaithful account of reality. There is now an inclination towards subjectivity. This is particularly evident from the forced questioning of data along the lines of who, what, why, when and how much? Such a constrained preconceived verificationist approach to data analysis may shape respondent's actions and thereby influence the meaning ascribed and interpretations negotiated by the researcher.

There appears to be no time for a researcher employing Strauss and Corbin's evolutionary model to trust the emergence of the social integration of everyday life. Clearly, the "torturing or forcing of data" (Glaser, 1992, p. 123) in the analytical process has distanced the method from its symbolic interactionist roots. Strauss and Corbin (1990a) even pointed out that "one need not subscribe to a symbolic interactionist perspective to use grounded theory" (p. 26). Glaser (1992) asserted that although the new method produces a credible research product it is not emergent in nature or from the perspective of the substantive area participants. In his own expressive terms, he said:

> "What is written in Strauss's book is out of the blue - a present piece with no historical reference on the idea level, and an almost new method borrowing an older name - grounded theory - and funny thing it produces simply what qualitative researchers have been doing for sixty years or more: **Forced Full Conceptual Description**" (p. 2).

Accordingly, one of the major challenges faced in pursuing the present study was the decision about which interpretation of the constant comparative method would be most

appropriate. While Strauss and Corbin's formulaic linear operations were useful in learning and working out the complexities of grounded theory and the esoteric language of vintage grounded theory caused initial frustration, the simplicity of the central idea of the constant comparative method as was espoused by Glaser and Strauss (1967) and later Glaser (1978) was seductive and used for the purpose of data analysis in the present study. The less rigidly defined terms and procedures had the potential to let the data speak for themselves and facilitate an openness that ensured a degree of faithfulness to the substantive area under study remained and thus that the ultimate aim of the study was achieved.

4.1.1 Substantive Coding Operationalised

4.1.1.1 Overview Analysis

Following either verbatim transcription of the unstructured interviews or the conversion of field notes into a narrative account, data were subjected to an overview analysis. I read each transcript or narrative account in its entirety to obtain a sense of the overall data. I then scanned and exposed data to brief thoughtful questioning asking *'what is going on?'* and *'what is being said about patient participation in nursing care?'* In an attempt to yield impressionistic codes I highlighted in italics in the text incidents, words and short phrases that appeared of interest or significant to the substantive area under study. I typed in the left-hand margin of the transcript related substantive codes that is codes, which label the substance of data (Stern, 1994). I conceptualised each fragment of data into as many substantive codes as possible in an attempt to ensure as much theoretical coverage of patient participation behaviour as possible. I used frequently 'in vivo' codes or more specifically the language of the informants to name a substantive code in an attempt to facilitate precision of meaning. I recorded in brief in the right hand margin ideas, hunches and working hypotheses that served to provide conceptual entrée into an otherwise more complex area of study.

While, at first, the data appeared to be a mass of confusing unrelated accounts, the overview analysis served to develop theoretical sensitivity that is an ability to see with analytical depth what is there (Strauss &Corbin, 1990a). Indeed, it prompted a review of the data albeit in a brief manner with a theoretical eye right from the start. It also actively encouraged the playing with and developing of ideas. In Appendix 12 (page 271refers) the overview analysis is exemplified using an extract of raw data from the first interview. The extract follows a discussion relating to the fluid or dynamic nature of patient participation and illustrates the diversity and number of codes generated from the overview analysis.

In the present study, the category *Establishing Readiness*, which seeks to describe the most distinctive antecedents or characteristics that appear repeatedly when patient participation occurs, did not emerge until the third interview. However, the idea that certain 'specifications' or 'criteria' needed to be met before patients participate in their care emanated during the overview analysis of the first interview. In the research exemplar in Appendix 12 (page 271 refers), the patient explains that varying levels of participation are dependent on nurses' linguistic interaction and non-verbal behaviour. It appears that nurses' actions and interactions can be instrumental in promoting, initiating or impeding patient participation in nursing care. Brief speculation about the necessity to achieve a certain 'climate' laid the foundation for a more detailed analysis. It also provided impetus for future data collection whereby following the tenets of theoretical sampling the concept could be explored and developed into a detailed category. For example in the second interview the opportunity to explore the 'cues' for participation behaviour was taken and in doing so prerequisites and antecedents for such behaviour were discovered further.

Interviewer	In a previous interview a patient mentioned that you pick up certain cues from the nurse about whether it is appropriate to participate in your care. What are your feelings about this?
Informant	Well you most certainly do. There are so many things you notice just by watching the nurse looking after you. Firstly, it is her general approach and perhaps her obvious tolerance. The nurse may simply invite or negotiate activities with you.... (Laughing). This is rare but it happened once. Mainly though, you just know from subtle manifestations such as the amount of information they give you, the look of interest on their face or the limitations they impose on your activities whether or not they are going to allow you to take part in your care. Often their dialogue is superficial and you know it is because they do not want you to do much for yourself or even do their job. (P 2)

While the initial overview coding process served its purpose well in terms of developing theoretical sensitivity and the theoretical sampling process it was not without criticism. Failure to facilitate verification and saturation and thus develop a theory that neither is rich nor with explanatory power lends credence to Glaser's (1978) assertion that if used alone the overview analysis is inadequate. A simultaneous microscopic analysis is necessary to achieve a level of abstraction and detail that unravels the complexity of patient participation.

4.1.1.2   Microscopic Analysis

The microscopic analysis of data involves word-by-word, sentence-by-sentence and line by line examination of the field data. It serves a dual purpose. Firstly, like the initial overview analysis it facilitates the generation of multiple substantive codes, which in turn results in full theoretical coverage of the phenomenon under study. Secondly, unlike the overview analysis it imposes rigour on the research process as it allows each code and category to be traced back to its original source. As Urguhart (2002) and Charmaz (2006) asserted line by line coding is key as it forces data to be considered in a detailed and systematic manner and therefore it is less likely that a story will be imposed on the data. Although fascinating and exciting to undertake the procedure is extremely time consuming and voluminous. An audiotaped 45-minute interview for instance resulted in 28 A4 pages that needed to be microscopically coded. Ultimately, the microscopic analysis generated some 5036 fragments of data and 2406 substantive codes. Planning the technical aspect of the in-depth coding required thoughtful reflection.

A data management system had to be devised whereby fragments of data, substantive codes, theoretical notes and memos could be recorded, retrieved and viewed simultaneously with ease at different points in time over the study's life. In describing the analytic process Glaser and Strauss (1967) offered a strategy for handling data however, while it was appealing it offered limited space for the recording of theoretical notes and memos and thereby had the potential to stifle creativity and the emergence of a rich theory. Since their strategy was also manually operated, it presented difficulty with data retrieval. Following much painstaking deliberation and experimentation a system using the Word Processing Programme Word for Windows was devised. The programme was advantageous in that it suited individual style, facilitated easy storage and retrieval of data, had a text search facility, and permitted the simultaneous viewing of data. As Morse (1991) asserted for most data sets, the process of coding can be quite comfortably performed with a word processing programme such as Microsoft Word. In the present study all data was stored on a personal computer that could only be accessed by the researcher using a secure password. A USB Stick securely password protected was also used to 'backup' computer files and folders. This with any hard copies of interview transcripts, field and theoretical notes and memos was kept securely in a locked cabinet that could only be accessed by the researcher.

In every file of field data I highlighted in bold in the text excerpts of raw data, words or sentences that appeared following much thought, reading, re-reading and astute questioning to offer some comprehension of the underlying processes of patient participation. Using the

cut and paste facility of the word processor I transferred to a separate file where they were numbered and coded accentuated fragments of data. As a result of constant, thoughtful questioning as recommended by Glaser (1978), I then generated substantive codes directly from the data.

Initially the in-depth immersion in the data generated multiple codes. Multiple code generation at the outset was deemed essential to account for all variation in patient participation action and interaction. However, as the analysis proceeded I generated fewer codes at such rapid speed as coding became more focused and similar phenomena were given the same code. I recorded theoretical notes relevant to each fragment of data in the same file. The theoretical notes 'picked up' where the substantive codes 'left off'. I recorded abstract thinking about extracts of raw data, the substantive codes, the clustering of codes to form categories, the properties and dimensions of potential categories within theoretical notes. The theoretical notes formed the first written descriptive rendition of what patient participation was all about. To preserve anonymity and to enable the fragments of data to be re-read in context I devised a system whereby the location of the raw data could be established with ease and relative speed. Appendix 13 (page 272 refers) exemplifies how I undertook the microscopic analysis. An extract of raw data from the field observations has been used to illustrate further how the category *Establishing Readiness* emerged.

Since the generation of grounded theory is also dependent on another strategy, that of memo writing or the theorising of ideas about the emergent theory, the formulation of memos became a central activity in the present study. I conducted memo writing concurrently with coding and categorising procedures. I found this to be a critical part of the study as it enabled key theoretical developments in the analysis to be elucidated. During both the substantive and theoretical coding activity in particular, I always had paper and a Dictaphone nearby in readiness for the immediate recording of ideas, which I later expanded, in typed-written memos. Glaser (1978) rightfully maintained that such instant recording is critical to the generation of grounded theory and should neither be hurried nor skipped.

While at the outset memo writing was considered to be tedious and time consuming, it soon became apparent that to enrich the analytic process, to make implicit thoughts explicit and to expand the data corpus, detailed analytic and self-reflective memos were essential. In the present study, I used analytic memos to record products of creative inductive and deductive thinking, questions, muses and speculations about data, the reviewed literature, and the emerging theory. They served to advance the data from the empirical to the theoretical level of abstraction. More specifically I used them to document the cognitive process

(comprehending, synthesising and theorising) and account for the development of substantive codes, categories, theoretical codes and ultimately the patterns of action and interaction between and among patients, nurses and other members of the health care team within the context of the acute surgical care environment.

Self-reflective memos comprised personal biases, distortions and reactions to the findings of the initial review of the literature, informant narratives and the products of observation, which in turn enabled the right degree of reflexivity (Sapsford & Abbott, 1992) to be gained. The reflective memos ensured that personal 'eyeglasses' did not shape the interpretation and colour unfairly what was emerging from the data. Selective extracts from both analytic and self-reflective memos are exposed in Appendix 14 (page 273 refers) to illustrate the evolutionary nature of both memo writing, the conceptualisation process and more specifically how one specific category that of *Establishing Readiness* emerged. The set of memos have been arranged according to the process of analysis. They illustrate how the category was formed, built and densified.

4.1.2   Theoretical Coding Operationalised

Through the conceptual sorting of memos, theoretical codes began to manifest. Like substantive codes, they are emergent but more conceptual and abstract in nature. Glaser (1978) explained that theoretical codes allow categories to be organised, to clarify what each category is in relation to other categories and to develop links between categories. In this way, links will lead to the development of theory. To assist in the process of theoretical coding or to weave the fractured story back together again, Glaser (1978, p. 72) recommended the use of a '"coding family". To transcend the empirical nature of the data and to think in theoretical terms theoretical codes from a diverse range of coding families can be used to guide the abstract conceptualisation (Glaser, 1978; 2005). Glaser (1978) asserted, "it is necessary for a grounded theorist to know many theoretical codes in order to be sensitive to rendering explicit the subtleties of the relationships in the data" (p. 72).

However, in the present study Glaser's (1978) 18 coding families and his more recently published array of theoretical codes (Glaser, 2005) were not used explicitly to guide the emergence of interrelationships between the saturated categories as it was felt that the application of such an analytical scheme could undermine the basic principles of open-mindedness and earned relevance and thus force theoretical perspective. In an attempt to adopt an essentially objectivist stance and ensure that theoretical codes were not forced but allowed to emerge or develop I made a decision to use the basic technique of questioning to

explicitly reveal the subtleties of the relationships between categories. At this point persistence was required to arrange and rearrange categories and continue asking questions until all categories related to each other. Questions I asked of the data and categories are included in Table 13:

Table 13   Questions asked of the Data during the Theoretical Coding Process
• What is going on in the data?
• What is the focus of the study and the relationship of the data to the study?
• How do the three categories (*Establishing Readiness, Shaping Work* and *Incurring Rewards and Costs*) relate to each other?
• Can any of the categories be moved to a higher level of abstraction?
• Can a code be designated to stand for all three categories?
• How can the three categories be explained?
• What is it that is helping nurses or patients to participate in their care?
• How do patients and nurses create the conditions necessary to include patients in their on-going health care?

The obligation to think 'theoretically' as distinct from 'descriptively', repeatedly pose questions about relationships, develop hypotheses and then test them back in the field enabled links between all categories to be built and a move to higher abstract or conceptual level to be made. Selective literature was also reviewed at this conceptual point in the study to add completeness to the theoretical description, give validation to the accuracy of the findings or illustrate how the findings differed from the published literature. Essentially literature was treated as data to be analysed and integrated into the emergent theory. Concepts from the literature had to earn their way into the emergent theory, just like any other concept. The process of synthesising or the merging of the categories to describe a typical composite pattern of participation alongside the process of theorising required a relentless search for answers, accurate recall, speculation, falsification, verification, lateral thinking but most importantly active continuous questioning. However, used in isolation these strategies or techniques of analysis were found insufficient. Identifying relationships between categories is a challenging process that requires much creative and rigorous analytical thinking. As Holton (2010) asserted theoretical coding for conceptual integration and having

trust in the emergence of a theoretical code is one of the key challenges facing the grounded theory researcher.

Visualising thoughts and the emergent analytic scheme as a whole helped me to blend the data into a coherent entity or integrated theoretical framework. Diagrammatic representation yielded great understanding of the conceptualisations being developed and readily enabled me to develop and manipulate the malleable theoretical schemes until the 'best' and most pragmatic and most parsimonious theoretical scheme for the linking of categories was developed.

Ultimately, the process of theoretical coding revealed a theoretical code or more specifically a basic social process. According to Glaser (1978), a basic social process is a type of core variable or category that is pervasive and processual in nature and which accounts for change over time. It must have at least two or more phases or stages. In the present study, a basic social process explains the emergent theory. The data revealed the evolution of a process, which was identified as the process of 'Engaging'. 'Engaging' is a three-phased process through which individual patients move in order to reach the goal of being able to participate in their care, during both the pre and postoperative period. The process commences on a person's entry to hospital for surgery and culminates when the patient is discharged from hospital. The process accounts for change over time and thus variation in patient and nurse action and interaction during the pre and postoperative period. Three dynamic and interrelated phases, *Establishing Readiness*, *Shaping a Role* and *Incurring Rewards and Costs* seek to describe how patients establish, develop, maintain or inhibit patient participation in practice.

To ensure that the emergent theoretical formulation explained what actors, in this case the patients and nurses took for granted in their social world I shared the theory with three individual patients and two individual nurses. Although because of the duration of the study and changes in patients and nursing staff it was not possible to share the full articulation of the discovered theory or conceptually abstract narrative with the people who provided the data, both patients and nurses spoke with enthusiasm of the potential significance of the research. All made confirmatory statements attesting to the credibility of the conceptualisation. Reactions such as '*it makes sense'*, '*it feels right*' and '*it has application beyond the surgical setting*' reinforced the comprehensibility of the theory and that it made sense to the patients and those practising within the context of an acute surgical care setting. As Guba and Lincoln (1985) asserted this is the most critical technique for establishing credibility. Indeed informant's views of the credibility of the findings and interpretation were

seen as crucial to the rigour of the theory. As Bryant and Charmaz (2007) wrote informants should "play a major a major role in directing as well as acting" (p.34).

4.2   Qualitative Data Analysis Software

At the outset of the present study, the feasibility of using a qualitative data analysis software programme to assist in the management of data and the analysis of qualitative material was investigated. Prior to the collection of data for use in the study I undertook a three day residential workshop programme using data collected from the pilot interviews to explore the value and challenges associated with the use of a theory-generation software program, in this case the Non-numerical Unstructured Data Indexing, Searching and Theorising program (NUDIST) originally developed by Richards and Richards (1994). This program, designed specifically for grounded theory, was at the time reputed to be most sophisticated program available for a PC Platform (Weitzman & Miles, 1995). While it is acknowledged that use of the NUDIST program, like other software programs, saves time and energy and can provide evidence of analytic rigour (Kelle, 1995), an organised storage file system for large amounts of data, easy systematic retrieval of text or codes from large data sets, an uncomplicated mechanism for the identification and cross-checking of category development and a system that enables memos to be attached to indexing categories to record on-going thoughts, it was felt strongly, that the computer-aided analysis minimised the personal experience of the process, and the situational and contextual factors which add depth to the emerging developments. More importantly, a feeling of being dominated by the software and its technical aspects emerged to the extent that it did not inspire original thought. This in itself would have been detrimental to intuition and creativity and resulted in myopic interpretation. As Dembrowski and Hammer-Lloyd (1995) and Denzin and Lincoln (1998) pointed out computers can take over to the detriment of the thinking process and make data analysis too mechanistic. Indeed, despite the capacity of software programmes for the storing and retrieving of coded data the largely mechanistic mind-set that results from their application is counter-creative to the conceptual imperative for generating good grounded theory. Although, it is to be acknowledged that the main burden in terms of analysis does lie with the researcher.

In attempting to use NUDIST it was also recognised that dissonance existed between NUDIST and grounded theory in that NUDIST started with the identification of codes or 'nodes' which were then broken down into hierarchies of smaller concepts which are included in the higher order ones. In other words, it employed a top down approach (Weitzman & Miles, 1995). The decision tree feature of the programme was too linear and hierarchical to

represent effectively the complex and multi-dimensional relationships of specific concepts within the experience of patient participation. In actuality with grounded theory, the process is the reverse, substantive codes are merged into higher levels of codes until a core category emerges. A hierarchical structure of codes is too limiting, as a theory is often more like a network of related categories than a hierarchy. As Webb (1999) asserted the imposition of a hierarchical structure is a distinct disadvantage of computer assisted qualitative data analysis software. In addition, owing to personal work style the use of the software resulted in feelings of distraction, being overwhelmed and at times alienated from the data. Frequently because of 'on screen coding' work on the codes was undertaken in isolation from the complete text leading to not only alienation but also decontextualisation of the data. Fear that the context of data will be lost and that the a researcher may become disengaged from the data is a warning reported by many qualitative researchers (Agar, 1991; Ely et al., 1993; Coffey at al., 1996; Catteral & Maclaran, 1997; Fielding & Lee, 1998) and developers of such software (Seidel & Kelle, 1995; Kelle & Laurie, 1995). In effect, Richards and Richards (1991) summarised the dangers eloquently stating that "...computer techniques are marginal to the tasks of grounded theory. The process of theory emergence requires a different ability: to see the data as a whole. To code and retrieve is to cut it up. The grounded theory method leaves text almost untouched "(p. 260).

Finally, as a result of the period of interruption in the present study and the associated expansive development and refinement of the processing abilities of many computer assisted qualitative data analysis software programmes due consideration was again given to using such software in phase two of the study. However, as the present study was too advanced, the data set in phase two was small and at this strategic point there was full engagement with the data, confidence in the robustness of the data management system already developed and the emergence of the substantive theory could be demonstrated, it was felt that to introduce a new data management system at this stage would not help conceptually or add to the rigour of the study. Indeed, Glaser (2003; 2005), Pope et al. (2000) and Holton (2007) asserted firmly that despite the technological advances with computer assisted qualitative data analysis software the use of computer software continues to restrict creativity, result in the loss of intimacy and engagement with the data and enforce analysis strategies that go against the methodological and theoretical orientations qualitative researchers see as the hallmark of their work. As Bryant and Charmaz (2007) reported, "grounded theorists continue to await a package that can replicate the complex capabilities of the human brain for conceptualisation of patterns of social behaviour" (p. 287).

4.3   Summary of Chapter

In summary, this chapter has explored critically the process of coding, reduction and theory development. Application of the constant comparative method has been made explicit. The development of substantive codes is described using extracts of raw data, theoretical notes and analytic and reflective memos. The process of abstraction has been detailed in relation to the development of one of the major categories that emerged in the study. The chapter has also examined critically some of the challenges and limitations associated with the contact comparative method of analysis and the strategies that were employed to enhance the rigour of the data analysis process. Finally, the chapter concluded with a critical debate on the role of software use in qualitative research or more specifically the coding process. Argument was presented as to why computer aided analysis was not undertaken in the present study.

The following chapter presents the three conceptual categories or phases that emerged from the inductive analytic process. A description of the properties of each of the categories generated from the data is presented.

CHAPTER 5   THE EMERGENT CONCEPTUAL CATEGORIES

5.0   Overview of the Chapter

This chapter presents the three dynamic, interrelated conceptual categories or phases, which form the basis of the emergent theory. The three phases; *Establishing Readiness*, *Shaping Work* and *Incurring Rewards and Costs* will be discussed discretely. The specific contextual determinants, which exerted an influence on or shaped the three phases as they were experienced by the patient and the nurse, are exposed. Segments of raw data and extracts from field records, theoretical notes and memos are used to provide rich description and explanatory power. Where appropriate, literature used as a source of data will be presented to expand the features of the categories. A more extensive engagement with the literature and a deeper analysis and interpretation will appear in Chapter 6. The interrelationship between the three conceptual categories will also be explicated in Chapter 6.

5.1   Establishing Readiness

5.1.1   Introduction

The phase *Establishing Readiness* describes the antecedents or conditions that need to exist in order to achieve a desired level of patient participation in nursing care within the context of the surgical care environment. The antecedents that emerged influenced significantly the extent and nature of patient participation as it was experienced by the patient from the point of admission for surgery until discharge. There was an array of factors that were conducive to the ideology of patient participation in nursing care. At the heart of the experience of participation and key to ensuring that the patient achieved a desired level of participation in care, was the need for the patient and the nurse, to engage and develop a positive connection or health care relationship. There was also a need for both patient and nurse to disclose and expose, in word or through demeanour, to each other, their beliefs and values about patient participation. Patients and nurses were also required to develop mutual understanding and agreement regarding the situational meaning and nature of patient participation in nursing care and more specifically the goals, roles and responsibilities that each should assume. Furthermore, to initiate or enable participation in care patients required access to relevant information, resources and expertise. From the perspective of the patient access and exposure to a wide spectrum of input concerning diagnosis, surgery, care and treatment was crucial to the development of expertise and the establishment of desired levels of participation in care. Specific contextual determinants were found to influence a patient's desire and readiness for participation in care. Crucially there was a need for the nursing practice paradigm and the surgical ward infrastructures and climate to be supportive

of a culture that promoted the enactment and promotion of patient participation in nursing care. It was also evident that determinants such as the knowledge, experience, attitude and behaviour of patients and nurses alike affected significantly the readiness of the patient to engage in a range of activities associated with participation in care.

5.1.2   Developing a Positive Connection

The calibre of the connection between the patient and nurse was central to the extent to which patients established readiness and accordingly achieved and maintained a desired level of participation in their care. A positive connection was perceived by patients, from the time of admission to discharge, to have a potent influence on their experience of participation in care. Positive in this context was defined as being a connection or relationship comprising distinct features, namely trust, confidence, respect and interpersonal sensitivity. Practice competence and contact whereby patients experienced sustained encounters with the same nurse or team of nurses were also deemed critical.

Patients were of the view that an inclination to trust and the need to have confidence in the dependability, knowledge and reliability of the nurse or nurses providing their care were conditions integral to the enactment of patient participation. As most patients vehemently pointed out the development of trust and confidence and thus a positive connection with a nurse influenced not only their desire to participate in their care but also the extent to which they established readiness and actually achieved a desired level of participation throughout their hospital experience. Accounts from patients confirmed that a positive connection was one of the most distinctive driving forces for the enactment of patient participation in nursing care.

Patients made explicit how such a relationship made a significant difference in a positive direction to patient participation. As one patient commented:

> The bona fide relationship I have with X [referring to a specific nurse] lies at the heart of me being able to participate in my care. I think the extent to which anyone participates in their care is very much dependent on the rapport you have with your nurse. With X I feel self-assured. I have faith in her and her ability. Without that special bond, I would not have developed the confidence to change my bag [pointing and referring to a stoma bag]. It is the rapport and faith I have in her that has enabled me to develop the self-belief I need to participate in my care or any purposeful discussion about my future. (P 8)

Trust was particularly important to patients in determining the role they would assume and the extent they would participate in their care. However, the relationship between trust and

the level of patient participation that actually occurred was diverse and often illogical. Many patients who expressed a desire to participate in their care in some shape or form reported overwhelmingly that high levels of trust in a nurse frequently lead to a desire to assume a passive or limited role. No patient characteristic such as age or gender was found to impact on this view. The patients who reported having high levels of trust in a nurse expressed a desire to handover their care, decision making and any problem solving to the nurse. Underlying this desire for a confined role was the assumption that nurses had the expertise to carry out care activities well, both in the technical sense of properly assimilating and interpreting data, and in the interpersonal one of acting in the best interests of the patient and clearly communicating findings and options. However, it was evident that on occasion limited patient activity or interaction was also triggered by low levels of trust in the nurse or even total distrust. The account of one patient albeit an extreme case illustrates the point:

> A trusting relationship is vital. Nurses should invest time in developing relationships with patients especially ones that are based on trust otherwise as a patient you are reluctant to take part in any type of activity. A lack of trust diminishes your desire and actual participation. (P 13)

The rationale for the view that distrust resulted in patient deactivation could not be explained logically although some patients reported that the risk of assuming an extensive role when levels of trust were low was too great. Low levels of trust occurred when patients could not be assured of receiving the necessary support if they were to engage in their care in a significant way. On the contrary, if low levels of trust or distrust were associated with a negative health care experience patients wished to assume a significant role in their care.

As the following interview extract reveals lack of trust was a motivator for wanting an increased level of participation:

Patient	The extent of participation depends a lot on the trust you have in the nursing establishment. I have little trust in the firm as mistakes are made. The nursing care my mother who was dying received was poor. My lack of trust has resulted in me having a staunch view about my position.
Researcher	I am sorry to hear this and of your loss. Do you think you could tell me a bit more about this and… (Patient interrupting)
Patient	My lack of trust makes me wary about everything. I am always on my guard. I don't trust the nurses and as a result I want to participate, you know be involved in everything especially if it is to do with my care, my surgery, my drugs and my future. (P 15)

Interestingly, where low levels of trust in a nurse were reported and/or efforts to build trust in a relationship were recounted as being unsuccessful, some patients advocated 'nurse shopping' as a critical engaging strategy. Patients explained how they sought out nurses whose approach instilled an acceptable degree of trust. Although it was recognised that approaching or trying to 'recruit' a different or new nurse to assume responsibility for their care was generally not an option many came to believe it necessary if they were to accomplish a desired level of participation. As one patient reported:

> If a nurse from the team assigned to my bay does not allow or give me opportunity to take part in any discussion about how I am getting on and on top of that I did not trust them I will find somebody else in the team who I know I could trust and work with. Sometimes you have to play detective or shop around to get a nurse that you feel you can trust and will allow you to take part in your care to the degree you want. It's not easy to recruit someone though (laughing) - You have to be cautious so as not to offend. (P 31)

In addition to trust being recognised as a key feature of the context in which most patient participation took place, patients also valued nurses who were sensitive, perceptive and courteous reporting that such features alongside an egalitarian form of communication were critical to achieving effective patient participation. To patients it was fundamental that they were listened to, understood and regarded as resourceful individuals. Having their knowledge and views about the role they wanted to assume recognised was seen to be remarkably important. A positive relationship was seen by patients to include respect for what the patient knows, senses and thinks of their symptoms, their plan of care, the treatment prescribed and the contribution they wish to make. Patients asserted that being respected as a human being and individual and having their illness experience, views and feelings about their role and contribution acknowledged were essential antecedents of patient participation.

Patients were also exceedingly conscious of how a nurse's communicative style could promote or hinder the establishment of a positive health care relationship and ultimately a participatory approach to care. Interactional style was deemed instrumentally important. The importance of being in a position of communication equality was seen by many patients to be crucial. A communication posture whereby there was reciprocal conversation, openness and honesty about thoughts and feelings was also seen to be critical to the establishment of effective participation. However, such a form of communication was reported by some to be the exception rather than the rule. In an extract presented overleaf one patient asserted passionately that:

Good communication should be the embedded norm to afford patients the opportunity of assuming an active role in their care. Face to face interaction on an equal pegging is vital. Without a doubt, the world in here needs to change. Most staff are detached and see themselves as superior to us. (P 32)

Nurses shared the view with patients that trust, confidence and communication equality were critical ingredients for the establishment of a model of nursing practice that promoted and encouraged varying levels of patient participation in nursing care. Some nurses, albeit mainly those from Ward A[1], stressed the importance of using engaging strategies to bring an essentially asymmetrical form of communication closer to a state of symmetry. Examples of the strategies employed for this sole purpose were reported and observed to include: *detection*, to establish views about facts like role preference; *persuasion*, to induce and secure a level of trust and *disclosure,* to reveal at opportune moments inside information such as where the patient was on the operating list or nuances of the consultant. As one nurse stressed in discussion about the value of an egalitarian form of communication:

To create an environment that promotes patient participation you need to listen and develop a solid understanding of your patient's position….communicate with them on an even footing, be open. You need to recognise patients as individuals and not be condescending. You have to spend time with them, make them feel special even trust them with personal information. (N 10)

To transform, using engaging techniques, what was normally, on admission, an asymmetrical form of communication into one, which more closely approximated symmetry, was for some nurses automatic. For others it was more challenging and less successful. Patients reported frequently how some nurses were not able to decrease the amount of control they exercised in conversation or encounters. As one patient recalled frustratingly:

The struggle I had to convince the nurse that I did not need a diabetic diet was unbelievable – she seemed to be grasping at straws to find evidence that her view about what I should eat was right – every time she entered my room she asserted that I must eat a diabetic diet – she clearly didn't trust my judgement. Knowing what I knew about my condition I definitely didn't trust her either. She was on some sort of power trip I think. I mean it was unbelievable – did she think I would put myself at risk in any way? (P 4)

The concept of trust within the context of a nurse-patient relationship and ultimately patient participation in nursing care was seen by patients and nurses to include both interpersonal

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[1] As described in Chapter 3 Ward A was the surgical ward where patient participation was applied significantly to service delivery. A clear participation strategy existed. Patients were viewed as participants in the business of healing, players in their recovery and experts on their needs, preferences and capabilities.

and technical elements. Many patients had strong convictions about the nature of trust. They perceived that a nurse's interpersonal sensitivity, skill and practice competence were crucial requisites for a trusting relationship. Patients felt that in order to begin to assume a participatory role at any level they needed to be assured of the nurse's interpersonal and practice competence. Assurance about categories of competence and, ultimately, trust was secured normally through care-giving activities, although frequently expertise was communicated through effective interaction. One patient described the need to have 'utter faith in the nurse's practical expertise and communication ability' (P 8) before entertaining any idea of participation in care. This patient likened such faith to his own professional role:

> Look, I'm a builder and, if someone wants something built, they have to have total faith in me and my work. It is not much different in here. If you don't have total confidence in your nurse's skill and her ability to communicate or share plans with you, you don't feel at ease taking part in things like discussions or decisions. If a client of mine doesn't trust me, he would never let me build his house. There would be no contract. It's the same principle isn't it? (P 8)

Many patients maintained that interpersonal competence specifically was critical if a desired participatory role was to be established and secured from admission until the point of departure from hospital. Patients reported that the admission interview was often the first opportunity, on arrival in hospital, to engage with the nurse. They referred to it as the foundation on which participation was built and that, if a nurse did not engage in a positive and competent manner at this time, the form of participation adopted was often restricted to what was described as 'basic activities of participation', such as describing health care experiences, receiving information, holding social conversation and the completion of menu and/or patient satisfaction cards. Indeed, it was evident that if a positive connection was not established at the time of admission to the ward, significant effort was required later on to repair the relationship and promote engagement in wide-ranging and more complex self-care activities and/or verbal forms of participation such as expression of concern, the asking of questions, the making of suggestions or the stating of preferences. In an extreme case, an interactional misalignment during an admission interview proved unrecoverable. As the patient explained:

> The initial feel I got from the nurse through her icy conversation told me that she was not interested in me or in developing any sort of rapport. Nothing she said or did produced an opportunity for me to participate in any discussion about my care. As a result, I clammed up for most of my stay and responded using mainly utterances such as yes or no. (P 3)

Clearly, the interactional style and competence of the nurse affected significantly a patient's desire and actual level of participation and was seen as pivotal if patient participation was to be promoted seriously and throughout both the pre and post-operative period. Many nurses themselves reported using specific micro-behaviours such as head nods, language and voice tone at different times during the pre and post-operative period to initiate and encourage patient participation. Observation and follow up interviews with nurses revealed engaging strategies, such as attending to a patient's individuality, the use of personalised and non-verbal interaction, acts of sincerity, purposeful openings and phrasings were consciously and unconsciously used to build trust and confidence in admission interviews and/or patient assessments which, in turn, resulted in opportunities for participation being introduced into patient encounters and conversations at the point of initial contact. Some nurses were observed to adjust their behaviour to promote and increase a patient's level of participation as much as they could. Encouragement, direction and persuasion were engaging strategies employed to facilitate early and on-going participation in care.

An extract from an observed nurse-patient interaction illustrates the point. The patient concerned had had an investigative laparotomy the previous morning and was getting out of bed for the first time.

The extract provides an account of the nurse's dialogue with the patient at the time and illustrates how trust, confidence and a pragmatic act of participation were initiated through the use of interactional sensitivity and competence:

> Now Mr X, shall we get you up. I'm sure you are dying to get out of that bed and stretch those legs (nurse smiling and placing hand on patients shoulder). I know you are probably a bit nervous with these two tubes but I'm here to help you. Come on let's have a go shall we (in a slighted raised and excited tone) – just take it slowly at your own pace and support your tummy (using a more serious and firm tone). It will be nice for X (referring to the first name of the patient's wife) to see you out of bed. She is so worried about you, you know. How about holding onto the arm of the chair first and then pulling yourself up slowly. At this point, the nurse stood back slightly but close enough to offer support – the patient was clearly anxious and somewhat reluctant but replied: 'I am not so sure I can get up myself', but a short while after he swung his legs round placing them on the floor while holding onto the chair – it was hard going for him but he did it – the nurse stood back and smiled at him – she then responded saying: 'Well done; you did that brilliantly, see you don't even need me. Well done'. The patient then proceeded to stand-up and place himself in his chair. (FN 101)

Clearly, certain characteristics of speech delivery and effortless interactional features were found to invite a patient's participation in care at any level. An extract from another nurse-patient encounter during the admission process illustrates the point further making explicit how effective interaction can facilitate the establishment of linguistic participation:

Nurse	(Smiling and holding out hand) Hello Mrs X [referring to her surname] how are you. My name is Nurse X or some patients just prefer to call me X [Referring to given name].
Patient	Hello I'm fine thank you. My name is X [Referring to given name]
Nurse	What do you like to be called?
Patient	X [referring to given name] is fine, although my husband has lots of names for me.
Nurse	I bet he has (smiling, laughing and leaning towards patient with open posture). Now X we need to have a chat about what you are here for and what proceedings will entail. Let me just read your letter from the GP and then we can take it from there.
Patient	Oh, oh right okay.
Nurse	Actually – Maybe I could read the letter out to you – that will tell you what I know.
	Nurse reads letter out aloud.
Nurse	So the GP is telling us that you have suffered from an alteration in your bowel habits for quite some time.
Patient	Yes that's right for about 6 months now. I have diarrhoea for about three days and then a period of constipation – it kind of alternates – I last went five days ago.
Nurse	(Nodding) That is very useful to know. It certainly seems we have reached a point where we've exhausted all medical treatment and now surgery of some kind is the next option. It's not a black and white situation by any means but I'd be interested to know how you feel about having an operation. (FN 146)

The patient then continued to tell her story, making explicit how the surgery would give her a new life.

The opportunistic discussion that occurred with the above patient following the observed encounter confirmed that patients believed that a nurse's discourse and ultimately their interpersonal competence frequently invited patient action and interaction. It appeared that through the use of language and particularly the use of varying levels of formality and informality, nonverbal communication such as positive nodding or smiling, accentuated honesty, voice tone and dialogue peppered with encouraging remarks nurses were able to

promote patient participation in varying forms. Verbal acts such as the asking of questions and asking for descriptions of health experiences, expressions of concern and opinion were also observed and frequently identified by patients as being strategies that invited patient participation throughout both the pre and post-operative period. As the aforementioned patient reported:

> The opening of her [referring to the nurse] conversation and her degree of informality and openness made me feel comfortable and that there was a need for me contribute to the interview. Even though I had only just met her she instantly made me feel that she respected what I had to say and that my view was going to be important. She made me feel my story was important to her and this made me want to play a part. (P 12)

The linguistic interaction and non-verbal behaviour of nurses created unmistakable openings for patient participation in nursing care. Varying communication strategies were employed to cultivate a positive health care relationship, which in turn resulted in patients partaking in their care. Patients were sensitive to nurses' narrative cues for participation however, the reverse was true of some nurses. Interpersonal sensitivity and an ability to recognise a patient's prompt for participation was not an attribute possessed by all nurses. Patients often commented that the more experienced nurse was continually alert to signals that indicated a patient's desire to participate in their care.

The opposite was observed to be true among the more junior nurses or students. As one patient claimed:

> The senior ones [referring to nurses of a Band 6 or 7] usually pick up on things [referring to narrative and non-verbal cues]. They pick up on your signals and realise you want to take part in things or that you don't (laughing). Seriously though the more senior staff are very perceptive...the juniors and the trainees [referring to student nurses] well they have a lot to learn about interaction and signals. (P 14)

Interestingly, the interpersonal and technical competence of the patient was also perceived by nurses to be critical to the enactment of patient participation in nursing care in general. Nurses needed to be assured of a patient's knowledge and skill. Patients frequently reported the need to create opportunities for their own competencies to be displayed in order to gain the trust and confidence of the nurse caring for them. Failure to demonstrate such competence resulted in many patients asserting that they were not afforded the opportunity to participate in their care to a desired level. Some nurses who held negative views of their patients as potentially capable and trustworthy partners reported that they were not likely to

enable patients to work with them and often took a lead in some activities such as decision-making. Several nurses talked about having strong feelings towards a few patients and even having favourite patients with whom they might engage more and encourage to participate in their care. Such patients were usually those that 'exhibited a willingness to assume a degree of control and responsibility and who had the skills necessary to take part in their care in any shape or form' (N 9). If patients did not appear to possess the ability or skill to participate in their care the scope of participation was usually limited to what they referred to as a very basic form of participation such as description of feeling or self-medication.

A patient's effort and contribution was limited by the deliberate employment of interactional strategies such as the use of closed questioning, monosyllabic responses to questions and non-verbal expressions or 'frowns'. Such disengaging strategies were used frequently by nurses to restrict and direct the way a patient participated in their care. An account elicited from a patient illustrates the point:

> I had this nurse who was just so disinterested in me. She was there to do her job and she actually went as far as slapping my hand when all I did was push the tape down to fix it firmly [referring to an intravenous infusion site]. At the same time she just looked at me, said nothing - just looked at me. Her look engineered my behaviour for sure. After this one incident, I just did what she said – you just knew not to try and do anything yourself. All the patients in the bay feel the same – we call her the iceberg. (P 29)

According to some patients, nursing jargon and rudeness were other common manipulative or disengaging strategies employed by nurses to reinforce the power imbalance and thus restrict opportunities for participation. For example when one patient reported asking about the possible complications associated with her surgery the nurse 'looked at me like I had a hole in my head and used language that was not English as I know it'.(P 27)

Observation of the bedside handover on Ward B also revealed a form of nurse behaviour that stifled any level of participation from the patient. Nurses tended to stand away from the bed to conduct the handover and were observed to whisper to each other about the care of patients to the extent that some nurses complained that they could not hear what was being said. To most patients the whispering was simply another form of discourtesy, a way to 'keep a distance from the patient and prevent any patient input'. (P 41). The focus of the bedside handover was also observed to be on tasks that needed to be done or had been done further excluding the patient from the handover. Overleaf, an extract from an observed bedside handover illustrates the point:

> This is Mr X. Fast from tonight for endoscopy tomorrow at 10. Had chest pain this
> a.m., given GTN with no effect. An ECG was done. No changes were noted.
> Doctor said not to worry just observe. Mr X in Bed [referring to the patient in the
> next bed who they had yet to approach. (FN 245)

Actions to inhibit participation often manifested in the form of general disrespect. Patients reported participation was often restricted by for example an expression of feeling or concern being met with either no response from the nurse or, where there was some discussion, the matter was abruptly dropped in the resumption or the continuation of a task. A few patients found their efforts to assert themselves or participate in dialogue about their case met with sarcasm or insults. As one patient reported:

> I needed one afternoon to take my prosthesis off as it was rubbing my stump
> quite badly. I told X [referring to a nurse] about this and how uncomfortable it was
> – I even told her my skin felt raw and you know what she said to me - come on
> Mr X [referring to the patients name] it's only been on for about 15 minutes, you
> need to be brave, you fought in the war do you really need to take the prosthesis
> off. (P 19)

A manifestation of disrespect for patients also involved ridiculing any initiative or form of participation on their part. As another patient recalled:

> I specifically asked at the shift handover if my appendicitis was caused by me
> eating wheat products such as pasta or cereal. I wanted to understand what had
> brought me in here at two in the morning. I addressed the question to the matron
> [referring to the Ward Manager] and all of them [referring to the nurses at the end
> of the bed] laughed and one mockingly said, "well I guess it might have if you
> believe in miracles". (P 24)

The use of intentional 'manipulative' or disengaging interactional strategies was particularly evident when a ward's climate was exceptionally demanding. This was usually the case during the immediate pre and/or post-operative period and was reported by nurses to be a way of coping with physical and psychological demands of an acute surgical ward. As one nurse asserted:

> Very often you intentionally monopolize the airwaves by talking more than
> listening or allowing. You do this to restrict a patient's participation especially
> when you are run off your feet. It's about self-preservation. (N 1)

On the contrary, less experienced nurses [referring to nurses of Band 2 and 4] were observed and found to use 'manipulative' strategies mechanically and thus failed to appreciate the impact of such behaviour on patient action and interaction. They too failed to

realise the effect of certain ward routines on the nurse-patient relationship and thus patient participation. For example, there was a distinct lack of awareness that the everyday completion of nursing documentation particularly the patient assessment template impeded opportunities for initiating participation during the admission process. Some qualified yet inexperienced nurses reported never considering that the consistent recording of patient detail during an assessment interview meant a number of communicative interactions that may have encouraged participation at any level were missed.

Most nursing students were very oblivious to the fact that a number of customary practices such as the admission assessment in the pre-operative period restricted significantly patient contribution. On the contrary, patients were very aware that the assessment interview if conducted by a student failed to establish whether a patient even wished to assume a participatory role. In the main, they asserted that any form of assessment if conducted by a student or a less experienced nurse [referring again to nurses of Band 2 and 4] stifled any form of participation beyond the act of answering questions.

For students an awareness of the conditions needed to encourage or advance the scope of patient participation was virtually non-existent at the level of patient care. The reverse was true of the more experienced nurse [Band 6 and 7]. A nurse's clinical experience and maturity was found to have a positive impact on the level of awareness of conditions that enhanced or inhibited opportunities for patient participation. However, despite this awareness practice was not always modified to facilitate participation. Patient safety, lack of time and fear of litigation were cited as reasons for not reviewing or adapting practices to invite patient participation in any form. As a Band 6 nurse explained:

> Filling in the assessment at the same time as talking to the patient detracts from the naturalness of the interaction. It is a kind of a bridge ... it does not facilitate participation. Completing pages of documentation with the patient in attendance is just one of the hidden elements that do little to encourage patient participation. Notes, well actually, the completion of them at the bedside are part of the bureaucratic structures on a ward that reinforce the separation between the patient and the nurse but you have to complete them in order to protect yourself and the patient – you have no choice in the matter. (N 4)

A further feature that was critical to the development of a positive connection between the nurse and the patient was the nature of the actual nurse-patient encounter. The constancy of the nurse-patient connection appeared to influence whether or not, and how patients participated in their care in both the pre and post-operative period. Both patients and nurses maintained that for a desired level of participation to be accomplished health care encounters

needed to be constant. It was clear that both patients and nurses felt that for participation to go beyond tokenism there was a need for the relationship between the nurse and the patient to be constant. According to patients, the primary value of an on-going relationship with the same nurse or team of nurses was that a measure of trust and confidence could be secured which in turn invited patient participation. Nurses reported that encounters with patients that were sufficiently enduring to allow a positive relationship and meaningful interaction to develop did much to ensure that patients achieved a state of readiness and accomplished a desired level of participation in their care. Sustained contact and the associated provision of continuous as opposed to fragmented care were deemed critical. Where encounters were brief such as when non-permanent staff were employed or nurses engaged in task-orientated nursing or had a high patient work ratio that prevented them from spending time engaging with or getting to know the patient a positive relationship did not evolve and participation was circumscribed. As one nurse described:

> If the ward is busy like on a Wednesday [referring to an operating day] most if not all of what I do is task orientated – I simply haven't the time to encourage any patient effort or contribution. I am too busy looking after patients especially when they are acutely ill. To be perfectly honest and I'm embarrassed to say this but my relationship with patients is superficial most of time as I'm rushed off my feet. You really do need time to connect with a patient to promote a practice that really enables a patient to participate in care activities properly. If you're busy you just can't and then if they are in and out because of the pressures for beds the situation is made worse. It's not the best but this the real world of nursing. (N 6)

Observation reinforced that high illness acuity often forced nurses to engage in task-orientated care irrespective of the system of care that was promoted on the ward. This is turn resulted in little attention and effort being placed on the development of a positive connection and thus on patient participation. The need to accomplish particular tasks made nurses less responsive to the patient's possible contributions. Patients themselves often reported that a nurse's enactment of a task and its associated activities, such as the documentation of nursing activity often stood in the way of their being able to engage in their care in any way. A number of patients perceived that patient records and the presence of technology on the ward particularly in the immediate postoperative period and usually in the first two days postoperatively affected the development of a relationship that fostered participation. Patients reported that 'documentation', 'computers' and 'medical technology' on the ward took up much nursing time and often lead to nurses spending little meaningful time with the patient to enable them to develop the confidence to begin to participate in their care. Some patients were of the view that 'form filling' and technology took precedence over caring for patients in a manner that promoted participatory activity or dialogue. They also reported that

nurses only spent time with them in the first day post operatively when machine alarms sounded. The exception was when a patient was overtly upset. Interviews with nurses confirmed this view as many only expected to have contact with patients in the first day postoperatively if they required specific clinical intervention. Furthermore, nurses also reported that despite the practice paradigm of the ward care in the immediate post-operative period was nearly always driven by tasks. As a nurse reported:

> In my experience in the first 24 hours after surgery, there is an entrenched fixation on caring for the patient's physiological functions – there is no significant interaction to encourage any degree or kind of patient participation – care is technical or procedural and needs to be. (N 11)

Undoubtedly, the normative expectation of individual nurses on an operating day or during the first few post-operative days was that there needed to be a focus on task driven or protocol led care. During this time, patients were visibly marginalised and seen to assume a more restrictive role, a finding that supports the seminal work of Szasz and Hollender, (1956) and Biley (1992). Care was given irrespective of the patient's desires and ability to contribute. The notable inclination to disengage with the patient during the immediate post-operative period was however defended by some patients irrespective of their desire to participate in their care in some shape or form. As one patient asserted:

> Overwork, hospital administration, lack of time – how do you expect nurses to have time to include us in our care even if they want to? When you come back from theatre they have to look after your pumps, drips and monitors and write in your records or on your charts. It doesn't leave them much time for anything else. Let's be sensible about it. You might want to be included but it's just not practical. You have to accept that. (P 5)

Illness acuity in most instances did not facilitate a practice that promoted a significant degree of patient participation as the patient was considered by many nurses to be inanimate. Dialogue in terms of relationship building, information giving or explanation was essentially foreign during the acute postoperative period and most notably when major surgical intervention was undertaken such as in the instances of a vascular, orthopaedic and abdominal surgery. Patients reported that in the main activities or verbal acts of participation did not occur until patients were less dependent on the expertise of the nurse. Significantly, most patients revealed that when a nurse got to know them as a person rather than a 'body in a bed' (P 27) they felt ready and able to begin to participate wholly or in part in their care.

This usually occurred during a time when the patient's dependency status was less acute. As one patient revealed:

> I think when nurses categorise you as being less needy they start talking to you and getting to know you – they start finding out if you want to participate in your care. When you demand less close attention and your care demands less recording most nurses try to develop a bond with you that encourages you to play a part in things. (P 41)

Furthermore, since sustained nurse-patient encounters were not always possible during periods of acute illness acts of participation were frequently restricted or delayed. As a nurse explained:

> Although on my ward there is a culture that invites and encourages participation patients are sometimes too heavy [referring to an acutely ill or unstable patient] postoperatively to be able to promote such a practice. Nurses need to be given respite from these demanding patients to help them cope. For respite you rely on agency nurses. This means that there is often limited continuity in care and in terms of participation patient input is limited or will vary as different nurses provide care in different ways .(N 7)

Observation revealed that when agency nurses were employed there was a tendency for them to concentrate on doing tasks such as completing vital sign recordings, dispensing medication and changing wound dressings. Opportunities to encourage a patient to participate in their care were therefore compromised. Informal discussion with agency nurses during a period of observation revealed that there was an unwritten expectation by the permanent ward staff that agency staff would complete essentially all the task orientated care within a given timeframe. Time for genuine engagement with patients was therefore restricted. This in itself resulted in a lack of motivation among many agency staff to include patients in their own care. As an agency nurse reported:

> As a non-permanent member of ward staff you need and are expected to complete all your designated jobs before the end of your shift. If you don't, you don't get asked to come back. You would like to include patients in the same way that permanent staff try to, but you do not have the time. You have little time to create openings for patients to participate in their care even if it is to ascertain properly how they think they are progressing. During the morning shift, for example you have the drug round to do and all the dressings and obs [referring to vital sign recordings]. There's this list of jobs that have to be done. (N 3)

The disparity in approach between the permanent and non-permanent staff often left patients confused about what they should or could be doing about their own care. Confusion among patients was exacerbated further by the fact that it was not uncommon during a four-day

period for one patient to be cared for by up to eleven nurses who might be either a permanent or a non-permanent member of staff. As one patient revealed:

> You just don't know what you are supposed to do – the boundaries change depending who is on the shift. (P 1)

In essence, success in terms of *Establishing Readiness* for a desired level of participation was dependent on a positive connection between the patient and the nurse at any point during the patients hospital stay. However, while a positive connection was dependent on elements such as trust, confidence, interpersonal sensitivity, practical competence and sustained contact contextual determinants within the ward had a significant impact on the connection that developed between the patient and the nurse.

Many patients conveyed that the approach of the ward manager and senior ward staff influenced considerably the development and nature of the nurse-patient relationship that evolved and thus the model of care delivery employed. Most were of the view that if the ward manager or the 'second in command' were not seen to engage with patients in a way that would encourage a positive connection to develop between patient and nurse then staff would not be inspired or persuaded to foster patient participation in nursing care. As one patient articulated:

> It's like any business, the modus operandi of the CEO or in this case the matron is hugely influential. The manner in which the matron provides care is critical as nurses clearly emulate the behaviour of the boss. (P 44)

Interestingly, a few nurses reported practising in a way that challenged their beliefs about the role of the patient. However, they complied with the accepted norm of not engaging fully with patients, as they believed that a general failure to emulate the practice paradigm sanctioned by the ward manager placed them in position of vulnerability. One newly appointed staff nurse reported challenging the ward's practice of not involving patients in the inter-shift handover and being subtly punished for not conforming to custom and practice:

> When I first arrived on the ward I was very enthusiastic – I guess I was idealistic too. I tried all the time to include my patients in a way that I would want to be included but not all nurses appreciated my way of working. After a while I began to realise that my trying to integrate my patients in conversation during handover was not looked on very favourably. I'm sure that is why I was never allowed to go home that bit early. It felt like I was the only one ever to be asked to take a shortened lunch break – call me paranoid but I'm sure it had something to do with my approach not being the accepted norm on here. I soon lost my mojo and did as all the other nurses did. (N 2)

On the contrary, positive role modelling by a ward manager and senior staff was reported to enable nurses to operationalise and apply engaging strategies that facilitated patient participation in nursing care at any level on an on-going basis. However, from the interviews with patients and nurses and the period of observation in the field the promotion of a participatory approach to care was seen only to be facilitated *continually* by senior staff on Ward A. On Wards B and C the same level of senior staff were seen to promote patient participation albeit not incessantly. Demographic data indicated that of the senior nurses who were observed to encourage activities associated with patient participation on a regular basis most had at least six years or more experience and expressed a strong personal commitment to the ideology of patient participation. Senior staff who promoted patient participation as the norm were observed to hold discussion groups with more junior staff and some were observed to assume a mentorship role to promote and maintain such a model of practice. According to nurses who worked on Ward A the clinical supervision programme and tailored support and guidance that was provided to new, inexperienced nurses did much to foster patient participation as an approach to care on the ward.

Many nurses from Ward A stressed that skill enhancement through education and support in clinical working was salient to the establishment of 'genuine' patient participation practices. Interestingly, there was also a staunch view held by many patients and nurses from all wards that the development of the interpersonal skills needed to promote patient participation in any form should be integral to all nurse education programmes both pre and post registration. As a newly qualified staff nurse and a patient informant explained:

> Patient participation can be implemented using any model of care delivery. It is all about developing enhanced communication skills and having them properly assessed and I don't just mean in an essay. You need to be competent and feel competent to communicate with your patient in a way that will encourage effort and any level of contribution. (N 7)

> This approach (referring to patient participation) presents real communication challenges to most nurses so why not help them develop the necessary skills. Skills training should be integral to all they learn. (P 43)

Finally, critical to the development of a positive connection between the nurse and the patient was the matter of resource. Patients reported unanimously that if the nursing practice paradigm or ward policy was to promote a form of patient participation, which is more than just symbolic effort, a review of practice resources was urgently required. Patients reported that economic constraint was the most obvious obstacle to patient participation in nursing care. Some patients spoke about the way that inexperienced staff and staffing pressure

particularly during the postoperative period influenced adversely the level of participation established or promoted.

Most nurses supported the view of patients advocating that a scarcity of time, a shortage of permanent staff and an impoverished skill mix had to be addressed if patients were to be given a real opportunity to participate in their care. As one nurse reported:

> Being short staffed prevents me from having the time to invite participation from patients. I want patients to have a proper input but when my back is to the wall and I am under pressure it is much easier to do things myself than wait around all day for the patient. (N 1)

In two extreme cases, it was reported by nurses that the demands of modern day practice and the scarcity of time inspired them to place emphasis on patient participation. Both reported that their approach had something to do with regaining elements in nursing that were perceived as being 'lost' or 'neglected', that is, those humanistic elements that were obscured by the pace and demands of a modern day practice. As one nurse commented:

> The chaos generated by the everyday audits [referring to a daily hand washing and bed vacancy audit] could prevent me from building a rapport and establishing a good relationship with my patients, but I am determined that such imposed routines will not take away what I call my protected time with my patients when I am able to encourage active participation opportunities. Being able to promote participation is integral to holistic care. Daily hand washing audits I acknowledge are important but they take you away from the patient and do not encourage you to engage your patient in their care. (N 10)

In summary, the calibre of the connection between the patient and nurse was critical to the extent to which patients established a readiness for a participatory role in their health care during both the pre and post-operative period. Trust, confidence, interpersonal sensitivity and interactional ability were pivotal to the development of a positive connection or health care relationship between the patient and the nurse. Furthermore, the leadership and management style of the ward manager and the availability of adequate resources were also associated strongly with the readiness of the patient to engage in a range of activities associated with participation in care.

5.1.3   Exposing and Exploring Opinion

Interview data revealed the importance of both the patient and the nurse being attuned to each other's views about patient participation. An acute propensity to be open and share views was seen to provide a sound platform for the establishment and advancement of

participation at any level. The exposure and exploration of opinion was also deemed critical if patient participation in the provision of nursing care was to be established and progressed to a degree of mutual satisfaction. Timing of self-exposure was also important. As one patient reported:

> Right from the outset the nurse needs to appreciate where you are coming from – You know - what your position is with respect to your care. When you are settling in you really need to disclose how you feel about participating in your care. I can't stress enough how important it is to lay bare your views early on. (P 31)

While most patients indicated that it was crucial to expose views about participation to the nurse at the time of admission, such exposure of self at this time, did on occasion, result in 'humiliation' or a degree of 'vulnerability' being experienced. This was especially the case if patients verbalised during an admission interview a desire to assume a participatory role and later recognised that 'their' nurse was reluctant to abandon the traditional caring role, delegate some control to them or even allow them to express opinions or share decision-making. As a consequence of experiencing feelings of 'vulnerability', patients reinforced the need for nurses to be 'open' and 'sincere' about their expectations of the patient's role at the point of admission. Some patients stressed passionately that nurses had a responsibility during the admission process to communicate frankly their expectations of the patient role in order that a team playing relationship, where it was so desired, could be established right from the outset. Patients reported that such openness also enabled them to process expectations and behave in such a manner so as to be able to 'fit in', develop a sense of alliance with the nurse, adapt to the views and practices associated with nursing care delivery on the ward or work towards creating a state of harmony. As one patient explained:

> Shortly after I arrived, I was asked by the nurse if I wanted to take part in my care. I explained to her that I would like to continue to give my own insulin. Little was said so it didn't dawn on me that the nurse wasn't happy about me giving my own insulin. Then, when it came to teatime, I did my usual blood test and gave myself my insulin. The nurse...the same nurse then came over to me during her medicine round. She said she had my insulin and I told her I had already given it. Well she was less than pleased. She was obviously not happy but hadn't said anything about this earlier on when we talked about my role preferences. I wish she had because all my humiliation could have been avoided. It would have saved me feeling like a naughty school girl. (P 11)

Although most patients felt strongly that self-exposure needed to commence at the time of admission to the ward, or soon thereafter, some reported deliberately limiting exposure of viewpoint until they experienced closeness with the nurse, or more crucially, they had established firmly the viewpoints of the nurse about everyday patient participation and its

scope. Patients asserted that, if they *knew* the nurse and *knew* they were committed to patient participation, it led to them wanting and assuming, from the point of entry to hospital, a substantive role in activities such as pain control, self-monitoring (such as the self-recording of fluid input and output), medicine administration and verbal forms of participation like decision-making and reporting during the bedside inter-shift handover.

In addition to the desire to be cognisant of nurses' views about participation, patients felt nurses needed to appreciate fully the meaning of participation from the perspective of the patient. All patients deduced there was a need for the nurse to attend to the patient's individuality and consider participation in association with that individuality. A similar view was expressed by some nurses. Getting to know the individual patient and recognising what participation means to a patient was seen as especially important in determining the level of participation to establish, facilitate and/or promote. Nurses agreed strongly that some patients lend themselves more naturally to the process of participation than others. Accordingly, most nurses conceded how important it was to sensitise themselves to how patient participation was perceived by individual patients. As one nurse asserted:

> There is a real need to take account of individual variances. You really need to know your patient's preferences and if they have the capacity to take on so called care activities – I mean really know them as every patient is so, so different in terms of what they can and want to do. (N 14)

The exposure by patients of viewpoints and feelings about roles, efforts and contributions influenced clearly the level of participation promoted or adopted. As one nurse revealed:

> You have to have a real handle on things (referring to patient's views on participation). If your patient reveals how much they want to participate in their care you can plan your work on that basis. If they play their cards close to their chest well that just makes it hard and you may end up not facilitating any level of real participation. (N 8)

Mutual respect for each other's views about patient participation was also seen to be crucial. Where both patients and nurses were open to two-way communication about their views and each other's views were *heard* and *regarded*, both patient and nurse believed there was a greater chance of desired levels of patient participation being established and maintained. Patients generally volunteered views about participation if the nurse created an atmosphere whereby they could disclose their views about their desired role in health care and they felt their views were *acknowledged and respected*. Conversely, unenthusiastic comments about participation were made if patient's perceived nurse's behaviours restricted or blocked

opportunities for discussion about role and views and opinion was overlooked or disregarded.

As one patient recalled bitterly:

> I could have easily learnt to bandage my own stump a lot earlier on but the particular nurse caring for me never really showed any interest in teaching me. She was a bad apple incapable of understanding that I wanted to learn how to look after my own stump. She rarely sat down with me even when things were quiet. She preferred to sit and chat at the nurses' station. This was obviously her way of avoiding me. We never talked about me contributing so I guess I just thought why bother or why worry. I just let her get on with it. (P 33)

Clearly, opportunity for discussion about desired roles and responsibilities was seen to be critical to the establishment of any level patient participation. However, a number of patients reported that little opportunity was provided for such meaningful dialogue. The inhibiting factors or determinants which impacted significantly on the patient and the nurse exposing opinion about patient participation and thus getting to know each other were lack of time, a negative patient or nurse attitude and the nature of the system of care organisation employed on the ward. As one patient confirmed:

> The way care is organised on here (referring to Ward C) does not really facilitate or encourage you to take part in your care. Care is given in such a regimented way. Nurses are assigned tasks they have to complete by X time and as a result they are running around like headless chickens trying to meet deadlines – one on one conversations about your input don't feature. (P 37)

Time was recognised as a scarce resource by not only patients but also nurses. Nurses reported that opportunities for reciprocal discussion about patient participation were particularly limited on operating days, during the immediate post-operative period (24 to 48 hours after surgery) or on days when there was a shortage of permanent staff. However, according to some patients a few nurses were capable of understanding what they were thinking and feeling about being able to participate in their care without exhaustive discussion. Views and desires were not always made explicit verbally but interpreted intuitively through observation of a patient's demeanour. As one patient pointed out:

> My nurse never actually asked me whether I wanted to participate in my care. She just automatically knew. We just connected. She was just so aware of my feelings. I don't know what made her so perceptive I guess she just picked up on so called vibes. I knew from the way she treated me that she believed I could contribute. (P 6)

In a similar vein, some nurses reported there was frequently no need to have comprehensive discussion about the level of participation that a patient desired. Some reported having an innate feeling about the desired level of participation required by patients. Furthermore, some nurses believed that their instinctive judgment about a patients desire to assume a participatory role was frequently *spot on*.

Nurses attributed their precision of interpretation to surgical expertise, skills of assessment and years of experience in the surgical field. On the contrary, very few patients provided testimony to the fact that such interpretation was always correct. According to most patients, an awareness of views and opinion about desired levels of participation demanded in-depth verbal discussion, perceptive observation of behaviour or demeanour and high levels of sensitivity on the part of the nurse. Most patients felt that such wisdom could not be derived solely from intuition. As a particular patient who had been assigned to one of the nurses who confessed to being able to make such innate judgements reported:

> No one can second-guess someone's views (referring to a patient's views about participation and its enactment). It's more complex than that. Everyone is different and it is essential to recognise that. I didn't make an out and out thing about participating in my care but my nurse just kept saying – 'I know you are a bit sceptical about taking on too much' or 'I know you don't want to burden yourself while you are in here so let me do it'. I'm not sure how she made that call. She never asked me. She literally thought I wanted her to be in the driver's seat. How wrong was she, hey? (P 17)

When opportunity did allow for meaningful discussion about patient participation incongruence in opinion about the enactment of everyday participation was frequently evident. Because of the contrasting views between nurses and patients and among nurses, patients were very mindful of the need to ascertain from each shift to the next what the firm view of the nurse caring for them was. The discovery of differences in opinion was deemed important to be able to minimise any incongruence and thus create an amicable care environment. Knowledge of nurses' views about patient participation was acquired essentially through verbal interaction. However, patients also reported needing to supplement such knowledge with information gained through observation and assessment of a nurse's demeanour. Many patients were of the staunch belief that incongruence in opinion was discerned most accurately from a combination of verbal exchange and observation of the nurse's demeanour and how duties were executed. Such in-depth assessment was deemed necessary as frequently nurses' exposed philosophical beliefs about care delivery that did not align with their actual practice. As one patient reported:

> By chatting with your nurse you usually get to know what their views are (referring to views about patient participation) but sometimes that's a bit misleading. Even after chatting you might not know exactly where you stand because what they say is one thing and do is another so it's important you watch closely. By watching the nurse at work you cotton on to what the nurse really thinks. You pick up clues. It's almost like you are the Old Bill (laughing). As plain as the nose on my face each a nurse's behaviour can alert you to the fact that they either do or don't mind you speaking up, asking questions, or taking part in your care. (P 38)

Many patients asserted fervently that to gain a realistic indication of a nurse's actual view about patient participation and the role patients should assume in-depth discussion and observation of practice was seen as obligatory. Since nurses' expressed ideals were not always realised or *witnessed* in practice patients alleged there was a definite need to have dialogue with nurses and *watch* or *survey* their behaviour to ascertain if any incongruence between them and the nurse existed in respect of the how patient participation was to be enacted.

Observation in the field confirmed a *mismatch* between the views and practices of many nurses. A distinct lack of alignment between nurses' purported views and their clinical behaviour was apparent. While many nurses expressed a commitment to employing a model of practice that promoted patient participation there was a lack of congruence between the views and practices of many nurses. The observed behaviour of some nurses who expressed a verbal commitment to patient participation did little to create a climate whereby patient participation could be established and promoted. Observation of a specific nurse-patient encounter during a medicine round revealed how a patient was marginalised from his care despite earlier expressions by the same nurse that she subscribed to the nursing philosophy that patients should participate actively in all aspects of their care. The unit of observation at the time involved a patient who had had his gall bladder removed 72 hours previously and who was due for some pain relief. The nurse entered the patient's bay and said '*here are your tablets'* and put them down on the table. She was asked by the patient why the tablets were different to the day before. Her reply was an abrupt '*because the doctor wants you to have them'*. Low priority was accorded to interacting with the patient. The continuation of the drug round and the signing of the medication chart restricted any form of discussion or elaboration. Priority was placed on the enactment of the drug round. Later the nurse was observed to return to the patient's bedside yet focused on caring for the intravenous infusion and wound drains and completing the patient's charts and nursing records. No reference was made to any medication or any earlier questioning. Recounting his admission experience the patient shared how during his assessment interview he had

been advised that the practice of the ward was such that all staff were *in favour of patients having input into their care.* He described how this was not always evident in practice and progressed to reinforce how features of behaviour in general provided useful insight into attitudes about patient participation.

What also manifested in everyday practice was that no single authoritative view or description about how patient participation should be enacted existed between nurses and patients. Both asserted that consensual opinion about patient participation and more specifically goals, roles and responsibilities could not be assumed. Accordingly, activities associated with patient participation could not be prescribed or promoted *wholesale.* Similarity of views about participation, its scope and enactment was clearly limited between patients and nurses. As one nurse stated:

> It is very rare that a patient shares your views about participation and what role they can assume. You can work towards developing some sort of agreement about participation but very rarely are your views the same at the outset. You more often than not have to reach a compromise about what it all means in the reality of everyday practice. (N 11)

The existence of polarised views about how patient participation may be enacted can also be gleaned from the different interpretations placed on the meaning of silence in an nurse-patient interaction. To some nurses the use of silence by a patient signified an obvious form of non-participation yet some patients reported using silence actively in an attempt to generate dialogue or an exchange of ideas and thus engender participation.

The situation is further complicated by the fact that a rich diversity of views existed not only between patients and nurses but also among nurses and patients. Patient participation was incredibly context-sensitive. Determinants, such as the type of illness, the nature of the condition, the patient's level of psychological distress or cognitive ability, the knowledge, experience and personality of the patient and nurse, the degree of trust either party had in their relationship and the nature of the ward climate, all impacted on perceptions about patient participation and how it should be and was enacted in practice.

In essence, however, everyday patient participation was defined broadly by both nurse and patient as being associated with a *form of work or* a *contribution being made by the patient* during both the pre and post-operative period. It was associated with increased knowledge, control and/or responsibility. Both patient and nurse were also of the view that participation involved engaging in a diverse range of activities or work associated with health care. The

activities cited were diverse, often dissimilar and dependent on individual circumstances. What patients and nurses did endorse jointly was that patient participation was associated with some form of intellectual and/or physical work or self-care activity. The work assumed by the patient was observed and reported by both patients and nurses to be dynamic in nature and extended to activities such as verbal forms of participation, namely the asking of questions, the describing of experiences, the making of suggestions and the stating of preferences or pragmatic activities relating to self-monitoring, goal setting, self-medication, and/or physical care. Patient participation clearly took many forms. The conceptual category titled Shaping a Role (Section 5.3 page 154 refers) will describe the range and variation in participatory behaviour and the levels at which a patient participated in their care.

Interestingly, most patients were of the view that there was a logical reason for the incongruity in opinion that existed between themselves and nurses. As one patient reported:

> It makes sense that there is a difference in opinion about what participation means and entails as patients and nurses have different experiences and priorities surely. (P 8)

Divergence of opinion about the features or dimensions of patient participation was also attributed to depth of understanding associated with the presenting illness or condition and the highly technical nature of surgical nursing care. Both patients and nurses coped with such incongruity in a number of ways. To mitigate or minimise the incongruence and achieve a degree of balance or agreement about each other's input into care many patients reported adjusting their behaviour. As one patient reflected:

> You alter or moderate your behaviour so as to fit in with each other's differences of opinion. Sometimes you bargain and upgrade your input other times you listen, cooperate and are guided. In other words, you learn to partner each other. It (referring to patient participation) is a cooperative venture after all. (P 35)

Observation revealed that not only did some patients modify their behaviour to achieve a state of harmony some were also able to influence the behaviour of nurses. Nurses themselves were also seen to moderate their behaviour to accommodate different conceptualisations about participation although less frequently than that of the patient.

Essentially behaviour adjustment to accommodate conflicting views and expectations about the practice of participation was sensibly dynamic and reciprocal. Observation of a specific admission assessment on Ward B illustrates the point. During an admission interview, the initial interaction between the patient and the nurse was observed to be conducted in a very

structured manner as noticeably the nurse was attempting to complete the assessment pro-forma and write down the answers to each question that the template dictated. Consequently, discussion or elaboration on topics raised was observed to be circumscribed. The patient's contribution was minimal and notably monosyllabic. Dialogue was focused on the nurse's agenda. Following an interval in conversation the patient in his own words asserted that the form of answers being provided was grounded in the way the assessment was organised. He expressed that he felt he was not being asked the right questions to enable him to contribute to the assessment. The patient proceeded to identify that there was an absence of topic follow up, assessment or evaluation and that his *concerns were not being covered.* Although startled (and later to share that this was an exceptional incident but a useful *wakeup call*), the nurse acknowledged and apologised that the features of the assessment pro-forma were such that a patient's opportunity to engage, express views or concerns were curtailed. Following a brief conversation about the importance of patients being able to contribute and participate more fully in the assessment process the nurse proceeded to continue with the assessment but departed from the conventional expectation.

Dialogue became more conversational in character, interactionally balanced and allowed for forms of patient expression and elaboration not afforded within the constraints of the assessment document. A number of distinct strategies were also observed to be introduced to inspire a spirit of incorporation and promote patient inclusion throughout the remainder of the assessment. Examples of such strategies included the use of discussion, encouragement, open-ended questioning and humour. The patient naturally enough responded by adjusting his behaviour. Answers to questions, which were initially minimal in nature, became more expansive. Strength of answer was also apparent. There too was evidence not apparent at the outset of the interview of the patient initiating an action sequence by for example asking questions and asking for advice. One such example related to the use of sleeping medication. Initially when asked about the taking of medication to facilitate sleep the patient replied in the affirmative. When the question about the activity of sleep was reformulated and asked in a more conversational manner the patient responded by not only describing his sleep patterns in detail but also by sharing his interpretation of the problem and by raising his preferences for taking a certain type of tablet and the reasoning process for his preference. He then proceeded to ask the nurse whether he needed to keep taking the same medication. A clear attempt was made by both nurse and patient to adjust behaviour to create a state of harmony and establish a mutually acceptable form of patient participation.

In the everyday world, departure from customary practice to promote patient participation was very rare. However, this was not observed to be the case on Ward A. The assessment documentation used with its pre-determined line of questioning was identical to that used on Ward B and C yet interactions were commonly observed to be more informal and a more relaxed interactional dynamic to facilitate opportunities for patient participation was regularly created. Patient interviews were also seen to encourage expression of feeling, emotions and views rather than emotional displays in the form of utterances or acknowledgment tokens like 'yeah' or 'hmmm'.

Nurses working on Ward A attributed their engaging approach to the facilitating conditions of the ward. The most overwhelming influence was reported to be that of the Ward Manager. The expressed commitment of the Ward Manager to patient participation and to developing in staff the wisdom and skill to facilitate such an approach to care was reported to have a powerful impact on the behaviour of nurses on the ward. In addition, nurses on Ward A asserted that the availability of advanced interpersonal skills training alongside a ward based mentorship programme to promote the transfer of such learning into practice was found to inspire an approach to nursing care delivery that promoted the enactment of patient participation at any level as the norm rather than the exception.

Although in general most nurses in the study reported making some attempt to engage patients in their care nurses who deemed themselves inexperienced or who alleged a growing unease with a patient participation philosophy reported difficulty in adjusting behaviour, breaking rules or deviating from practices such as structured admission assessments. As one student nurse described:

> The paperwork or the lack of space to write does not encourage you to invite qualification or more information from the patient. You dare not explore anything in any depth. You have to work with the system that is in place. It is actually very difficult to challenge as a student. (N 5)

Inexperienced qualified nurses significantly those from Wards B and C also reported that an exploration of a patient's views about participation was exceedingly difficult when phrases such as *what do you think you would like to do* or *to what extent would you like to participate in your care'* were commonly rebutted with responses such as *I don't know, you're the nurse*.

On Ward A, where an ethos of patient participation was evidently cultivated and staff reported receiving training to enhance the skills needed to encourage exposure of opinion and thereby promote a culture of participation, a variety of strategies were observed to be

employed to accommodate incongruity, resolve differences, avoid communication challenges and alleviate the expressed anxiety about an active patient role. Examples of strategies employed effectively included the use of negotiation, persuasion, direction, pauses, humour, mitigated phrases and interactional styles such as the use of greetings, which positioned both participants similarly. All such strategies were observed to contribute to the creation of a mutual and interactionally balanced atmosphere, which in turn engendered a host of opportunities for the exposure of opinion and ultimately a patient's participation. Nurses reported such strategies also enabled them to adapt to differences in understanding about patient participation and how care should be delivered and achieve a mutually agreed level of participation.

A very specific strategy employed only by nurses on Ward A to draw out or expose patient's views and establish a form of patient participation right from the outset was the use of a form of listing. Listing options that a patient could reasonably participate in was considered a useful strategy to establish and facilitate different forms of participation. As one nurse reported:

> If you ask patients what their view is about participation they don't really tell you but if you give them a list of things they can do to enable them to participate in their care they will usually say something like 'yes I'd like to do that'. I think it's important to give them an idea about what they can do – be up front with them, help them decide. (N 10)

The 'listing' strategy was used successfully by a number of nurses however observation revealed use of this technique resulted in some patients feeling *somewhat startled* or *panicked* especially if one option was to take no action or they had previously encountered a paternalistic style of health care.

However, as one nurse asserted following a conversation about the feelings such a strategy could generate among patients:

> Come on, it has to be about how you put it to patients – if you say bluntly you can do X Y and Z what do you think then patients don't like it much. Whereas if you say something like this isn't a black and white situation but there are a number of ways you can take part in your care – you can chose what you do or don't do.... they will respond and share their views and concerns with you. (N 8)

Clearly, use of the 'listing' strategy demanded skill, an open, non-directive and non-threatening manner. The listing of options needed also to be in a logical sequence and of sufficient clarity to enable patients to perceive that there was a real opportunity to take part in

their care. Furthermore, it was evident that a number of patients and nurses felt it was vital to offer an opportunity to reconsider how a patient could participate in their care on another occasion even if on the face of it a firm decision had been made at the outset.

Many nurses were also observed to expose personal preferences to extrapolate views and invite an active patient contribution. An extract of data from an observed conversation between a nurse and a patient with a newly formed stoma provides an example of the effective use of such a strategy. The nurse in discussing the patient's care made the comment that *if I was in your shoes I think I would want to have a say in the type of appliance that is used and how easy it will be to manage* (N 13). Such exposure of self in conversational talk was observed to enhance patient participation as it increased the flow of conversation and reciprocal dialogue and encouraged the patient to disclose his view and contribute to the reasoning or decision making process relating to stoma appliances. Exploration of the value of employing a strategy like the sharing of personal views with patients to promote patient participation did however reveal varying responses. The more experienced nurse appeared to find personal disclosure or the sharing of legitimate views about participation and aspects of care unproblematic. Clinical experience and competence was reported by many nurses to provide the stability and confidence needed to share views appropriately within the context of relationships with patients. As an experienced staff nurse shared:

> Patient participation more often than not demands that you share your views about a lot of things with patients. In most cases, sharing your views feeds patients and encourages them to participate more in their care and even make their own decisions. In saying this you need to know what the correct level of disclosure is – there are no written laws about it. Through experience, you just know how much to share and what the balance is. (N 11)

Student nurses on the other hand grappled with what exactly they could share with the patient. As one student reported *I do worry about expressing my views and the depth to which I should convey my opinions to patients* (N 12). According to all student nurses and a few newly qualified nurses the view was that, *we are not taught to share personal views with patients, rather advised against it* (N 2).

It was thus unsurprising that many nursing staff felt that the implementation of patient participation into the prevailing health care system required a formal and systematic educational programme, which included how to communicate sensitively, and effectively and to what extent personal views should or should not be exposed. Interestingly, many nurses,

including students spoke of the need to have necessary communication competencies assessed formally. As one nurse reported:

> This (referring to the need to assess formally communication skills associated with engaging patients) would go a long way towards developing local understanding and expertise with respect to patient participation. We really need a sound strategy to enable us to develop the specific skills and expertise in this area. (N 3)

Many nurses felt they were not prepared enough to move to a culture that supported the exposure and exchange of personal viewpoints, demanded the use of advanced communication strategies and ultimately promoted patient participation at varying levels. Some nurses also admitted to having a limited capacity to manage the potential conflict, risk, insecurity and stress associated with the exposure of divergent views about patient participation and the promotion of such a form of practice. As one nurse reflecting the view of many reported:

> I have been a staff nurse for a year now and I have still not developed the expertise or maturity I need to instigate or maintain proper patient participation. There is no specific course that focuses on the tactics I need to develop. That's a bit unsettling. (N10)

Similarly, a few patients felt unable to cope with the disharmony that emerged because of incongruence of opinion about role function. The lack of ability to manage such discord resulted in many patients tolerating a form of practice whereby the nurse was often the dominant actor and care was predominantly nurse-driven even though they believed that this was not the correct thing to do. One patient alluded to the fact that the main reason as to why he allowed his care to be nurse driven, an approach he felt *ill at ease with* was that he did not want to *rock the boat* or be labelled as *difficult* or *awkward*. This patient equated such labelling with receiving a poor quality of care. As he explained:

> I think it is wrong in this day and age that some nurses browbeat you into taking a back seat. We are in a situation now where the nurse is the service provider and the patient the customer and that requires a change in the way the nurse presents herself. Surely I am entitled to have a say about my medication – I know what works and what doesn't but in saying that my goal is to get home. For that to happen I need to keep them happy and on side (referring to the nurses). I don't agree with what they want to do with my sleeping tablets but my hands are tied – I don't have a cat in hell's chance of going home this weekend if I challenge what they are doing or am seen to be awkward. They'll just string things out if I do that and I'll be left here until Monday. (P 23)

In an exceptional case, a dissimilar view about the timing of a particular form of patient work resulted in a patient resisting orders. As one patient recalls:

> On one occasion my nurse stood over me and I guess tried to intimidate me and get me to obey her orders to empty my bag (referring to a wound drain) just before visiting. Had I done what she demanded, the smell would have been awful for my visitors. In fact I refused to do it and she just stood there with her hands on her hips until she realised I was not taking the party line. I have to say that if people like her (referring to the nurse) cannot work in a cooperative manner then they shouldn't be working as nurses. I didn't want to be difficult but I wasn't prepared to compromise my position. (P 40)

A number of determining characteristics influenced significantly the extent to which a patient modified their behaviour to *tone down* divergent views or reach what was described by one patient as *a mutually acceptable arrangement about patient participation*. The type of illness, whether it was acute or chronic was critical, with the latter offering a lesser desire to modify behaviour due to prolonged experience and expert patient knowledge. Patients with both acute and chronic health problems were specifically sampled and they accordingly revealed less or more willingness to participate in their care. Patients with acute problems such as appendicitis or acute abdominal pain and relatively little clinical knowledge of their problem manifested a reluctance to participate extensively until their condition was considered less acute. By contrast, patients with chronic or longer-term illnesses such as arterial disease or cancer expressed support for a more inclusive role in verbal and physical work or self-care activities right from the outset.

Reflecting on her experience of discussing treatment options for breast cancer with her assigned nurse one patient commented:

> I am knowledgeable about the variety of treatments that are available to me. I have explored them all and I am also well versed in the side effects, potential suffering and complications that I may experience. I made the decision to have surgery and radiation not chemotherapy. I've read so much about it and I am very informed. I don't need a nurse to try and influence my decision. I know the nurse thinks chemo is by best option – she has made that clear to me in word and writing (referring to the nursing notes), but health care isn't about purely deciding for patients as it has a knock-on effect on your social and personal life, so I need to have a say in how my life is going to be affected. (P 17)

In summary while patients felt it critical to be aware of the nurse's firm viewpoints about patient participation nurses themselves also felt it was vitally important to have a clear understanding of patient's views and desires about participation. Most patients and nurses reported that a core requirement for the establishment of effective participation at any level

was the need to be attuned to the each other's views about participation and be able to accommodate individual sensitivities.

5.1.4 Developing Expertise

Interviews with patients and nurses underscored the need for patients in preparing for a participatory role to have access to relevant information and explanation about aspects of their health care. More specifically, patients felt there was a need to acquire information and develop knowledge about impending procedures, their surgery, the treatment being considered, and ultimately *the full care package*. Many also spoke of the need to develop *wisdom* and *intellectual* and *technical skills* prior to participating in their care.

Information or knowledge exchange was perceived by patients to be a core requirement for any level of participation. Many patients expressed the view that information giving was a normative expectation associated with patient participation and that being receptive to information was critical to the establishment of a health care relationship where a patient's contribution was to be recognised and promoted. Information was seen as a basic building block or an *indispensable element* of the participatory process. As one patient reflected:

> You have to be knowledgeable about so many things only then can you make a judgement or really have a say in your care. One of the main obstacles is lack of knowledge. You can't simply be an empty vessel. You have to be clued-up. (P 16)

Knowledge acquisition prevented what some described as *helplessness or total reliance on the nurse*. Irrespective of background patients described how information gave them *courage* to *ask informed questions* and *raise problems* with the nurse and *look at all options or both sides of the coin*. A lack of knowledge left the patient dependent on the nurse and often accepting of a deferential role. However, in an exceptional case a patient did report how being *overdosed and flooded* with procedural information had an adverse effect on his desire to participate in his care as it led to apprehension and ambivalence.

The majority of patients were firmly of the opinion that any level of participation demanded a narrowing of the competence gap between the patient and the nurse. More specifically patients asserted that a lack of knowledge or ability impeded participatory activities like decision-making or physical activities such as the changing of a wound dressing or emptying of a drain. Indeed information exchange and the associated narrowing of the competence gap between nurse and patient was seen to shape the nature of patient's work and facilitate greater participation. As one patient reported:

I've learnt a lot from them (referring to nurses). I've learnt about adjusting my insulin. I can raise it and lower it. At first I would call the nurse all the time but now I manage it all myself. Now I only call if there is something I'm really not sure about. (P 13)

In many cases once essential information had been obtained by the patient many described an insatiable hunger for input into their care. As some patients became increasingly knowledgeable they also reported developing a more critical approach to their care and increasing their levels of participation. As one patient stated:

When you are given a range of information to read you begin to mull it over and apply it to your case. It makes you question things more and soon realise there are a lot of people in the system who know what they are doing but a lot who don't. Sometimes you have to take action consistent with the information you are given not with what the nurse says. (P 27)

Significant was that a patient's developing expertise was dependent on the information being imparted in a manner that the patient could understand fully. It was imperative that information and the nurse's expert knowledge were exposed in a way that would enhance the patient's desire to participate in their care. As one patient stated:

Things you have to learn are often very complex. Unless you really get to grips with what you are being told and realise the importance of what is actually being said you really are reluctant to do or say much. You depend so much on what is being served to you but also on the nurse imparting it in a way that you can understand it. I laugh now but in the beginning I remember one nurse kept referring to 'effluent'. Did I know what that was? No. I hadn't a clue. It's laughable now but at the time it aroused some fear I tell you - so much so, I was reluctant even to touch this here thing in case it fell off. (referring to a drainage bag). (P 8)

Nurses were of a similar view. As one nurse reflected:

You have to package what you are going to tell the patient thoughtfully and sensitively. If you don't you blunt their motivation to participate in their care. A lack of understanding can lead to patients participating in what I would call trivial or micro level decisions. If you present or share information in an unfortunate way you can leave a patient in ignorance and damage any chance you have of encouraging any level of participation. In fact, I would go as far as saying you can even alienate them. It's really a matter of balance. (N 7)

Many nurses reinforced that without access to an appropriate information base patients would not attain the means or authority to participate in their care. The view of one nurse reflected that of many:

> Activities performed by patients will not occur if the patient does not have the necessary knowledge and skill. More often than not patients need to expand their knowledge base in order to be able to ask questions, state preferences and offer opinion. If you don't share information with them, you disempower them. My role as a nurse is to help patients learn… grant them a license to get involved if you like. In fact, from a very practical point of view nurses and patients need to pool their resources to encourage participation and extend its scope before and after surgery. (N 9)

Clearly if patients were to be offered opportunity to participate in aspects of their care information and knowledge needed to be at the disposal of the patient. When patients gleaned information, developed a growing repertoire of knowledge about their condition, and care a participatory role was assumed by many. The increasing expertise gave patients confidence to take action. Knowledge authorised patients to act.

In practice, patients received a constant input of information. Nurses because of their consistent presence were the significant participants in information giving. Nurses were seen by patients to have a pivotal role in cultivating or expanding a patient's knowledge and intellectual and/or technical skills base. Inescapably, accurate, relevant and sensitively provided information and education were seen to be integral to effective patient participation. In particular, the presentation mode or data format employed by either a nurse or another health care professional emerged as a critical factor in empowering the patient to participate in their care. What was very evident was that for patients to have the capacity to participate in their care nurses needed to ensure that the informative or educational interventions employed to impart new knowledge and information were relevant, appropriate and related to the learning needs of each patient. The strategies employed needed to be *fit for purpose*. As many patients reported that a complex matrix of life experiences, physical and socio-cultural factors such as educational background had an impact on knowledge and skill acquisition interactional and learning strategies had to be tailored to meet the needs of the individual patient. As one patient with an intricate history and diagnosis of malignancy of the bladder and bowel stressed:

> I couldn't take it all in at first – even now I'm not sure I'm up to speed. My situation is full of twists and turns. I'm just a normal person from off the street (laughing). I don't have a degree. I left school at sixteen for God's sake. I basically needed made to order on the job training. (P 6)

The interventions employed to develop patient expertise needed to be varied and the command of manner needed to be such that the nurse worked specifically with the patient's non-verbal cues. Tone and volume of voice, rate of speech and the use of silence all had a

critical impact on understanding, skill acquisition and ultimately participatory activity. As one patient following a discussion on the need for new knowledge and information to enable participation revealed:

> Nurses need to know how to pitch their teaching. No one size fits all if you know what I mean. They need to vary their approach to ensure you understand everything. If nurses genuinely want you to have an input they need to pick up on your thinking, your feelings and what I call your want to speak signals. They can't be wooden in the way they teach you. My nurse was great. She recognised all my tension and anger and used things like pre-prepared photos, a model and then gave me pamphlets to read. We also rehearsed things when I was unsure. Her approach and the variety of tactics she used really helped my depth of understanding and the by product was I contributed to my care even more than I anticipated I would. (P19)

The importance of nurses tailoring a programme of education to the learning needs of the patient was further illuminated by another patient who had had a nephrectomy for renal calculi. The patient had found the verbal expression of information difficult to assimilate but, on the recommendation of the nurse, the patient found that the initiation of a diary of information, which was later used to inform discussions with the nurse about future treatment and care packages on discharge, did much to enhance feelings of control, the activity of question asking and self-monitoring and, in essence, participatory activity. The need to employ a range of educational strategies or interventions to encourage participatory activities was also stressed by many nurses. Most talked about the need for strategy to be linked firmly with patient need. As one nurse reported:

> The way in which you deliver your teaching varies from patient to patient and should always be based on your understanding of the patient as a person and an assessment of their circumstances at the time. You have to be able to make a judgment about the patient's own resources and capacity to learn. (N11)

Although for most patients and nurses, the desired outcome associated with the development of expertise was an active patient orientation or an advanced level of patient participation in one exceptional case it did result in a patient assuming an essentially limited role. Using participation in decision making as an example a patient reflecting on her experience of having to decide on the appropriate form of treatment for an overactive thyroid illustrates the point:

> Don't get me wrong I've had all the treatment options presented to me. Not just once but a dozen times. I know what's what. I know having been briefed that most people would want to decide for themselves what road to take but I'm not one of them. Decision time means exit time for me. (P16)

The same patient later on in the interview went on to explain that although she had made the decision to assume a level of participation involving little commitment or action she perceived that her choice to *exit* from the decision making process was her unique way of participating directly in her care. She equated the decision to *exit* with participation albeit circumscribed, a concept to be explored in the conceptual category labelled *Shaping Work*. As the patient asserted in the extract presented overleaf:

> I didn't take the decision to exit lightly. It was my choice to exclude myself at that point. How do I explain it? I guess I saw myself as a partner but in this instance as a sleeping partner but still a participant if that makes sense (P16)

Interestingly, a number of patients whose preferences were to participate in their care at varying levels emphasized that in developing expertise there was also the need to develop *proper insight* into the risks associated with their verbal or physical care activities. There was a sense that they needed to be advised of the *worthiness of their investment* and the potential *stakes*. As one patient who was managing his own Hickman line asserted:

> You need to know what could go wrong and what the threats are to your safety if you like. Until you understand all this you can't make a proper a decision about the extent to which you are going to contribute. (P 17)

Some nurses were of the same opinion:

> In promoting participation among your patients you do need to be honest and upfront. You have to communicate risk to a patient – the risk associated with their participation. If you don't tell them about the risks as well as the benefits how can you say you are engaging with the patient. (N 1)

For the majority of patients the development of expertise provided a form of supplementary energy that facilitated active and explicit participation. The growing repertoire of knowledge and skill gleaned from exposure to information and the expertise of the nurse and other health care professionals such as the doctor or physiotherapist frequently resulted in increasing confidence and an ability to take action and reveal views or judgements. As one patient who had repeated problems with urinary flow through his catheter revealed:

> It played up (referring to his urinary catheter). Oh the pain was terrible – like nothing on earth – it hurt like fury. They offered me some pills. I blasted them and said pills won't work – it's the catheter pipe. I knew it was the blasted pipe that just needed to be tampered with. I knew from what had happened the day before and during the night on a number of occasions that it was a clot. The pain was the same so I knew exactly what was going on and what needed to be done and I told them. (P 11)

On the contrary, some patients despite what was described as patient intelligence did vary in their ability to use such wisdom. During a period of observation in the field, a patient revealed how he felt the wound dressing applied that morning was *put on the wrong way* and subsequently resulted in leakage from the wound. However, despite knowing what was referred to as the *best way* to put the dressing on the patient submitted to an intervention, which he believed, would be unsuccessful. The patient attributed this acceptance to a desire to *fit in* and fear of an undesirable response from the nurse. Interestingly, later on that same day observation revealed that the same patient had reached the end of his ability to endure. The patient had become so distressed by the leakage and discomfort caused by the dressing that he demanded its removal. Reflecting on this experience the patient alluded to the need to accept more personal responsibility for his care and review his perceptions of appropriate patient behaviour. As he disclosed during informal discussion:

> I was a bit silly (laughing). I should have used my energy to tell them what dressing was best. I've been in here for 8 days now so I know what dressing suits my wound. I've worked that one out. My priority should have been to tell the nurse and not be so accepting. (FN 221)

In addition to the acquisition of knowledge, the development of an appropriate repertoire of intellectual and technical skills also inspired in patients increasing confidence and courage to participate in the more physical aspects of their care. The development of technical skills was situation dependent but included skills such as the ability to change a stoma bag, manage a wound dressing, administer medication, fit prosthesis or maintain a fluid balance chart. Expertise associated with practical or technical skills were seen to be critical to the process of patient participation as was the amount and quality of performance feedback and the enthusiasm and support received from the nurse while developing such skills.

The development of essentially intellectual skills or skills associated with thought processes was also seen to be a key requirement for patient participation. Such skills shaped the role and behaviour of many patients. Principally, patients conveyed a need to be able to analyse incoming information. Furthermore, patients also described the need to be able to synthesise that same information into an integrated and meaningful whole. As information was analysed by patients and integrated into their subjective experience there was an increasing ability to interpret events and to participate or take action based on the information or expertise gained. The following account from an interview with a patient illustrates how patients progressively processed information and experience, reflected critically and began to use an increasing body of knowledge to form opinion about their care and take independent action:

> The pain here (referring to the wound site) was unbearable really it was. I asked for some pain relief and I was given those bloody codeine things. I can't remember their real name but they had codeine in them. They made the pain better but made me feel terrible. I was actually sick....sick and spaced out. I had them a second time and they did the same thing to me so the time after that when I needed something for pain having realised what the bloody tablets do to you I asked for something different. I told them categorically I would not take the codeine. Boy I wasn't going to take those things again I tell you. (FN 513)

In spite of the need to develop and/or expand patient knowledge and acquire a range of skills, physical and/or intellectual, to facilitate or encourage patient participation, nursing action in the form of the sharing of information, resources and expertise was limited to key times. Most notably the sharing of knowledge concerning diagnosis, surgery, care and treatment was essentially only observed in the pre-operative period if symptoms were not exaggerated or post-operatively when the patient's condition was considered less acute usually 24-48 hours after surgery, a point confirmed through patient interviews. The majority of nurses were of the view that when a patient was acutely ill there was a continuous need to focus on and interpret the patient's status. During such time, the sharing of information or expertise was restricted consciously. As one nurse reported:

> When a patient is acutely ill or incapacitated before or immediately after surgery you need to help them conserve their energy. You have to delay energy sapping activities like participation when they are not well or have not recovered enough. You make a judgement all the time about whether the patient has the personal resources to assimilate information or manage increased activity. (N 4)

Many patients shared this same viewpoint. As one patient depicted:

> The learning to enable you to take part in your care can only really happen when you have stopped worrying about your basic existence. Only when survival is not preoccupying your thoughts can you begin to learn about things that will enable you to participate in your care. During my first 24 hours in here I was still in shock about being in hospital. I certainly didn't feel well enough even to have a conversation with the nurse. (P 7)

Patients were of the view that knowledge and skill acquisition was an essential antecedent of patient participation however the sharing of information, resources and expertise between the patient and the nurse or other health care professional needed to be at a time when the patient was *ready and able to learn*. Most patients and nurses agreed that the empowering or enabling dimension of the nurse's role needed to be conserved during periods of acute illness or until the patient was *ready to learn*. Empowering emerged as a major dimension of the nurse's work that promoted patient participation during both the pre and post-operative period.

Examples of activities drawn from observational data which depict an element of empowering included: pre-operative teaching and the provision of guidance on how to order meals, empty a urinary catheter, complete a fluid balance chart, position one's arm to maintain the flow of an intravenous infusion and how and when to undertake arm exercises after a mastectomy and the withdrawing of nursing presence and reducing of assistance in terms of personal hygiene or mobility. Indeed, nurses during interview perceived that empowering activities in general assisted patients to attain the means and authority to participate in their care within the limits of their condition.

Similarly, patients recognised that the extent of their participation in different aspects of their care was dependent on the nurses enabling ability or more specifically their ability to facilitate knowledge expansion, develop, and improve skill performance as appropriate. With much assertion, patients reported how critical it was for nurses to possess a repertoire of enabling skills if they were to empower patients to participate in their care. *Teaching, coaching, encouraging and supporting* were terms used by many patients to describe the empowering skills needed by nurses to assist in knowledge and skill acquisition, which would ultimately facilitate patient participation. Without exception, all patients affirmed that effective and timely communication of information and the subsequent development of knowledge and expertise were at the heart of patient participation. The use of enabling skills or strategies to develop and/or enhance a patient's expertise was reported by patients to not only provide reassurance and inspire self-confidence but also increase the amount and scope of a patient activity relative to each patient's circumstances.

Of concern to many patients was that the enabling dimension of the nurse's role was not evident throughout their period of hospitalisation. A strong element of on-going support and guidance was reported to be needed for participation to be maintained from the point of admission to discharge however, this was not always forthcoming. According to many patients, opportunities that presented themselves for continuing dialogue and information exchange were not always utilised. Furthermore, patients reported that, while most nurses provided information of their own accord, some actively had to seek information about aspects of their care or *aggressively* request time is spent with them demonstrating specific skills. A few patients who desired more information than was given reported feeling *unable to ask for it*. Even the more self-confessed assertive patient reported difficulty asking for basic information. Such reluctance to seek access to information was essentially associated with a perceived lack of nursing time. As one patient revealed during a period of observation the *opportunities for me to practice administering my drugs were limited as nurses had little time to show me how it should be done* (P 44). Many patients believed teaching was simply not

integrated into the *demanding work schedule of the nurse* and blamed *hospital administration* or the *emphasis placed on a target driven health care system* (P 41).

Nurses themselves reported that information exchange and the development of expertise to promote an expanded patient role did demand that more time be spent with a patient. However many asserted that once patients were able to participate in aspects of their care or nursing work of their own accord staff resources were saved. As one nurse contended:

> Granted there is a cost associated with the outlay of information…a cost in terms of time. Your capacity is challenged however once a patient is informed and educated and is able to take on a more active role this has a direct impact on resources such as your time. You really can save some of your time for other duties – In the long run complaints on the ward, which demand huge amounts of time, are also reduced. (N 13)

Another factor that patients believed had a significant impact on information exchange, knowledge and skill development and thus patient participation was undoubtedly the transient nature of the work force. Such transiency made information exchange difficult. Non-permanent staff spoke of how they could only impart a cursory level of information to the patient owing to having only a *superficial understanding of a patient's care*. As a non-permanent member of the ward staff explained:

> As an agency nurse, you don't get a detailed handover as you might only be there for one shift. Patients then are often left in limbo land until a more regular member of staff arrives on duty. They may have to wait to do a particular activity as I won't know how things are done or how much they should or shouldn't be doing. (N 4)

On the contrary, irrespective of the employment conditions of the nurse, some patients reported that they felt information or knowledge was on occasion withheld for a specific reason namely to ensure patients assumed a more acquiescent role. Some patients even believed nurses used highly technical or euphemistic terms when discussing care to limit knowledge acquisition and ultimately patient input. As one patient alleged:

> Some staff keep you at arm's length by talking in code. You haven't a clue what they are talking about sometimes. It feels like they are literally trying to exclude you. (P 9)

More specifically many patients reported believing that nurses used professional jargon consciously during bedside handovers to marginalise patients or put limits on a participatory role. Some patients perceived nursing jargon was used both consciously to exclude patients and as a means of ensuring control and authority. The following extract illustrates the point:

It's a bit of a joke. They tell you the shift handover is conducted at the bedside so that you can listen and participate in the discussion. That's all well and good but you can't understand any of it…I haven't a clue what they are on about half the time but then I think that was their plan. It's a joke because I couldn't ask questions even if I wanted to as they controlled and I have to say manipulated the conversation so that I wouldn't have a clue. (P11)

Many patients were of the view that use of lay terminology fostered in the eyes of some nurses unwanted patient intelligence and input. However, in the view of one patient the use of jargon was understandable as it was seen *to ease the pressure of time' and 'illuminate clinical expertise and thereby instil confidence*. Many nurses were oblivious to the impact that professional dialogue had on patient participation and ultimately the behaviour of patients.

The outcome of the lack of understanding of professional dialogue used at the bedside and a lack of explanation about aspects of care was that patients sometimes went to extreme measures to gain information about their illness or care. Some reported seeking information from other patients, friends or relatives and then using the assortment of misconceptions or contradictory information as a basis for not participating in their care or in one case self-sabotage. The following scenario illustrates the point. Medication was refused, the experience of which lead to adverse effects on health status. As the patient recalled:

Nobody explained what my new tablets were for. When I tried to ask I always got 'in a minute Mr X'. I asked the chap in the next bed and he said he thought they were the same thing as rat poison – some stuff you used to kill rats by making them bleed. Well when I heard this I stopped taking the tablets (referring to warfarin). I just stacked them in my locker. It didn't go down well when they found them. My surgery was postponed and the doctor was summoned. (P23)

Of note was that many nurses advocated that the 'use of professional dialogue' and the 'withholding or limiting of information' was deliberate but that such action was to protect the patient from undue stress and harm. As one nurse asserted in a very forthright manner:

It is not about not wanting to promote patient engagement it is about the professional ethic of protecting patients from negative or exploitative experiences. You do deliberately withhold information for fear of alarming the patient. (N 5)

Only a few nurses linked the use of professional language and withholding or limiting of information with a desire to main control and authority over a patient. On the contrary, the extreme view about the role of information in promoting participation illuminated a protective response from a very experienced nurse.

Providing patients with full information about their illness and care to enable them to have more of a say is not ethical. Yes I do limit what I tell them and not only to protect them but also to protect myself. I got my badge (referring to her registered nurse badge) through hard work and ability – it demonstrates I am competent so why should they be allowed to question me. Why should I need to provide them with detailed information to let this happen – in a sense they should be eager to accept my view and care. If I can be totally honest withholding information prevents their asking questions and alleviates me of that stress. No one gives that a thought. (N11)

In summary patients perceived that the acquisition of information associated with their package of care and the development of an appropriate knowledge base and a repertoire of intellectual and practical skills were critical to the enactment of patient participation. The development of expertise had a clear impact on the establishment and scope of patient participation. What were especially important were the interventions employed by nurses to enhance understanding, meaning and develop the necessary knowledge and skill base. Interventions needed to be timely and tailored to the learning needs of the patients. Furthermore, to establish and promote participation throughout the patient's surgical experience and instil in patients the confidence to participate in their care in the pre and post-operative period, a nurse's interpersonal communication and enabling skills needed to be well developed.

5.2   Summary of Conceptual Category

In summary, this conceptual category makes explicit that distinctive antecedents or conditions need to exist in order to establish readiness and achieve a desired and meaningful level of patient participation in nursing care within the context of the surgical care environment. To engender a climate that is conducive to patient participation care and for patients to be able participate in their care both patient and nurse need to connect, expose and share opinion and possess specific skills and knowledge relating to each patients unique illness experience. Clearly to create a climate that inspires patients to participate in care is not without challenge however unless an environment is forged in readiness for participatory practice only tokenistic participatory actions or interactions will be enacted and such a model of practice will not be advanced.

The next conceptual category labelled *Shaping Work* illuminates the dynamic and varied levels of patient participation.

5.3   Shaping Work

5.3.1   Introduction

The phase labelled *Shaping Work* explains the range and variation in participatory behaviour and the levels at which patients participated in their own care throughout their surgical experience. The phase involved patients engaging in varying kinds of explicit and implicit work or self-care activities and the nurse moving from being an expert care provider to being a participant with the patient to improve a patients' capabilities with respect to self-care activity or work . The scope of the work of both patient and nurse was shaped by a complex matrix of factors within the acute surgical care context itself. Specific contextual determinants, such as the level of illness or symptom distress and the ward's nursing practice paradigm and how it was translated into mainstream practice, all had a notable impact on the enactment of patient participation at any level and thus the patient's level of work. Determinants such as, patient preference, the expertise, experience and attitude of individual patients and nurses, the amount of support patients received in the care delivery process, the emphasis placed on educational preparation and the extent of professional relationship trust, were also found to influence the shape, scope or intensity of the work that patients engaged in. Contextual and interactional conditions present on a day-to-day basis modified levels of patient and nurses work throughout the patients' hospital stay.

5.3.2   Overview of the Patient's Work

As discussed in the phase titled *Establishing Readiness* (Section 5.1.3 page 129 refers) divergent and contradictory views about patient participation existed between and among patients and nurses. However in spite of the differing views about the meaning of patient participant there was consensus of opinion that patient participation involved patient's immersing themselves in different modes of work throughout their hospital journey. Work was aligned to a range of conceptualised behaviours, interactions and functional activities, which demanded either intellectual or physical effort. Indeed most patients reported engaging in work in the form of self-care activities or a set of reciprocal tasks with the nurse. Self-care activities were dynamic and essentially related to adaptation and adjustment following surgical intervention. They were multi-faceted in nature and inextricably linked to those activities undertaken with the intent of facilitating recovery, managing symptoms, preventing complications, influencing care decisions and/or restoring or promoting health and self-control or facilitating a peaceful end. All self-care activities were also undertaken in a manner that either supplemented or substituted nursing services.

The dynamic nature of the patient's work was recognised by most patients and was corroborated by nurses in the field. There was a high degree of unanimity about the existence of distinctive levels of participation among both patients and nurses, whatever the personal proclivities. Patient participation was reported and observed to be enacted at different levels of intensity, the level of activity being shaped by contextual circumstances. As one patient whose view reflected those of many explained:

> Looking back, the extent of my input varied. My work (laughing) was dependent on how well I felt or how comfortable I felt with something. You can't really contribute to the same level all the time anyway can you? Seriously, there is a time for high and low demand from us. (P 4)

The act of engagement in work or self-care activities was discrete and/or recognisable. Discrete self-care activities involved expenditure of effort and, according to patient reports, were usually associated with unnoticed behaviours or actions such as personal housekeeping or managing body position. Such activities were also assumed in a manner that supplemented a nurse's care. According to patients, recognisable self-care activities were essentially those activities that involved an outlay of effort, even resolve and courage and were recognised easily by nurses. Examples of such activities that emerged from the field included tasks such as self-monitoring or other specific clinical duties such as those associated with wound or medication management. Essentially, such self-care activities were undertaken in a way that substituted nursing care. They were in the main activities traditionally performed by the nurse.

Patients engaged in different forms of work or self-care activities throughout their hospital experience, the nature of which they reported was dependent on factors such as the people involved, the extent to which the patient made full use of the information, resources and expertise available to them and the ward context. According to most patients, there was no form of work or activity that was seen as the ideal form of participation. No one form of work was seen as superior or took precedence over another. As one patient made clear:

> Listening to and learning from my nurse is in no way less important to me than contributing to decisions about where I am going to go after here (referring to discharge from the ward). I can participate by virtue of the way I think and feel not just by what I do or say. One is no more important than the other. (P17)

Nurses also recognised that a patient's participation in self-care activities varied in intensity throughout both the pre and post-operative period. Nurses conceptualised that there were different types and gradations of patient participation but also that no one activity or level of participation assumed primacy over the other.

As one nurse explained:

> There are sort of clear cut levels (referring to patient participation) depending on where the patient is at. Patients may jump from say level 1 to level 6 and then back to 1. Level 1 might be about having input at a very uncomplicated but important level, like receiving information before their op. Level 6 on the other hand might involve a patient making an on-going contribution to their care by, for example, taking responsibility for the administration of pain relief or interpreting their symptoms or contributing to any sort of decision about their care. No one level is more or less important than another. The actual level of participation will naturally change depending on circumstances. (N 11)

Like patients, nurses reported that a number of contextual dimensions determined the level of participation. In particular, the nature of the health care need itself had an impact on the level of patient participation. Firstly the type of illness and whether it was acute, with much symptom distress and resolved quickly or chronic that is of a long term duration was significant. The voice of the patient who was admitted to the ward critically ill, as an emergency admission, for diagnostic procedure or in severe distress or pain pre- or post-operatively expressed frequently that work or self-care activities beyond those associated with personal hygiene, managing body position, menu choice, gentle ambulation, feeding oneself or silent work, such as actively listening to dialogue about their care, had minimal relevance to them until their level of symptom distress had improved.

On the contrary, chronic or more specifically longer term complex, multi-dimensional illnesses requiring either minor or major surgery, extended or even life-long treatment, such as vascular or gastrointestinal disorders including carcinoma, resulted in greater and more complex levels of participation being desired and assumed right from the outset due to the view that chronic illness demanded considerable input and energy from the patient in terms of maintaining health status and managing emotional stability. A patient facing cancer confirmed this viewpoint reporting that he had assumed a significant role in his care package *from the word go* as he had a *significant stake in decisions and faced many disruptions* as a result of his disease. (P 17).

Many nurses expressed similar views alleging that the nature of a patient's condition was linked critically to the level of patient participation enacted. As one nurse asserted:

> There is a difference in terms of contribution or participation if one patient is having exploratory investigations and another is having let's say a stoma formation for colorectal cancer. Things that a have a longer term impact on the patient are things you would want the patient to have a say in. After all the patient has to live with it as there is rarely a cure. If on the other hand their condition is life threatening you would want in my view that the patient would accept what has to be done and that it would be the right thing to do medically. A patients' level of participation is clearly limited in an emergency situation or immediately post operatively but saying that information still needs to be given to the patient so that they are involved in some way. (N 9)

Despite the majority of nurses reporting that the nature of the patient's illness had an impact on the level of patient contribution, many nurses affirmed that irrespective of the type of illness and the seriousness of the patient's condition some patients had *more potential* for participation than others. As a nurse in discussing determinants that impact on levels of patient participation summarised;

> You really can't have a blanket view about levels of patient participation. In my experience, you can't link it to just a patient's illness status either... or even things like their age or intelligence. At the end of the day, some patients, irrespective of their condition or background, have more potential than others. Some bode well with the idea of participating fully and actively whereas some show signs of only being able to participate in a small kind of way. (N 12)

The view that some patient's had limited potential or capacity to participate in any level of work or self-care activity was reinforced by a number of patients' particularly those with cognitive and functional disabilities. Clearly developing self-efficacy in knowledge, ability and skill was not always possible. As one 80 year old patient with arthritis and a newly formed stoma asserted rather tearfully:

> I simply don't have the ability to learn these new, new things. The girls have tried to help me and I've watched them change this bag over and over again but my physical limitations do not let me. I have the determination but just can't move on from there. (P 47)

Notably the concept of non-participation did not feature among the views of *any* patients. Many patients reported wanting to be *cared for* when seriously ill but at the same time they also asserted that some level of participation was *always* desired and should *always* be possible. Participation even in a passive or limited way was deemed important to patients so as to be able to experience some sense of personal control and achievement.

Observation in the field provided testimony to this viewpoint. Following major abdominal surgery a patient who had a naso-gastric tube in situ and who was unable to take any fluids orally was insistent on performing his oral hygiene himself despite it being a struggle. Opportunistic discussion with the same patient revealed a desire of not wanting to *lose all control* over the pacing and carrying out of daily routines. The desire to perform mouth care was fundamental to the patient's emotional wellbeing and the need to be somewhat self-reliant or as he described *a collaborator in his care* (P 29). Mouth care performed by the nurse triggered in this patient a degree of emotional distress, which was linked to *being disabled*. Clearly, to this patient participation even in its basic form needed to be an integral part of his care experience. He perceived that it should not be a *bolt-on extra*. Indeed most patient's and many nurses reported categorically that patient participation irrespective of level should be embedded within mainstream nursing practice rather than being ad hoc, an optimal extra or as one patient stated *a luxury.* (P 40)

The provision of a setting or climate that facilitates or encourages patient participation was also identified as being critical to the level of patient work assumed throughout the patient's hospital experience. As one patient talking about the climate needed to engender such a model of practice asserted:

> The foundations have to be built. No matter what the scope of your role is the important thing is that a patient centred approach is the hub of all that is done. (P 5)

The majority of patients from Ward A reported the presence of an environment that encouraged explicit patient work or self-care activities. Interviews with nurses and patients from this ward indicated there was a high awareness of the value of a patient's work and an explicit practice mentality that encouraged nurses and other health care professionals to focus on its achievement. Accordingly, patient participation appeared to pervade all levels of care activity on this ward. Conversely on Wards B and C patient participation in the form of work or self-care activities did not permeate *all* elements of nursing work and in some instances nurses themselves were dismissive of patient's assuming any level of work. Such disengaging behaviour was noted during time spent in the field. Some nurses were observed not to be very forthcoming with regards to information exchange. Furthermore, their skills set in the form of interactions were found to be limited. Dialogue between some nurses and their assigned patients was found to be superficial and courteous giving the impression of busyness or a lack of interest.

Limited eye contact was noted, formal terms of address appeared to be intentionally used to decrease or limit any level of patient participation, a view confirmed during opportunistic discussion when a nurse asserted that she had to *use such a clinical approach to reduce the demands placed on her from a patient wanting to become over-involved.* (N14)

Patients attributed much of this notable disengaging behaviour to nurses wanting to distance themselves from the patient or simply *block out any level of patient* engagement. As one patient in talking about disengaging behaviour recalled:

> Some - not all - purposefully maintain an efficient attitude to prevent or destroy any level of participation. (P 30)

For patient participation as a model or practice to be effective patients and many nurses believed it needed to permeate all levels of care activity on the ward. Encouraging participation even at what was described as a basic level was deemed critical to developing an ethos where participation was deemed a priority. As one nurse working on Ward A reported

> The modus operandi of routine surgical care on this ward is not professionally determined. Patients participate in their care throughout their stay at whatever level they are able. The extent of the contribution does vary. Notice I say extent as they always participate in some way. It's completely absurd to say no one patient does not participate in their care in some way or form. Some forms may just not be as obvious as others. Take for example the patient assuming a listening role this is participating isn't it? (N 7)

5.3.3 The Dimensions of the Patients' Work

Patients who asserted that they participated in their care reported that the key focus of their work was on building health literacy, improving health outcomes, enhancing recovery, ensuring safe care, preventing complications, strengthening self-care, articulating views and influencing nursing care decisions. As one patient in discussing the nature of his engagement in work and the reason for his effort explained:

> I have asked loads of questions about my feeding tube because at home I will have to manage it myself. I have to understand totally my complex feeding regime. I have always watched over it just to make sure no air goes in near the end. It's all very demanding you know but essential for my survival. (P 48)

Throughout the patients' hospital stay work in the form of self-care activities or procedural nursing tasks either supplemented or substituted the work that nurses did not do or that

patients perceived nurses should do. In extreme cases, the activities assumed by the patient corrected the work of some nurses. As one patient disclosed:

> I knew what I had to do to help myself. I had to invest effort to accelerate my recovery. At the same time, I had to keep a watch out for cowboys (laughing). Many a time I had to do this dressing again as they (referring to nurses) did not secure it properly. (P 37)

Patients' accounts indicated that the level of intensity associated with patient participation ranged from what was described as *limited, restrictive, subtle, discrete or silent work to a more complex, inclusive, complete, observable, recognisable or obvious* level of *labour*. There were instances when a patients' work or their capacity, desire or ability to engage in physical and/or intellectual self-care activities was limited or restricted. On the contrary, patients' reports also confirmed that their experience of participation extended to the performance of physical and intellectual activities which were of a more inclusive and complex nature. The level of activity was undertaken in whichever combination of 'mix and match' appeared appropriate at the time. As one patient recalled:

> One day you might purely be involved by being told about your operation and how you are getting on and on another day you have more definite input as your nurse might ask you to make a choice about something to do with your care or recovery. You might even have input into something more physical like I did. I learnt to empty this here urine bag. (referring to a urinary catheter bag) (P 7)

Nurses also reported that work associated with patient participation comprised diverse, multi-faceted activities, which were context-sensitive. The main distinguishing feature between the different levels of participation or more specifically the patients work or self-care activities was the degree to which patients participated in service delivery and management. Levels were delineated in terms of the extent and nature of the role or work the patient and nurse assumed. However, irrespective of the nature of the patients' work patients asserted forcefully that at any level there was always a clear active patient orientation. Movement in terms of 'more or less' participation was context dependent and most often reliant on the informal or formal *agreement* between the patient and the nurse. The work of the patient in the form of self-care activities or procedural nursing tasks was constantly negotiated, defined and refined with the level of activity reflecting patient preference, ability and willingness and the impact of contextual and interactional influences.

Patients affirmed that participation was a complex phenomenon, which involved multi-faceted and dynamic patient activity. They recognised that they participated in many different ways, at different levels and at different times during either the pre or the post-operative period and

that, their level of participation was not devoid of context. They made explicit how the level of participation was dependent on a number of contextual factors other than the seriousness of their illness. Factors such as a patient's duration of contact with the nurse shortened with shift rotation, the development of trust in the nurse, the nurse's ability to adapt their role to facilitate participation at any level and the personal characteristics of the nurse, such as the degree of empathy or confidence possessed, all had a significant impact on their level of participation. In an interview where a patient, a retired nurse, was asked to comment on his level of participation and recall what factors enhanced or restricted the different levels of work he had undertaken, the patient explained:

> It's not as straight forward as you think. Quite a few things have an impact on your level of contribution at any one point. Your....your enthusiasm and the nurse's ability to modify her behaviour to enable different kinds of participation are important - in fact nurses having participation as a core value is critical to the success of you having input. Care is not just about rescuing anymore...not like in my day (laughing). Anything that encourages a degree of self-responsibility will encourage you to participate in your care. Before my surgery the only really way I participated was by providing information for the admission assessment. This to me was an essential but uncomplicated form of participation. I was in too much discomfort to do much else so that was fine. But afterwards... after my surgery, it was little things that directed my energies to have more input into my care. Simple things like allowing flexibility in routine encouraged me to participate in my recovery. Allowing me to take my tablets and keep the same routine as I had at home increased my contribution. Being asked to compare the effects of oral pain medication with intramuscular injections also encouraged me to participate more intensely as I felt that the nurses recognised my ability to judge not as a nurse but as a patient. (P 18)

Interestingly the level of patient work assumed on Wards B and C was observed to be undertaken in a one-off or ad hoc manner. It was rarely because of a deliberate plan of care or action. Practices on Ward A were however quite distinct as patient participation in some form was usually integral to all activity and part of a negotiated plan of care. The lack of a formal negotiated plan of work on Wards B and C appeared unproblematic to most patients as many felt nurses at the outset of each shift made a concerted effort to discuss the work to be undertaken. However, the lack of formal agreement about the work to be assumed by the patient resulted in one patient being unwittingly coerced to perform more *nursing tasks* than they were prepared to do. In an isolated case, a patient reported how a lack of clarity regarding his role left him bemused and confused.

This same patient reported how he would have liked to have had a relationship founded on the concept of reciprocity in order to understand fully what was meant by acceptable patient behaviour.

5.3.4   Restrictive Forms of Patient Work

Where participation was reported to be circumscribed or limited to subtle activities, the work of the patient was in the main discrete and had a particularly narrow focus. As one patient affirmed, activities at this level are *basic even straightforward*. Principally, restrictive forms of patient work centred on linguistic communication, information gathering and transfer, information receptivity and/or uncomplicated physical activities, frequently delegated by the nurse. Care at the bedside in this context was essentially professionally determined with the patient adopting an active role but with restricted contribution. Table 14 provides a sample of specific restrictive forms of work undertaken by the patient at particular times during their surgical experience. The examples are drawn from data collected in the field.

Table 14   Restrictive Forms of Patient Work
• Providing information about illness, symptoms and experience. • Maintaining composure • Managing body position • Feeding oneself • Seeking opinions • Sharing clinical ideas, opinions and concerns • Processing of information • Acknowledging expertise of nurse • Undertaking delegated tasks such as the completion of menu cards and hygiene care.

Despite the patients work at any point during the patient's surgical experience being of a restrictive or passive nature critically all patients still perceived themselves as being functional participants in their care. Most patients asserted that despite the potentially passive nature of some activities there was always an element of active patient input associated with their role. No one patient adopted a restrictive or passive form of work throughout his or her entire surgical experience. Strikingly some patients reported how on occasion an apparently passive role was deliberately assumed in the face of perceived exclusion from care delivery or clinical decision-making. In cases where the nurse was considered to be 'disengaged' from the patient, the passive position adopted was perceived to be an assertive articulation of participation.

Certainly, many patients deemed they had participated in their care not just by virtue of visible efforts in relation to activities of living or their interaction with the nurse, but also by virtue of thoughts, feelings and behaviour. As one patient reported:

> She (referring to the staff nurse) didn't ask me how I felt about changing the tablets I had been on for years, 17 in fact , so I said to myself if they can't be bothered to ask you let them sort out what you should be on. I deliberately kept quiet. I could have aired my views if I had wanted to but it was my choice to keep stum. I suppose I was what you could call a sleeping partner but this was my choice. It's similar to being a silent partner in a business you choose not to actively participate in the management of operations but you are still a partner. (P 16)

Where patients chose to assume a restrictive role in their care and/or recovery all had their own reasons for doing so. There was no apparent variation in terms of patient characteristic such as age, gender and prior hospital experience. Motives for participating in a restrictive capacity included a *lack of real desire, feeling too unwell, being happy to submit to the experts or it being appropriate at the time*. However, the most frequently used description to illuminate why a restrictive role was assumed included *not really being listened to, not really being recognised and/or lacking information.* Assuming a restrictive role or even deliberately or defiantly engaging in an act of detachment did not in most cases align with non-participation, exclusion, paternalism, automatic failure or deligitimization of the participatory process. For many patients they considered that they had participated in their care even though they had not perceived themselves as having appraised and discussed options or as having had a significant influence over the selection of a course of action. As two patients when discussing the complexity of the levels of participation explained:

> I didn't add to the conversation about removing my feeding tube. I didn't but this didn't mean I didn't contribute to the decision to remove it. It also didn't mean I wasn't in control. I did participate albeit in a subtle way. My symptoms or my ability to tolerate my food and my reporting of a lack of nausea and vomiting for four days told the nurse this was the right course of action and in this way I did contribute to the decision to have the tube removed although in what you might call an understated way. (laughing) (P 12)

> My lack of enthusiasm was deliberate but this didn't equate with not contributing or not participating. I think really people are confused about what participation really is. Surely it is about whatever level the patient is most comfortable with. (P 43)

Assuming an acquiescent role or more restrictive or discrete activities was also in atypical instances associated with needing to *play the game, or do the accepted thing*.

As one patient explained:

> When she's on (referring to a particular staff nurse) you tend to do as you are told. I don't have a problem with that as I just want to get out of here. I just go along with things, follow the rules. It's all a bit amusing. Part of a game in a sense but you just play along with it. (P 4)

5.3.5 Restrictive Forms of Patient Work – The Impact on the Work of the Nurse

The work of the nurse when a patient's engagement in work or self-care activities was restricted was intensive and clinically focussed. The major function of a nurse's work at this time was to get *patients through the critical days* (N 6). Significant emphasis was placed on information giving, clinical safety and the physical aspects of care or clinical duties such as intense vital sign monitoring, information sharing and/or professional communication. Most nurses were of the view that when a patient assumed a restrictive role the key focus was on doing to, doing for and providing for. Table 15 provides a sample of the work activities undertaken by the nurse when patients' activities were restricted. The activities were gleaned directly from data gathered in the field.

Table 15   Restrictive Forms of Patient Work – The Work of the Nurse
• Receiving, monitoring, recording, organising, conveying and sharing information with patients and other staff • Physical care such as feeding and toileting • Clinical and/or technical tasks • Administrative work • Focussed clinical conversation • Actively soliciting patient input through the delegation of basic tasks such a hygiene tasks

The clinical focus of a nurse's work during the time when patients had to, or opted to, assume a restricted role was depicted by one nurse:

> When a patient is unable to contribute a great deal like when they come back from theatre or if they are in a bad way when they are admitted my obligation is to keep them alive. My work centres on my clinical responsibilities and keeping them alive or stabilising them. My focus has to be their physical wellbeing in the first instance…the so-called survival tasks, not how to encourage participation. (N 8)

Observation in the field confirmed that when a patient's work was limited the nurse's role was normally associated with linguistic communication and complex clinical duties.

When a patient, due to illness acuity, assumed only a subtle form of work such as information sharing or information processing the key domain of the nurse's work was observed to be the execution of technical or clinical tasks. This was most notable in the immediate post-operative period or if a patient was admitted as an emergency admission and acutely ill. Patients at this time were asked only to participate in basic tasks such as their hygiene care or menu completion for the following day. However interestingly, during opportunistic discussion in the field many nurses reported that an invitation to patients to wash themselves or complete a menu was not offered to promote a basic level of patient participation during periods of acute illness but because it helped them get through all their work within the shift.

Many nurses deprecated this motive, reported not alerting patients to this intention however, all readily shared, that the easiest way to dissipate the burden of the surgical workload, and in some instances, low staff patient ratios or a transient workforce was to ask and encourage patients to assume *trivial* activities of living such as personal housekeeping. Interestingly a few patients deciphered these intentions. As one patient reflected:

> When I was still quite poorly I was asked to do little things and I naturally assumed this was to reduce workload demand… you know reduce the hefty workload many of the nurses were saddled with at busy times. (P 30)

5.3.6   Inclusive Forms of Patient Work

Where the patients' form of work was reported as being all-inclusive, obvious and of an expansive nature, there was a change in focus. Care was not professionally driven. More control was put back to the bedside with the patient and the nurse frequently working together to achieve mutual goals. Work was essentially collaborative. Work or self-care activities normally substituted what patients perceived was nursing work. The activities were essentially co-determined but context dependent. They included aspects of self-monitoring, self-medication, self-diagnosis and self-management. Commonly quoted reasons for assuming an inclusive role included wanting to; *do their own little bit, get home quicker, speed up recovery, regain personal control and gain health benefit*. Some patients also reported that inclusive self-care activities and especially the performance of perceived nursing duties enabled them *to display gratitude for the service received in the early days* (referring to the times when care was professionally driven) or *show appreciation to the nurse*. Patient characteristics such as physical disability, age-related memory decline and occupation used as a measure of intellectual ability did however, have some impact on the extent to which patients assumed an all-inclusive role.

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Physical disability or limitation as in some cases of arthritis or when the patient was undergoing intravenous therapy prevented some patients from undertaking intricate clinical tasks demanding fine motor skills. In one case, assuming an all-inclusive form of work was linked to occupational skills and experience. As a patient whose occupation involved project management reported:

> I operate in an environment where self-management is not only a right but a responsibility. I guess my job had a driving influence on how I behaved in here. I wanted to know all the facts and figures and I mean all of them. I questioned until I knew them by rote. I wanted to monitor my own progress and learn how to look after my wound. This was important to me so I had to learn about the complexities associated with my change of dressing. I had to. (P 31)

In exceptional circumstances dissatisfaction with the service received and even the need to correct nurse's errors was cited as a reason for overt inclusive participation. As one patient reported:

> I make a point of recording all the drink I've had. If I didn't do this they (referring to the nurses) would come over at the end of the shift and try and estimate how much I've drunk and the amount would be inaccurate. The same applies to this (referring to a dressing on a gangrenous toe). On some shifts if I didn't change this myself after my shower it would never get done. Some of them (referring to the nurses) never look at it and the toe is what brought me in here. (P 27)

Table 16 provides examples of inclusive forms of patient work observed in the field.

Table   16 Inclusive Forms of Patient Work
• Contracting and assuming an integral role in the assessment, planning, implementation and evaluation of care. • Challenging staff about hand hygiene practices • Performing tasks relating to the care of their condition • Administrative work – for example reading own charts, making entries in nursing notes or on charts. • Recording and/or asking questions. • Completing written exercises about their conditions for example puzzles, filling in blanks, puzzles and problem solving • Engagement in clinical' and social conversation • Developing expertise –'Advanced fact finding' • Exploration of choice • Having disagreements or making controversial suggestions

To patients, inclusive forms of work involved varied complex 'intellectual and physical' activities and having input in *significant* aspects of their care and activities of living. Procedural nursing work and specific self-care activities were selected and engaged in following mutual agreement between the patient and the nurse. As discussed in the conceptual category labelled *Establishing Readiness* (Section 5.1 page 112 refers) antecedents such as patient and nurse capacity, expertise and commitment were found to have an impact on the inclusive work or self-care activities patients undertook. Assuming a more complex and often perceived challenging role was reliant on a number of other contextual determinants. In particular, patients affirmed that they needed; an understanding and a 'memory' for information associated with their illness, care and treatment, skill in relation to asking questions, requesting information, communicating expectations, sharing and/or making decisions and a sensitivity and awareness of the meaning of non-verbal communication. As one patient reported to *undertake a central role in your care you need ability and personality* (P 27). Hence, not all patients were accepting of an all-inclusive role, prepared or able to take on an inclusive form of work.

The following extract from an interview with a 74-year-old patient following a stoma formation for carcinoma of the bowel illustrates the point. The patient asserted:

> This kind of approach we have been talking about (referring to inclusive patient participation as a model of practice – discussed earlier in the interview) doesn't suit everyone surely. Not everybody is able to take on such a challenge. Lord I don't stand a chance. I'm struggling myself as there is so much to take in and remember so much so that they are going to have a nurse come in to me when I go home. I get the sequence of events with a bag change all muddled. (P 5)

In assuming an inclusive role patients also spoke of the costs they incurred as a result of such obvious participation. There was a firm view that to take on an all-inclusive role patients needed to be able to manage the impact of such activity in terms of increased responsibility or potential conflict in the relationship they had with their nurse. Although patients spoke about the beneficial nature to themselves; the nurse and the operations of the ward the outcomes associated with taking on inclusive activities of self-care were fluid in nature and highly unpredictable. The rewards and the costs incurred as a result of assuming and sustaining an inclusive role and also a restrictive role will be discussed within the conceptual category labelled *Incurring Rewards and Costs* (Section 5.5 page 172 refers).

5.3.7 Inclusive Forms of Patient Work – The Impact on the Work of the Nurse

The work of the nurse at a time when a patient assumed an inclusive role or undertook to take on inclusive self-care activities was dynamic, varied and multi-dimensional. Clearly, because of patients' taking on inclusive forms of work there was a notable attenuation of nursing activity.

Table 17 provides examples of nursing activities undertaken when the patient assumed an inclusive role.

Table 17   Inclusive Forms of Patient Work – The Work of the Nurse
• Contracting a plan of care • Sharing expertise and skills and providing information through teaching or coaching • Discussing options, alternatives, risks and benefits • Engagement in 'care' and social conversation • Sharing aims, expectations and intentions • Recognising and acknowledging expertise of patient • Enabling and Supporting • Listening, sharing and disagreeing

Much of the work undertaken by a nurse when inclusive activities were assumed by the patient was focused on complementing or assisting patients with their work or self-care activities. A variety of nursing strategies were adopted to assist the patient with this inclusive role and to be able to respond to the immediacy of the situation. Nurses reported how critical it was to instil confidence and maximise the motivation of patients to participate in their care. Patients needed also to be empowered to assume more control over their care. The importance of education, skill development and communication as strategies for facilitating an inclusive role were stressed. The empowering dimension of the nurse's work was critical if inclusive patient input was to be promoted and sustained. As one patient asserted:

> I'm where I'm at now (10 days post amputation) caring for my stump making decisions about appliances only because X (referring to the nurse) was my teacher. She was there for me all the time encouraging me to do all this. The support I got from her was immense. As I say I wouldn't be where I'm at now if it wasn't for her. (P 21)

Nursing work associated with empowerment although seen as critical was challenging in terms of availability of time, nursing knowledge and expertise.

Many nurses identified that they had a key role in terms of assisting the patient to attain the means, opportunity and ability to assume an inclusive role but most reported not being able to assume sufficiently an enabling or empowering role as they were challenged by the pressures of time and workload. Some reported that their skill was also tested. As one nurse reported:

> I would so love to help all my patients develop the knowledge and skills to enable them to assume a real role in their care... you know really get them absorbed in their care but I simply can't manage it all the time. You've seen the ward it's like a mad house on certain days (referring to operating days and times when there are staff shortages). I don't have time for any sort of break let alone spending time with my patient to help them say self-administer or extend their activity level in any way. I don't have the time to step back and facilitate. I have to get the job done, change the IVs, the dressings and do the drug round. (N 3)

Integral to the empowering dimension of the nurse's work were activities associated with teaching and coaching. Teaching was used to expand a patient's knowledge base, mature comprehension and improve skill performance where necessary. Coaching enabled the nurse to provide the necessary on-going support and guidance to the patient as their experience of partaking in inclusive activities unfolded. Within the surgical context, the coaching dimension of the nurse's role was observed in a number of nursing activities such as the provision of guidance on the use of analgesia, strategies for relaxation and movement, self-medication, leg exercises, arm exercises after mastectomy, care of a wound, increasing mobility after surgery and discussion about treatment options and after care. More specifically nurses, in assuming a coaching role to facilitate patient thought and participation in inclusive forms of work such as complex decision-making or the undertaking of intricate physical activities, were observed to use a very non-directive approach to skill or practice competence. Strategies such as the skilful use of questioning techniques to enable patient's to identify their own solutions and actions and techniques to *transfer skill to* the patient rather than doing it *for* them were noted to be used intentionally and repeatedly.

In actuality, the empowering dimension of the nurse's role was an essential ingredient in the cultivation of complex participatory skills needed for inclusive forms of patient work. Many patients maintained that the enabling skills of the nurses helped create an environment where so called 'risks' associated with inclusive forms of work could be taken, frustrations could be shared, fears could be allayed, support associated with intensive input could be reinforced and a more critical approach could be adopted.

As one patient asserted:

> With my nurse's support I developed the resources to enable me to take on difficult or complicated tasks and challenge staff. I learnt what I now call the basic grammar of participation. (P 32)

During interview, nurses when discussing about patients assuming a multi-faceted or more elaborate role made frequent reference to their coaching work, which was both planned as well as incidental. As one nurse reflected:

> My patient wanted to be able to have a shower on his own and care for his wound and catheter at the same time. For him to do this I had to spend time with him not just have a one off one to one. I had to repeatedly spend time with him and if you like watch him from a distance so he felt secure. I had to show him how to position himself and how to take the dressing off when he was ready to turn the water on. He then had to learn how to cover it all up when he got out of the shower. He had to have the resources to do this and I had to instil confidence or courage so he could do all this himself. This meant I had to be around quite a lot especially when he had a shower first. As time went on I sometimes appeared in the bathroom unannounced. I did this until he had gained the confidence to do it totally himself. He was afraid about the discomfort and getting his wound wet or letting his bag fall – he had to be pushed a bit so I needed to persuade him that he could do it and then stand back and this took time. He called me his trainer actually probably because of his interest in the races...he's mad on the races. (laughing) (N 8)

The encouraging dimension of the nurse's coaching work also emerged as being very important when a patient assumed an inclusive role. Many nurses reflected that encouragement was imperative when a patient was keen to assume a more active and elaborate role but was at the same time uncertain or nervous about participating in their care at this level. As one nurse explained:

> After surgery, many patients are reluctant to do any deep breathing or move about in bed, get up even because of the IVs, drains and the pain. For those that do want to get going so to speak and really get involved you do have to encourage them. Having sometimes just a presence encourages your patient to participate or do the exercises, manage their tubes, get up and wash and even fill in their charts or discuss what happens next. You really have to inspire confidence to the nth degree for this high level of patient activity we are talking about – it's important to the patient. (N 14)

5.4 Summary of Conceptual Category

In summary, this category has described how patient participation was enacted within the acute surgical care setting, a clinical setting previously neglected by many earlier research studies. Patient participation within the surgical care context comprised a diverse range of work or self-care activities. The level of participation assumed by a patient was that which was appropriate at the time. No single key was found to unlock what patient participation should involve in terms of work or self-care activity. Activities were undertaken at a level and with a focus that was meaningful to the patient at any one time. The work of most patients waxed and waned in synchrony with the surgical setting climate, the context and characteristics of the individual patient and nurse. Many contextual determinants within the surgical area of practice, within the patient and the nurse shaped the level of patient participation and thus the work of both the patient and the nurse. Any level of patient participation or more specifically work undertaken by the patient brought challenges to the individual patient and nursing staff. Clearly to promote any level of patient participation nurses need to possess specific skills in how to engage patients and support them in their efforts. Furthermore, it could be suggested that both patient and nurse need to be resolutely clear about their role and the nature of the work or self-care activity to be performed. Time has to be spent defining, agreeing and refining the work of each participant. Resources to support the work of patients and the work of nurses in promoting and strengthening patient self-care need also to be ring-fenced.

The next conceptual category labelled *Incurring Rewards and Costs* describes the impact of patient participation on the individual nurse and patient and the quality of care provision generally.

5.5   Incurring Rewards and Costs

5.5.1   Introduction

The phase categorised as *Incurring Rewards and Costs* explains the varied effects of patient participation on the individual patient, the nurse and surgical ward performance and resources. While the impact of participation at any level was tidal in nature and context dependent the outcomes associated with such a model of practice were essentially beneficial and rewarding to the patient. However, on occasion patient participation did elicit a protective response from some quarters and in the extreme placed adverse demands and pressure on patients and nurses alike. For some the experience was painful and humbling. Specific strategies of action and interaction were employed by patients to sustain continued participation, manage the adverse effects of undertaking work or self-care activities and survive what some termed '*the ordeal'*. Nurses to enable patients to cope with the challenging impact of participation also used explicit interventions. Nurses themselves also engaged in a range of behaviours to endure the challenging experience.

5.5.2   The Rewards

Patient participation in nursing care delivery at any level was widely recognised by both patients and nurses as being a *'good thing'*. The ultimate reward was that such a model of practice ensured in most instances that nursing care fitted around patients' needs and preferences. Sharing the *driving seat* or assuming a *central role* in care activity was for many patients a key benefit of participation although it was reported that '*there is still a long way to go before patients' needs genuinely drive mainstream nursing care practice* (P 39). The specific rewards as described by patients and nurses are outlined in Figure 7 overleaf.

Figure 7 - The Rewards of Patient Participation

5.5.2.1 High Quality Patient Experience

Patients frequently reported that their participation resulted in a high quality experience. In the main, the majority of patients reported that participation whether restrictive or inclusive had a positive impact on surgical outcome, recovery and degree of satisfaction with their nursing care. Some patients reported how it specifically *demystified expert knowledge, boosted confidence and reduced the boredom post-surgery*. However, strikingly the positive effects were most evident when patient participation irrespective of level was integral to the patient's total surgical experience. As one patient reflected:

> By working my way through my experience in here I've really been able to make headway with my recovery and now early discharge is a possibility. To be honest, the effort I put into all of my care before and after my op helped me resume control rather effortlessly. My experience has been kind of… kind of ideal. (P 5)

Of the patients and predominantly those from Ward A who reported participation being integral to most elements of nursing care in the pre and post-operative period, all alleged, that their experience had led to better adjustments being made to surgical outcomes, an increase in the effectiveness of therapeutic activities such as rehabilitation or motion exercises and an enhanced health care literacy. Patients frequently spoke of how their participation led to a better recall of information, a deeper understanding of their condition and confidence to manage their condition or take part in aspects of their care.

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Furthermore, patients spoke about better relationships with nurses and a greater ability to discuss issues with nurses, doctors and other health professionals. The explicit rewards associated with '*on-going*' patient participation were also seen as drivers for sustaining and increasing patient engagement in general.

One-off or ad-hoc episodes of participation did nevertheless have a positive impact on the patient's surgical experience. An example of how a patient's specific action contributed to their wellbeing postoperatively can be drawn from one particular exemplar. A patient who was experiencing difficulty sleeping post-operatively was observed to be asked to provide an opinion about how rest and sleep could be better facilitated for him. The patient reported that the ward did not accommodate his normal sleeping schedule and that practices such as delayed medication administration, investigative test scheduling late in the afternoon and room location all prevented him from sleeping. In sharing this information with the nurse interventions to accommodate his normal sleeping pattern were introduced. The patient, during a later period of observation, reported how the screening of his bed area during times of rest and an alteration to his medication regimen with blood being taken earlier in the day contributed to the creation of an environment that enhanced his rest and sleep. He went on to remark how his positive experience of participation or '*chipping in*' had also encouraged him to sustain a level of participation in care delivery throughout his hospital stay. As he revealed:

> My view about something as basic as being unable to sleep made a real difference. The whole episode made me realise that my contribution was important and I guess it made me wake up and smell the coffee (laughing). Truthfully, the impact of my input into this very small thing made me assert myself more every day. (P 13)

Other patients described how their participation in individual activities associated with their care such as the administration and adjustment of medication, the management of appliances and the monitoring of performance and progress led to improved disease control, more informed decision-making, heightened vigilance, feelings of self-worth and a hospital stay that was shorter than expected or planned.

The positive gains associated with any one act of participation did create among many a strong view that participation should be embraced throughout a patient's entire health care experience. The high quality experience associated with distinct or unique self-care activities contributed to a firm desire for continuous participation. For some this desire became a reality in practice. As one patient revealed in an extract presented overleaf:

Once I realised how important it was to tell the staff what this wound seepage looked like or what my pain was like, I was determined to carry on voicing my opinion about things. I'm convinced my feedback about my pain for example ensured I received proper pain relief and I did need that. Being able to secure pain relief in itself made me want to get more involved in different aspects of my care. I actually got quite involved in most things, nothing too sophisticated mind but I did get involved in some way every day. The more I actually benefitted and made a difference the more I was drawn in. (P 20)

Although the positive outcomes associated with specific self-care activities did contribute to some patients sustaining a level of participation throughout their period of hospitalisation continuous participation only followed if sufficient resources such as knowledge and skill were at the disposal of the patient. Where knowledge, understanding or information was not shared, or jargon was used to regulate understanding, or interactions between the nurse and the patient were deliberately limited, feelings of exclusion had an adverse impact on the extent to which patient participation was sustained. A sense of marginalisation frequently resulted in patients undertaking only occasional self-care activities or making only a very limited contribution to their care. In an exceptional case, a patient disclosed how a lack of engagement or more specifically a lack of knowledge and information about his surgery and discharge date affected adversely his powers of concentration for other tasks namely the administration of his own medication and the conduct of remedial and relaxation exercises. He described how the anguish he experienced about being *kept in the dark* eventually led to a decrease in the time invested in rehabilitative exercises and the termination of the self-administration of medicine. Interestingly, despite the reported alienation little attempt was made to adjust behaviour to seek resolution primarily because the patient perceived his care to be generally effective. The same patient did however report that had he been more seriously ill and deemed his care ineffective he would have sought to obtain more information about his condition and care package.

Feelings of control and usefulness in the reinstating of a self-care role were other reported paybacks of patient participation. Forms of participation such as the receipt of day-to-day information about care and in some cases having access to notes and care plans frequently resulted in an increase in self-reliance and self-control and a decrease in anxiety. Well-informed patients were also inspired to take on an even more active service orientation.

An extract from an interview with a patient illustrates how participation in the form of simply receiving information encouraged a more inclusive or self-governing role. As the patient reflected:

> Just being given a wee bit of information every so often about how you are doing makes you relax and feel valued. It makes you feel part and parcel of everything. As you gather more and more information you grow, you grow until eventually you gain the confidence to accept responsibility for something that's a bit more demanding of you and makes you less needy. (P 29)

Clearly, the more patients understood about their condition, the more they were able to participate in their care for a sustained period. Many patients concluded that information exchange and retention was indeed crucial if participation at any level was to be sustained. One patient admitted to a ward with acute bowel obstruction also expressed how he felt his participation in educational activities would prevent readmission and facilitate self-management of his condition on discharge. As he revealed:

> All the discussions that were arranged for me with the dietician and all my probing and I have to say even doing those little quizzes helped me learn about what I should eat and what I should avoid. I now know what symptoms to watch out for and hopefully I will now be able to prevent an emergency episode again. (P 31)

However, the intensity of effort to participate or more specifically be and stay sufficiently well informed about progress, care and the future demands was for some exhausting and draining. As one patient explained:

> My surgery you know was very complex (Oesophagectomy and gastric tube reconstruction). It was life changing for me. The biggest challenge for me was to gather all the facts to make the best possible decision about treatment, care and the future. It wasn't easy to collect and make sense of all the information. I felt quite bulldozed. The pressure I put on myself was intense. (P 17)

Patients who participated in their care to a greater or more inclusive extent reported benefiting personally from the supportive environment such a level of participation frequently generated. They spoke of how a nurse's encouragement frequently gave rise to what some described as emotional well-being and feelings of *competence, self-worth, influence and importance*. Patients also described how a nurse's overt recognition of the added responsibility they assumed, the gradual reduction in assistance and the teaching and learning of specific skills such as eye drop installation inspired confidence and courage to continue or even extend further the scope of their participation. The so-called culture of support that emerged with a participatory model of practice did result in patients reporting

that they felt free to ask questions, get help when they needed it and make mistakes without blame or shame. It was also found to diminish apathy and dependency on the nurse.

The empowering dimension of the nurse's work resulted in feelings of security and self-assurance among many patients. The effective use of presence, a form of encouragement used to promote participation contributed frequently to feelings of wellbeing, confidence and security. During time spent in the field, patients following surgery were often observed because of pain or fear not too move sufficiently. In spite of explanation, they remained somewhat reluctant to mobilise or participate in a range of motion exercises. Many nurses consequently chose to gradually reduce their assistance but be present during times when specific activities such as rehabilitation exercises were scheduled to be undertaken. In this way, the nurse provided guidance and support and worked with the patient to give confidence and confirm that the activity was appropriate and being executed competently. Verbal exchange with patients confirmed that although nursing assistance was withdrawn the continued presence of the nurse contributed significantly to increased patient activity and feelings of self-confidence, which in turn led to sustained participation in care activities. In discussing the value of patient participation in the longer-term patients spoke of how a positive experience of participation would encourage them to sustain a pro-participatory attitude that would remain with them for future encounters in the health care system. For many, the experience of participation developed a new or fresh perspective on the role of the patient, which in itself left some encouraged to take steps to undertake constantly a range of different self-care activities. As one patient engaged in self-critical reflection said:

> It would never have occurred to me to express an opinion on anything to do with my care. I just thought that was the way the world was in here. I think I just had an archaic view of health care. From my input in developing that plan that was kept at the foot of my bed I learnt that it was okay to voice how I felt, to question and contribute to what was written about me. In a way I've matured quite a lot. Certainly, the more often I inputted into things, the more I began to realise that I could have a say in my care and even the shift handover we spoke about (laughing). Being able to invest in my care really made me feel good and want to invest even further. The interest rate was good. (laughing) (P 31)

Interestingly a number of the nurses interviewed described how the experience of patient participation at any level challenged and changed entrenched perceptions and attitudes about the role of the patient. Exposure to patient participation on Ward A certainly resulted in some nurses learning and as a consequence revising their perceptions of the limits that should be placed on patients. The experience in itself also provided some with a new view of patient-professional relationships and engendered in a few a spirit of genuine commitment to

patient participation. Having been witness to the positive effects of patient participation the attitudes and practices of many nurses changed from that of defensiveness to being one of cooperative working with patients to make care better. As a newly appointed nurse to Ward A conveyed:

> Starting work here (referring to Ward A) really challenged my view about the patient's role. At first I felt very threatened and had mixed reservations. I wasn't totally committed – although I didn't tell anyone that. I did initially feel very uncomfortable with patients doing too much but having seen what it's all about and how it improves care I will now always campaign for the patient voice to be heard. It is no longer a controversial issue for me. It's my old role that is flawed. (N 5)

5.5.2.2   Safer Care

Two cases provide explicit examples of how patient participation contributed to the promotion of safer care. More specifically the cases exemplify how the risk of experiencing an adverse event was reduced. The extracts of raw data illuminate how some patients recognized and informed nurses of lapses in care in time to prevent an adverse event. The data makes explicit how patient participation resulted in a decrease in medication error, improved patient safety and a continued active patient orientation. However, unfortunately in both cases sustained participation in this context was reported to be triggered by the anxious response that medication administration error inevitably produced. As the two patients revealed:

> Some nurses always seemed to forget to give me my injection (referring to subcutaneous heparin injections). They would take my drug chart away to prepare the injection but never come back or when they did it was so late I had to wait until the next dose. I was then given the option of being taught how to do the injections myself. I was nervous but did start doing them because I knew if I did them I would always get them on time and (laughing) be sure that the hands giving the injection were clean. (P 13)

> I questioned whether I really should have my warfarin before my surgery. The nurse said yes but just before I put it in my mouth, she said no wait a minute I'll check. She checked and bobs your uncle I wasn't supposed to have it. Needless to say, from there on in I checked about every dose. I've taken warfarin for years and know how critical dosage is. (P 19)

While a number of patients admitted to engaging in activities associated with medicine administration to prevent medication error a few reported not feeling sufficiently confident or articulate enough to take on error-preventing behaviours. Participating by questioning a nurse about their practice was frequently avoided even if the patient recognised that the nurses' behaviour placed them at a degree of risk. This kind of reluctance was particularly apparent if the nurse was of a senior rank.

Verbal acts of participation that essentially questioned a nurse's practice generated fear and vulnerability among some. Furthermore, despite understanding the importance of error preventing interventions specifically and believing that patients had a right to safety some felt unable to contribute to the safety of their health care, as they believed strongly that few nurses would be receptive to such patient input. Some patients also assumed they might endure hardship if participation was linked to criticism about nursing practice. One patient's story illustrates the point:

> At a point when I was in considerable pain, I asked the nurse assigned to my bay for some pain relief. She said I couldn't have any more as I had only just had some a few hours ago. I knew that wasn't right so I asked again and possibly even a third time, but each time she said it wasn't possible. I was in such discomfort that I ended up asking another nurse to check if I was due for anything. I wasn't due for any of my regular meds but could have something for the break-through pain that was on the front of the chart. Interestingly I never saw my original nurse for the rest of the shift. I didn't even get a bowl to wash that morning. (P 19)

Those patients that were able to take on a challenge particularly in the context of medicine administration reported having *an extrovert personality, natural courage or confidence in their ability to protect themselves from clinical errors*. Indeed personal characteristics such as self-confidence, self-belief and assertiveness were identified as affecting participation in this context. As one patient remarked, *if you don't have the confidence to report human error you suffer a nurse's incompetence* (P 45).

Many nurses themselves also recognised how patient participation in specific self-care activities could contribute to the safe delivery of care. One particular nurse stressed how encouraging a patient to read and offer comment on the admission assessment and formulated care plan lead to an *increased accuracy in diagnosis and nursing records* (N 5). However, despite many nurses reporting that in their experience enhancing a patient's role could help ensure safer care and prevent the occurrence of harm most were candid about the fact that when patients were undertaking roles traditionally assumed by a nurse constant and sometimes intense surveillance was demanded particularly within the context of administration of medicine, self-monitoring and infection control. When explored further the desire to survey or monitor patient activity was most commonly associated with the fact that nurses believed firmly that the main responsibility for patient safety remained in their hands. As one ward manager maintained:

> The drive for patients to assume a key role in patient safety has come about as a result of many tragedies and I support this approach but you cannot forget that

patients have to work alongside the nurse, as it is the nurse who is ultimately responsible for patient safety. (N 17)

5.5.2.3   Team Working

Many patients described how a participatory role at any level promoted an *esprit de corps,* which in itself encouraged patients to sustain a participatory role for the duration of their hospital stay. As one patient explained:

> The range of things I described earlier….you know all the examples I gave you (referring to a number of self-management practices such as the administration of pain relief, the positioning of the arm to maintain IV flow, and the changing of a wound dressing) resulted in a win win situation as far as I'm concerned. The intensity of my get-up-and-go (laughing) meant I was less reliant on others and the icing on the cake was that I felt I had really achieved something. I achieved the goals I had set myself and I believe I helped my nurse pull hers off too. X (referring to the nurse's first name) was delighted with my effort and made a point of saying what a great team we make. That meant a lot to me as it showed we were working towards the same end. It was incredibly encouraging actually. The so-called team spirit served me well as it made me even more determined to maintain a certain amount of oomph and work with my nurse. (P 7)

Some patients concluded that the enactment of specific tasks or clinical duties such as the reporting of progress during the inter-shift handover, the accessing and reading of nursing notes or the self-monitoring of body temperature and blood sugar levels not only promoted *joint effort and an improvement in care* it also *plugged* gaps in service provision. However, assuming a role to *plug* a gap in services was seen by a few patients to be *unacceptable and unsafe.*

For the majority of patients a collaborative working relationship contributed to a higher quality care and an acceptable level of patient satisfaction. As one patient recalled:

> Taking on a few jobs as I call them (referring to the recording of blood sugar levels and the management of a wound drain) tuned me into my care and what the future held for me. It was important for me to learn new skills and assume the right level of responsibility ready for when I go home. On the flip side, it also provided added value for the staff particularly when they were stretched. In this sense we became a team. Granted I plugged the gaps and provided early warning signals when things were not quite right but at the same time, I enjoyed the camaraderie. In a sense, I was reimbursed for my work by really being made to feel part of a team. (P11)

Similarly, many nurses spoke of the value of different forms of participation in terms of teamwork and partnership working. Many were of the view that patient participation at any

level brought benefit over and above what nurses would achieve working alone or in isolation from the patient. To many nurses the alliance that emerged between them and the patient when self-care activities were assumed was both energising and satisfying. It too resulted in an improved understanding of the patient's health problems and specific needs and according to one nurse *ensured the patient was treated as an individual rather than an object of some disease entity'.*(N 14)

Clearly many nurses associated patient participation with enhanced nurse-patient relationships and communication. As one nurse reflected:

> One of the legitimate outcomes associated with your patient having a real stake in his care is the satisfaction they and you get from pooling resources. It is so rewarding and really energises you. (N 4)

5.5.2.4 Surgical Ward Performance

Patient participation in work or self-care activities was also seen as a bonus for ward management. More specifically, it was seen by nurses to contribute to an increase in service capacity and efficiency gain. Undeniably, many forms of participation or self-care activities lessened patient helplessness and nurse dependency and reduced inpatient costs due to early discharge. Having a lay and professional workforce increased clearly service efficiency. As a senior nurse asserted:

> Budgets and staff time are already stretched so if you do encourage a patient to take on some of the so-called clinical duties like maintaining a fluid chart time effort can be saved. In some instances, beds are also freed up more readily as patients if they participate in a meaningful way often get discharged quicker than others. Their views about the little things also save money. They challenge long–cherished activities which can save money. We stopped buying disposable slippers as a result of patient feedback – this saved us a fortune and is what I call the hidden value of patient participation that no one talks about (laughing). Going back though the so-called release from clinical duties does also enhance a patient's personal care as it allows a bit more time to be spent on more important things like maybe focusing on the teaching role. (N 6)

While many senior nurses spoke of the capacity and efficiency gain associated with patient participation many also spoke of the added value of learning more about the patients experience in general and thus being better able to understand patients' needs and priorities. Such knowledge was also reported to improve the experience of patients and carers and improve service provision. As a senior nurse during a discussion about the cost savings associated with patient participation affirmed:

The most significant benefit of patients participating in their care is not associated with reducing expenditure per se. It is about learning more about what patients really want. You then use this knowledge to improve the care you provide to others. There is this knock on effect as learning about the patients experience through discussion or them completing their satisfaction card helps to inform continuous improvement and if you like transform your services. (N 1)

5.5.3   The Costs

Although patient participation at any level was essentially reported to have a positive impact on the overall patient experience, sprinkled among the accounts of patients was a litany of incidences, which inferred that the outcomes associated with participation were variable, highly emotive and unpredictable. Clearly, for some patients and nurses the outcomes associated with patient participation were of a destructive or less favourable nature. The adverse effects of patient participation were in the main associated with emotional discomfort and the challenging demands placed on patient, nurse and ward resources. In exceptional cases, the impact of patient participation in nursing work or self-care activities was demoralising or caustic. As one patient articulated:

Most of the time my self-monitoring was really appreciated and I would say valued but there was one individual who from day one was always hypocritical of everything I did. She found fault with everything and made me feel so vulnerable…..vulnerable to error that is. It was incredible actually she just made me feel so nervous. I think because she was so scathing about what I had taken on when she was around I tended to just bungle everything. She was so off-putting. (P 7)

The more common and specific costs associated with patient participation and reported by patients and nurses alike are outlined in Figure 8 overleaf.

Figure 8 - The Costs of Patient Participation
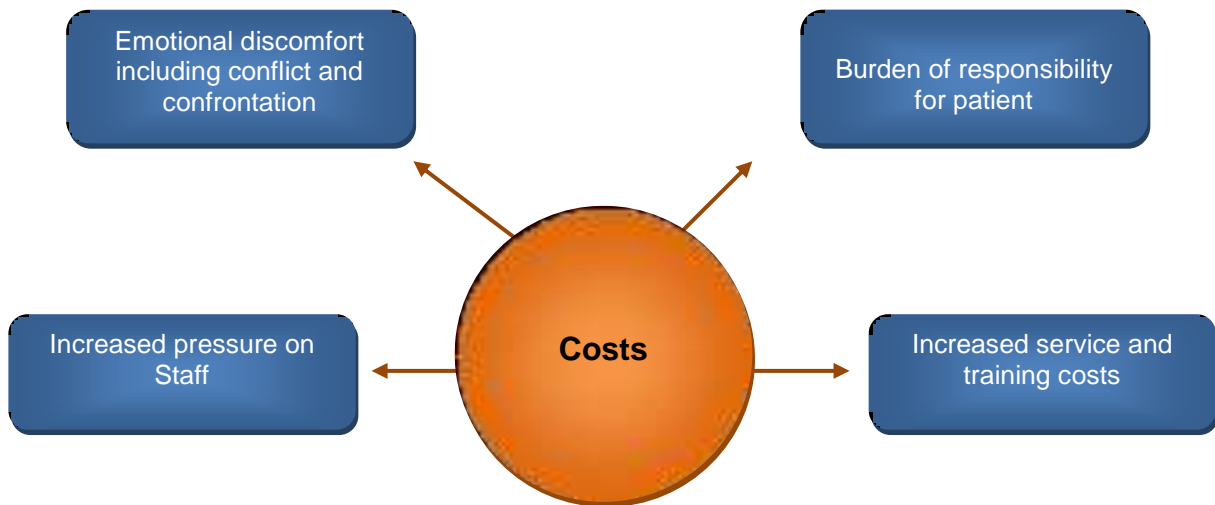
5.5.3.1   Emotional Discomfort

Patients as a result of engaging in different forms of participation for any length of time often experienced what they referred to as *unacceptable levels of stress, anxiety or fear* owing to the perceived level of responsibility they assumed. A few patients also revealed that *being left to get on with it* imposed a measure of isolation from the nursing staff, which in turn triggered undue worry, a view affirmed by one particular patient:

> I felt sort of cut off as they (the nurses) let me get on with things. I guess they just thought well if he's doing it we don't have to bother too much with him. It really was nerve-racking. (P 7)

Some patients described how participatory activities such as self-medication, decision making about complex elements of their care or treatment and self-surveillance in the form of the taking and recording of temperatures and fluid input and output had an adverse effect on their experience and well-being. The potential risk of inaccuracy or error associated with self-monitoring created among some a degree of *dread*. As one patient revealed:

> There are times when I felt I could do it properly (referring to the self-recording of a fluid balance chart) but other times particularly if I was having an off day when I worried constantly about the accuracy of my recording and adding up. There were times when I felt sick with worry. I was never good at maths anyway. This was made worse when a nurse stood and inspected my chart and said nothing. Now I'm ready for the off I do question why I put myself through all that. (P 11)

Most patients assuming a role in self-surveillance reported a fear of doing something wrong unintentionally or intentionally not doing the correct thing despite having the knowledge or skill to interpret symptoms or manage the task at hand. Concern about *self-harm* was

essentially associated with self-management practices such as medicine administration, wound management or more specifically infection control practices. In one specific case, a patient described how their contribution to self-surveillance or more specifically being asked to identify and report complications and adverse effects during a blood transfusion led to persistent worry and fear. As the patient revealed:

> I was asked to tell the nurse if I experienced any one of a long list of complications, as they would need to stop the drip immediately. From the time the blood was put up I had a gnawing pain in my tummy as I was so worried about missing something and dying (laughing). I didn't sleep a wink. The pressure was too much. I just didn't have the nerve to handle it. (P 5)

For some patients there was a specific fear associated with *doing too much and* reducing the control of the nurse. For some participation also carried heavy responsibility and risk when prior experience was such that the patient was accustomed to having every aspect of care and treatment monitored and administered by others. In an exceptional case, one patient reported how they experienced a depth of participation that was far too intense. This in turn resulted in emotional strain, anger, resentment and controversy. As the patient asserted:

> She (referring to the nurse) told me there was no such thing as too much participation. She gave me the entire blurb about the benefits but she hadn't a bloody clue. Her perseverance was insane. (raised voice). In fact, what she put upon me was ludicrous (referring to his own administration of Diclofenac suppositories for pain relief). I did it because of the pain but it lead to a real row I tell you and me threatening to leave. There is no way I should have been asked to do something like this. (P 3)

When restrictive participation or more specifically *doing very little* or settling for *proxy care* was the preferred choice some patients experienced torment or a degree of fear about the fact that their limited contribution or passive role would not be welcomed even though they believed that in doing this they were still adopting an active patient orientation. The majority of patients assuming a restrictive role did however speak about the *immense relief'* they felt from not assuming any significant responsibility for their care or decisions about their care during the acute phase of their illness or surgical experience. Selecting to take on only simple self-care activities such as menu choice or the sharing of information about their condition alleviated a degree of anxiety for some. As one patient reported:

> The fact that I could rely on the nurse for most things was an enormous relief. The stress when I found out I wouldn't have to do anything too clinical just evaporated. I was literally terrified about being asked to do something too gory. (P 22)

On the contrary, where participation or self-care activities were limited by the nurse without consultation, patients, irrespective of personal circumstances and their illness context, reported feeling *angry, anxious, worthless and even alienated from their care*. A deliberate attempt to limit participation in care or decisions about care was associated with depersonalisation and isolation. Patients also expressed that such distancing meant that their human dignity was being denied. In an atypical case, a patient blamed herself for the notable attempt by the nurse not to engage with her. The patient attributed this behaviour and in particular the rationing of discourse about her care to her own lack of knowledge and anxiety.

In another extreme case the effect of restriction placed on a patient or more specifically the amount information that a patient was given resulted in what one patient referred to as *default from treatment* and a complaint being made about being intimidated to the point that there was no option but to follow orders.

Restrictions on acts of participation imposed by the nurse also raised the issue of tokenism, which patients recognised as one of the key challenges associated with patient participation. A number of patients did actually report how much lip service was paid to the process of participation. As one patient reported: *there was a quick pursuit of views when I was admitted, but this was quickly followed by a return to old habits – in other words, after being admitted there was no commitment to including me at all.* (P 22)

One of the most caustic effects of patient participation at any level was the exposure of both the patient and nurse to conflict. Conflict among nurses was evident but rare and was reported to be due to opposing views about the extent or nature of patient participation. Conflict between patients and nurses was more prevalent and most commonly arose when patients undertook work or self-care activities which caused the nurse *unnecessary stress* or when a role which was seen by the nurse to be their domain or territory was assumed by a patient. Examples of specific self-care activities which were associated commonly with conflict included the execution of clinical tasks namely in the context of the management of pain, self as opposed to professional-surveillance, medication administration and adjustment and acts which involved information exchange and decision making about care packages. Many patients asserted that conflict most frequently stemmed from encounters where they felt *patronised, put-down or undervalued*. It also often manifested in the form of arguments about daily routine and was often reported by patients as being difficult to manage especially when some nurses namely the non-permanent staff conceded an unwillingness to share *care* with the patient.

Adjustment of behaviour by both patient and nurse was necessary to seek resolution from conflict. A variety of strategies and behaviours were employed by both parties to minimise variance and seek resolution. Observation and later opportunistic discussion revealed how patient behaviours such as prolonged eye contact, active listening, gestures such as nodding and smiling, the use of humour, direct questioning and requests for elaboration were employed as a means to minimise dissent and sustain desired or achieved levels of participation. Patients maintained such behaviours did much to *keep the nurse onside*. In extreme circumstances, conflict because of undertaking a single or a range of acts of participation resulted in non-compliance with care packages.

In addition to the exposure of conflict levels of participation also resulted in what some nurses called an erosion of professional boundaries. A few nurses described how acts of participation particular those of an inclusive nature threatened their professional identity and authority, which in turn resulted in what one nurse referred to as a *loss of clinical independence*. To minimise or seek resolution associated with discord the work of both the patient and the nurse had to be mutually agreed. Parameters for nurse and patient responsibility needed to be clear to both parties. As a nurse in talking about the resolution of dispute maintained:

> The important thing is to have agreement between yourself and the patient. Agreement about who will do what and when. It's how it (referring to patient participation) works. The starting point is agreeing the way forward. It's not always easy but it can be done. (N 1)

Taken to the extreme it was apparent that some nurses felt that inclusive forms of patient work or self-care activities were challenging and emotionally draining as they contributed to experiences of existential anxiety and a lack of security. In one case, a patient assuming an *inappropriate role* led to a nurse employing strategies to avoid the patient. Another used a particular line of talk to dissuade patients from participating in their care. As the nurse shared:

> When patients take on physical tasks after their operation….like an obsessive monitoring role I'm not entirely sure footed as I know what the potential risks associated with their behaviour may be. To compensate for my...what some would call risk aversion I suppose I almost scare them into letting me take back some of the tasks. I do this in a nice way but my conversation does focus on the potential dangers and I guess I am quite assertive with it... It usually works too. (laughing) (N13)

Among a few nurses, significant patient input in essentially clinical tasks triggered an angry response. Interestingly patients and some nurses attributed such anger to a lack of understanding or professional ignorance about the scope of a patient's role and responsibilities in contemporary nursing practice, undesirable learned behaviours and a lack of skill to engage patients in their care. As a nurse asserted:

> Some of the wards in this hospital have become locked in a culture that is out-of-date and inappropriate for facilitating any sort of patient participation. It's appalling. If I am sent to help out elsewhere in the unit, I hate it. One shift elsewhere is enough. (N 2)

Feelings of hostility were also evident among some nurses as for some patient participation at any level conflicted with the professional ethic of protecting patients. It was also associated with expressions of apprehension about accountability and as the following extract reveals many nurses articulated feelings of discomfort particularly when the patient failed to manifest behaviours expected by the nurse:

> You have to admit that a patient taking on what is really my role is not on. Take the filling in of charts or the change of a dressing, that's crossing the line. I won't have it. There has to be an acceptable role for patients and getting involved to that extent is not it. In all honesty, if my patients do not comply with their role parameters I restrict my contact and they become a low priority. I have to approve what they want to do. Sounds harsh but I do have a job to do and it is one for which I am accountable and that needs to be remembered. It took me three years to train as a nurse so why now would I give up on all I have learnt. You are trained to think of yourself as the expert. Does my training not count for anything? (N 8)

Interestingly, the notion of being trained to be the expert was a view expressed by many nurses. Interaction where knowledge, responsibility and control were equal was unfamiliar territory to some nurses irrespective of when they registered as a nurse. Although nurses who registered in the last ten years reported having values associated with patient participation in nursing care incorporated in their training, nearly all had values and behaviour patterns that were associated with nurse centred care. Patient participation was not a core value observed extensively in practice. Most attributed their nurse-centred approach to care to the fact that they had a duty of care to look after, as far as possible, the health, safety and welfare of their patient and should this duty not be fulfilled litigation may result. Allowing a patient to contribute to nursing practice was deemed by a few to be too challenging or too *risky*. As one nurse asserted *the relinquishing of professional skills and responsibility to essentially lay people or smart alecks without qualifications is too much of a challenge for me*

(N 8). On the other hand, many nurses did admit to feeling ill- equipped to deal with a way of working that placed the patient at the centre of their care. As one nurse explained:

> I recognise the value of patients participating in their care but it is unrealistic to expect me to take on board such an approach to care. It's not against my views but it is contrary to how I have been trained. It's ironic that during my training and I have to say all the study I have done since that I have been socialised to believe I am an expert so anything that challenges that is additional stress. I can't be expected to keep up with all these rising expectations especially without the skill and time to learn about them. It's just all too much and I don't quite understand what is needed to make patient participation a reality. (N 6)

On being asked about staff losing 'control' or giving more of it to the patient, a ward manager advised strongly that when nursing staff experience a loss of control they need to be compensated. Such compensation was reported to help the nurse move from defensiveness to cooperation with such an approach to care. The manager affirmed that:

> When a new nurse on the ward feels uncomfortable or struggles with the fact that they are losing control or their professional boundaries are being eroded in supporting them it is important to give them a different sort of control maybe over their work environment or perhaps the staffing in their bay. If you don't do this, participation as a model of care cannot be sustained, as staff feel challenged and resentful. (N 4)

Generally, it was clear that for both nurses and patients to withstand the challenges associated with patient participation and thus enable a patient to sustain any level of participation encouragement and on-going support was needed by the patient and the nurse alike. The creation of a culture of support was seen as key. Managing the challenges and sustaining a level of patient participation was more complex than simply providing the correct infrastructures. Nurses realised that there was a need to encourage patients to recognise their existing skills, and to develop new ones, at a pace that suited their particular circumstances and personal resources. Continued support and monitoring of progress was deemed critical to offset the stress that some patients experienced as a result of participating in their care. As one nurse who had enabled a patient to start administering his own complex prescription of medication asserted:

> You need to supervise albeit it at a distance. It's important, as you are then able to detect early warning signs of difficulties especially if the patient is wary of the commitment involved. (N 13)

Praise and reinforcement were commonly used to help patients manage the adverse consequences of participation such as fear and anguish. Field observation indicated that the

use of humour was also important in helping a patient to withstand the burden associated with some forms of participation. As one patient reported:

> When your nurse has a sense of humour and you can have a laugh with her you feel more comfortable. Often joking and laughter reduces the anxiety associated with taking on that bit of responsibility for your care. (P 11)

Interestingly some patients were observed to wait for certain nurses to come on duty before they would discuss certain care issues or participate in any clinical tasks. Certain nurses appeared to be able to alleviate a degree of anxiety associated with participation. The following extract from a field note illustrates the point:

> All morning the patient has barely spoken to the nurse caring for him. There has been no real two-way dialogue. Now there is a change of shift and while the new nurse was scanning the patients' charts and within a few minutes of her arriving at the bedside, the patient commented: hey X (referring to the nurses first name) I've been drinking a lot more and the drainage from my NG (referring to a naso-gastric tube) has been much less this morning, so I was wondering if it could come out. I don't feel sick at all, so I'm sure my fluids will stay down. The nurse replied saying she would consult the doctor. (FN 201)

Later discussion with the patient revealed that he had waited for this specific nurse to arrive on duty before he engaged in questions about his care, a strategy termed *nurse shopping* (P 31) and discussed earlier in the chapter (Section 5.1.2 page 115 refers). The patient explained that he had done this as he related better to the replacement nurse and shared the same sense of humour. The patient also described how he felt comfortable voicing his views with this one particular nurse as any decision to be made would be made together. Her interactional style was deemed facilitative.

The use of empathy demonstrating sensitivity and the use of confirmatory responses were also especially important in enabling the patient to deal with any stress associated with participatory behaviour. Confirming with a patient that it was acceptable and normal to experience for example trepidation was seen as critical if participation was to be sustained. As one nurse explained:

> To encourage any patient to participate in their care you have to work through the emotions they experience as a result of taking on that burden. You need to validate their feelings and given them permission to be scared then you have to work on improving their perspective of the value of their input. In this way, they learn to cope with what is only actually a bit of uncertainty. (N 10)

5.5.3.2   Resource Demands

Patient participation at any level did incur a price in terms of both the patient and nurse's role and the demands placed on them. Although most patients and nurses recognised the benefits of patient participation, there were obvious challenges confronting both parties if such a practice was to be sustained throughout the patient's surgical experience and not be seen as a tokenistic initiative. Nurses spoke of the demands placed on them in terms of time, energy, workload, enthusiasm and commitment. Many also spoke of the difficulty of trying to establish net alone sustain an all-embracing role for the patient in the acute care setting. This was particularly challenging when the inter-changeability of nursing staff due to work patterns such as shift rotations and days off when working 12 hour shifts shortened the length of contact between anyone patient and nurse and also forced patients to establish relationships afresh with sequential replacement staff.

Similarly, patients spoke of the confusion and uncertainty that arose because of having to work with many different nurses during their hospital stay, many of which gave various directions about their care. Role ambiguity was a salient issue for patients when there was transience in the nursing workforce.

There were also the practical matters such as the time that needed to be spent with patients to promote and sustain a degree of participation. Within the context of the surgical environment, both patients and nurses reported that the most significant resource requirement for participation was staff time. As a ward manager asserted:

> There are outlays associated with patient participation. You do need a dedicated and realistic budget. You have to make provision for staff to be able to spend time with patients but most importantly you need resources to train and support staff. This is vital to its success. (N 10)

The empowering dimension of the nurse's role and the need to develop associated educative and supportive skills to foster patient participation also demanded time. As one nurse during a conversation about the need to promote, facilitate or support inclusive self-care activities detailed:

> It's hard when you are working on a busy acute ward to keep this in mind (referring to the need to enable patients to assume an inclusive role). It is a way of working that requires constant vigilance in the chaotic world of acute health care delivery. It really is hard to actualise patient participation all the time. It needs to pervade everything you do and this in itself is very demanding on your

time. You do need support whether it is in the form of time, training or something like supervision. (N 4)

Many nurses spoke of the considerable frustration they experienced when the ward was busy as time to encourage, maintain or increase the level of participation being undertaken by the patient was limited significantly. Patients themselves remarked on the importance of the ward environment in encouraging participation in care activities or discussion. When for instance the ward was busy or not conducive to divulging confidential information personal or intimate discussion about care was limited. As one patient detailed:

> I wasn't able to discuss anything much related to my personal life after surgery. I wanted to but the hustle and bustle of the ward meant I couldn't. The nurses were busy and there was also no privacy as all sorts of people were in and out. I was in the middle of the ward with only those thin curtains to provide privacy. (P 5)

The creation of an environment that would sustain patient participation was deemed an immense challenge. A general lack of resources to promote a culture of 'true' participation caused intense frustration and in some cases even resulted in nurses despite an espoused commitment to such an approach to care returning to routines with little patient participation. One nurse spoke of how patient participation had to be the responsibility of everyone and could not be sidelined to the role of one or two individuals. The same nurse went on to report how she *withered due to the lack of commitment from colleagues or individuals championing such an approach to care*. To sustain participation as model of care and make it a way of life nurses were firmly of the view that additional human and physical resources were needed alongside leadership and managerial support. As one nurse stressed:

> To achieve sustained patient participation it is critical to include those who have influence over the service and its resources not just the nurse at the bedside. Wide adoption will initially be very costly. The return later on will be priceless. (N 1)

Many nurses asserted that patient participation could not be *squeezed into already overextended budgets and staff time* (N 11). Interestingly while most nurses recognised that there was a need for enough staff and resource to facilitate patient participation few reported ever requesting more staff or resources in the form of time for fear of being labelled as not being able to cope.

Many nurses made clear that specific resources for matters such as staff training were needed if participation was to be sustained in the longer term. Some declared a fear about the increase in the number of patient complaints, which would in turn demand much time in

terms of investigation and resolution, although the numbers could not be quantified. As a senior staff nurse confirmed in an extract presented overleaf:

> A common theme that has emerged with patient participation is that patients feel more confident in expressing views about the service and this has led to a rise in our complaints. This is one of the more challenging and somewhat demoralising aspects of patient participation. (N 13)

However, as many nurses asserted, particularly those from Ward A, once patient participation becomes a way of life and enters every level of service provision patients are less inclined to complain and more often than not provide positive feedback bringing great satisfaction to nurses and the organisation as a whole. As a senior nurse testified:

> Receiving positive feedback as opposed to complaints about care is very rewarding and in the current climate, it also gives us a competitive edge when tendering for services or when being reviewed by regulators such as the CQC (Care Quality Commission) and the most important regulator of all, the patient. The very positive feedback from patients really taking part in their care is what makes you do the job in these challenging times. (N 3)

5.6 Summary of Conceptual Category

In summary, there was clear evidence of benefit associated with patient participation at all levels. For many patients and nurses it was a rewarding experience for others it was less favourable and attracted many negative reactions and aroused strong emotion. For widespread reward, patient participation cannot be seen to be peripheral to the main business of nursing care. There is clearly a lot nurses can do to strengthen patient engagement and improve the patient's experience of participation in care. In view of the rewards that can be achieved the need to encourage, sustain and support a range of self-care activities should be given greater priority in mainstream clinical practice and nurse education programmes. There needs to be a form of reorientation from traditional models of practice towards new forms of thinking about patient-nurse relations with adaptions being made to the clinical context. Nurses need also to be convinced of the incentives associated with implementing a participatory model of nursing practice. Finally given the potential impact of patient participation on staff, physical and fiscal resources there is a need to quantify in economic terms the added value of meaningful patient participation to ensure that such a way of working is adequately compensated.

5.7   **Summary of Chapter**

This chapter has presented each of the three dynamic, interrelated conceptual categories or phases, which form the basis of the emergent theory. Each phase has been reported separately. Extracts of raw data were used to supplement text and add human insight and dimension to the analysis.

The next chapter proceeds to discuss the interrelationship between the three emergent conceptual categories. The full grounded theory, which provides a vehicle for conceptualising and integrating the three categories, is examined. How the theory and its underpinning assumptions are embedded in existing theory and literature will be discussed. The extent to which the study findings define new theory or knowledge is also made explicit

CHAPTER 6   THE EMERGENT THEORY EXPLAINED AND DISCUSSED

6.0   Overview of the Chapter

This chapter presents the theory that emerged from the process of constant comparison. The emergent theory labelled *Engaging in Nursing Care* explains how patient participation in nursing care within an acute surgical care setting is established, developed, maintained or inhibited. The theory is presented through a series of underpinning assumptions and in what Glaser and Strauss (1967:115) termed 'discussional' style. The relationship between the three conceptual categories: *Establishing Readiness*, *Shaping Work* and *Incurring Rewards and Costs*, examined discretely in Chapter 5, is made explicit. Where appropriate, literature is used to refute, enrich and provide authentication for the emergent theory. The relationship between the theory, its underpinning assumptions and existing substantive theories, conceptual models and research and scholarly literature is described in detail to illustrate how the emergent theoretical scheme differs from what is currently known about patient participation in nursing care within the context of the surgical care setting.

6.1   Overview of the Emergent Theory – Engaging in Nursing Care

The emergent theory provides a rigorous structuring of the theoretical realisations that evolved from the process of analytic integration. It provides a rich and purposeful view of the complex phenomenon of patient participation in nursing care as it is experienced within the context of the acute surgical care environment. The theory depicts patient participation in nursing care as an evolutionary dynamic process. It explains the multifaceted and changing nature of patient participation as experienced by patients during the pre and post-operative period. A distinctive three-staged process of patient participation exists. Three phases (*Establishing Readiness*, *Shaping Work* and *Incurring Rewards and Costs*) describe how patients engage in their nursing care with nurses and thus achieve, or attempt to accomplish, patient and/or nurse desired levels of participation.

Figure 9 overleaf presents a representation of the emergent theory. It depicts the phases of patient participation in nursing care and outlines the contextual determinants that have an impact on each of the three interrelated phases.

Figure 9   The Emergent Theory of Patient Participation:
Engaging in Nursing Care
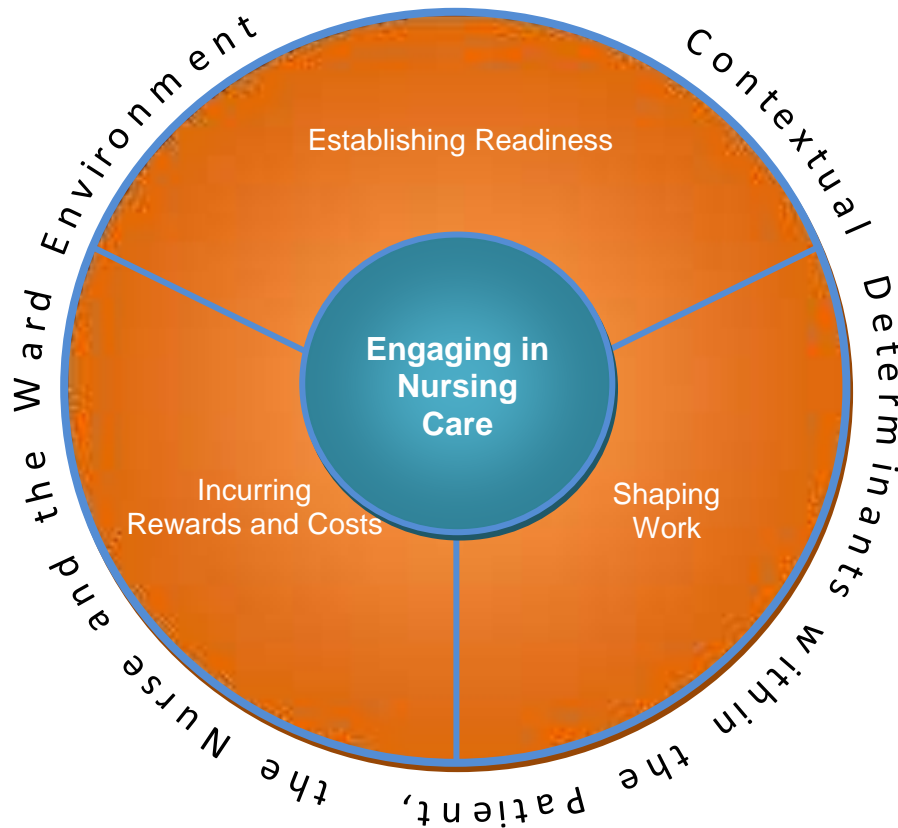
In conceptual terms, the theory is explained through a basic social process. The process details how patients establish readiness for, are prepared for, shape, make a contribution to and manage interactions, cognitive processes and nursing work or self-care activities in either a transitive or an intransitive manner. Fundamentally, the process exposes how patient's engage in their nursing care from the point of admission to discharge and accounts for changes in patient and nurse interaction and behaviour over time. It also explains the strategies of interaction and action that patients and nurses employ to initiate, promote, maintain and manage the diverse impact of such a form of practice. The effects that the immediate, specific and general contextual determinants have on engaging interactions and/or actions at any point in time during the patient's surgical care experience are also made explicit.

The emergence in the present study of a dynamic process with definable phases is supported by the writings of many authors who affirm that patient participation is an on-going progressive process carefully initiated and sustained for the purpose of meeting mutually determined goals (Brearley, 1990; Cahill, 1996; Gallant et al., 2002; Maly et al., 2004; Hook, 2006). However, most of the work cited is based on expert opinion developed through

detailed theoretical analyses of the concept as opposed to empirical findings based on the views of patients and nurses and the systematic observation of nursing practice in the real world. The findings of the present study expose knowledge relating to the process of patient participation as experienced by patients and nurses in modern surgical nursing practice. As detailed in Chapter 4 (section 4.1.2 page 106 refers) support for the emergent conceptualisation was gleaned from both patients and nurses. Both patients and nurses held congruent views about the process of engaging in nursing care within the context of the surgical care setting. There were corresponding views about engaging being a dynamic, three phased, context sensitive process, comprising a range of conceptualised interactions, cognitive behaviours and activities that both patient and nurse were involved in to optimise the patient's experience of patient participation in care. There was also congruence of viewpoint about the need for patient participation to be rooted in mainstream surgical nursing practice from the point of admission to discharge in some shape or form. Variation in perception and expectation about patient participation in care did however present albeit only about the levels of enactment of everyday patient participation. It was evident from the data that many patients and nurses espoused differences of opinion about levels of patient participation and how nursing care should be delivered. Dissimilarity in viewpoint about the enactment of patient participation was however not consistent. It was linked to type of illness, individual attitude, knowledge, experience and interpersonal and practical competence. Of note is that in spite of this incongruence both patients and nurses agreed that patient participation was multifaceted in nature and inextricably linked to those activities undertaken with the intent of facilitating recovery, managing symptoms, preventing complications, influencing care decisions and/or restoring or promoting health and self-control or facilitating a peaceful end. There was also congruence of opinion about levels of patient participation being individually determined and ideally agreeable to both patient and nurse.

In the present study, the word e*ngaging* was central to the introduction and advancement of patient participation in nursing care within the surgical care context. In practice the process of engaging is about the intensity and authentic or genuine contribution that a patient makes to their nursing care from the point of admission until discharge. It relates to the investment, commitment and motivation that patients and nurses demonstrate and the various interactions and actions that each party must undertake to establish, support and sustain a desired level of patient participation in nursing care. The emergent theory reveals that when a patient engages in nursing care they participate proactively in it, the intensity or contribution being context dependent and defined by whatever level the patient and the nurse are most comfortable with. The term *engaging* integrates the three emergent conceptual phases into a logical and understandable whole and is essentially the organising thread of the theory.

Engaging interactions, behaviours and activities resonate through each of the three phases of the conceptualisation. Engaging ascribes an active orientation to both patient and nurse from admission to discharge. A gerund (a verb ending in 'ing') has been used to describe the process by which patients participate in nursing care as it implies movement or change over time and thus emphasises the dynamic orientation of patient participation. It also accounts for the wide variation in patient and nurse behaviour and interaction during the pre- and post-operative period.

While each phase of the process of engaging in nursing care has been presented discretely in Chapter 5, in practice the three phases share an association, tend to overlap and are repeated and dictated by changes in patient and contextual circumstances. There is clearly an interrelationship between each of the three conceptual categories. During the process of engaging in nursing care, a patient embarks on a journey. During the initial phase of the journey that of 'Establishing Readiness', conditions that need to exist in order to establish or achieve desired levels of participation or engagement are developed by both the patient and the nurse. To enable patients to participate in their care both patient and nurse need to connect, expose and share opinion and possess specific skills and knowledge relating to each patient's unique illness experience. The second phase, Shaping Work is dependent entirely on the conditions or foundations laid in the earlier phase. The shape or nature of patient participation is influenced significantly by the conditions that are developed during the phase 'Establishing Readiness'. The pre-requisites for patient participation impact on and affect how patient participation is shaped or the extent to which patient's engage in varying kinds of work or self-care activities. For example, for many patients and nurses, an element of trust was needed to encourage or advance the scope of patient participation in nursing care. Failure to develop a reciprocal trusting relationship affected significantly the work that was undertaken by both patient and nurse and often resulted in only limited patient activity being undertaken such as that of menu completion or tokenistic participatory actions and interactions being enacted. On the contrary, if a trusting relationship developed between the patient and nurse, patients commonly reported engaging in higher level physical and intellectual activity such as complex decision making or self surveillance. The third phase, Incurring Rewards and Costs, was also affected by the nature of the patient's experience through the other two phases. Situational reality was such that the rewards or costs associated with patient participation were influenced significantly by the extent to which conditions to establish readiness existed and the nature of the patient's level of engagement. There was clearly a strong association between the three phases. The antecedents and shape of the patient's work had an undeniable impact on the individual patient, the nurse and the surgical care environment. For example if on admission to hospital a patient failed to gain

access to relevant information about their care or condition and they also failed to master a particular skill, the nature of their work was restricted which in turn led to costs aligned to stress, anxiety or fear. There was a clear connection between each of the phases of the process. A matrix of interrelated activities existed. The process of engaging in nursing care was continually shaped and reshaped in response to complexities inherent in each of the three phases. What happened in each unique phase impacted on or influenced the action, interaction or behaviour in the remaining phases. There was an obvious link between the various activities, which comprised the work of the patient and nurse in each phase.

In the present study, engaging in surgical nursing care is a transforming process constructed through action and interaction. The knowledge, mastery of skills, motivation and commitment associated with patient participation are constructed primarily through communication and activity. The process is inescapably labour-intensive. It is aligned to specific capabilities that patients and nurses within the surgical care context develop and a range of conceptualised interactions, cognitive behaviours and activities that both parties are involved in to optimise the patient's experience of participation. More specifically engaging is allied to implicit or explicit tasks, work or self-care activities that are undertaken by the patient and the nurse throughout the pre and/or post-operative period. It is associated with skills of disclosure, detection, persuasion, negotiation, manipulation, and/or survival all needed and employed by either a patient and/or a nurse at any point in time to foster, establish, shape and maintain a desired level of patient participation in nursing care.

In actuality, the emergent process of engaging in nursing care offers a new way of looking at patient participation and assigns a specific shape to how patients participate in their nursing care in modern surgical practice. Engaging in contemporary surgical nursing practice is about patients proactively, and in varying ways, sharing responsibility with nurses and participating or contributing in some form to a pathway for optimal recovery, health or in some instances end of life.

In the present study one of the key assumptions underpinning the process of engaging is that at any point in the patient's experience an active patient orientation in some form is always desired and valued by the patient though not by all nurses. The sick role as defined by T Parsons (1957) and the passivity-activity model proposed by Szasz and Hollander (1956) and Biley (1982)) were in the main rejected by patients in the present study. A form of participation albeit restrictive was always desired and expected irrespective of illness acuity, a finding that challenges the early work of Waterworth and Luker (1990) who advocated that not all patient's wanted to participate in their own care, even if they were capable.

A central tenet of the emergent theory was that patient participation in nursing care must be treated as a practice imperative and rooted in mainstream surgical nursing practice rather than just discrete activities such as decision-making. Through the eyes of most patients and nurses, patient participation had to be integral to the patients' total surgical experience or journey. However, critically, the level of participation needed to be individually determined and ideally agreeable to both patient and nurse. For participation in nursing care to be authentic as opposed to tokenistic, patients need, from the point of admission to discharge, to engage as participants in some shape or form with the nurse and their care. A guiding principle of effective participation was the need for patients to engage early enough to be able to make a difference. Both patient and nurse also had to view nursing as a collaborative endeavour between two people who were, in fact, strangers but brought together for a specific purpose. The emergent conceptualisation recognised two involved or engaged participants.

6.2 Relationship of the Emergent Theory to Related or Relevant Substantive Theories

6.2.1 Engagement Theories

In the present study, the emergent theory covers unchartered territory in the field of acute surgical care. It is the first substantive and empirically grounded conceptualisation to explain the *process* of patient participation as it occurs in the surgical care setting. As revealed in Chapter 2 there is a paucity of nursing theories and theories generated in other disciplines whose propositions could account for or characterise the process of patient participation in the context of surgical nursing practice. No grounded or empirically tested theory that is comparable fully to the emergent theory of engaging within the context of surgical nursing care is evident within existing published literature.

Engagement theories (Pike & Kuh, 2005; Kearsley & Schneiderman, 2011) from the education arena were found to comprise similar features or assumptions to the theory that emerged from the present study but no one theory was sufficiently generalisable or of a level of conceptualisation that could describe and account for how patients might engage in their nursing care within the acute surgical care setting.

Engagement theory in the context of education invites comparison and shares many features of the theoretical explanation being proposed for patient participation. Effective, meaningful and authentic student engagement in educational activities demands a number of attributes that are also critical to patient participation within the context of surgical care practice.

Missions and operating philosophies, the surrounding environment, financial support, competence beliefs, ability to cope with bias and disparity in practice all have a significant impact on student engagement in the same way that they have an impact on the patient's readiness and ability to participate in their nursing care. However, while low-level abstraction theories derived from the context of education can contribute to an understanding of patient engagement in nursing care and be shared usefully between disciplines without empirical testing in the world where such theories will be applied, credibility and utility is limited. A theory that is unique to nursing, grounded and supported by data from insider perspective and observable practices in the real world is more likely to describe dimensions or characteristics of a situation more accurately than one borrowed from anther discipline.

In the present study, the theory that emerged from the milieu of surgical nursing practice provides a distinctive body of new knowledge and advances understanding of the process of patient participation. The theory is credible in that it was discovered through data analysis, which included engaging patients and nurses in the surgical setting in the analytic process. The virtue of the constant comparative method was that it enabled me to test empirically the emergent theory and ensure that the underpinning assumptions reflected modern day surgical nursing practice. The theory provides nurses in the field of surgery with new knowledge that can be applied to enhance the practice of participation in everyday nursing care.

6.2.2   Theory of Interpersonal Relations in Nursing

In the present study, features of the process of *Engaging in Nursing Care* parallel some of the assumptions underpinning Peplau's theory of interpersonal relations (Peplau, 1988). Antecedents such as developing a positive connection identified in the conceptual category *Establishing Readiness* are consistent with the attributes Peplau deems critical to the establishment of an effective nurse-patient relationship. In the present study, patients on establishing a degree of readiness to participate in their care begin to engage in a range of conceptualised behaviours, interactions and functional activities that demand either intellectual or physical effort. Indeed most patients reported engaging in work in the form of self-care activities or a set of reciprocal tasks *with* the nurse. Peplau in her writings made explicit how both parties should work *with* each other to develop an effective relationship. However, a key distinction between the present study and the guiding assumptions underpinning Peplau's work is that, within the context of acute surgical care, most patients and nurses were of the view that when a patient assumed a 'restrictive role', albeit that there was still an element of active patient input and they perceived themselves as being functional

participants in their care, the key focus was on *doing to, doing for and providing for rather than working with.* This in itself makes explicit that the clinical utility of any theory cannot be extended easily beyond the nursing speciality from where it emerged. The practicalities of using in the surgical care setting a theory constructed for a particular clinical specialty in Peplau's case mental health care needs to be explored and evaluated systematically most notably because the views of patients and nurses and the nature of the work situation have an influence on the specific roles undertaken by the patient and the nurse.

6.2.3   The Self-Care Deficit Theory

Aspects of the emergent theory are also allied to Orem's (1991) self-care deficit theory of nursing discussed earlier in Chapter 2. In the process of engaging as in Orem's self-care deficit theory, emphasis is placed on how the nurse helps patients accomplish desired levels of participation, which may take the form of steadily moving towards responsible self-care actions, enabling the patient to assume responsibility for decisions relating to their care or making adjustments to interruptions in self-care abilities. However, a key distinction between the theory that emerged in the present study and Orem's Self-care Deficit Theory is that, in the process of engaging, interactions and actions undertaken by the nurse to encourage a patient to assume self-care activities or work are normally driven by the patient's desired level of patient participation as opposed to the nurse's desire to promote self-care. The reality was that a nurse could not predict what level of participation every patient desired. It was a matter of judgment that had to be made at the time, as participation in self-care activities or work and/or tasks normally performed by the nurse was influenced by a wide range of general and specific contextual determinants, including the patient's ability to make rational decisions, the desire to be 'nurtured' and a patient's desire to protect him or herself from anxiety and fear.

Orem's conceptualisation paid little attention to exploring contextual issues such as physical or emotional factors all of which in the present study had an impact on levels of participation assumed by the patient. In the present study, there were times when patients were unable to make decisions or choices or perform specific tasks as factors, such as anxiety, fear, pain or physical or intellectual ability, limited participatory interaction or behaviour. The emergent theory in describing how the work of the patient and nurse is shaped during the process of engaging considers a complex matrix of contextual determinants within the patient, the nurse and the ward environment which exert a specific influence on the shape and level of the patient participation. Orem in her self-care deficit theory paid little attention to contextual information. Indeed the lack of empirical testing associated with Orem's interpretation and

explanation as discussed in Chapter 2 could have contributed to the lack of attention being placed on the importance of context in promoting self-care.

6.3　　　Summary

Although the emergent theory shares assumptions with a range of theories within and outside of the discipline of nursing, no existing theory describes the complex and specific dimensions of patient participation. No single or unique theory exists currently to explain how patients engage in their nursing care in the context of surgical care practice. Given the impact of contextual determinants on patient participation, the promotion of any theory in nursing practice should not be encouraged without an analysis of the health care context in which it is to be used. 'Engaging' is the first theory to focus specifically on patient participation in nursing care as an individualistic concept, that is, the *individual* patient engaging in *all elements of the nursing care process* in the context of the surgical care environment. It provides a fresh perspective and deep understanding of the complexity of the concept within the context of surgical nursing practice.

6.4　　　Relationship of the Emergent Theory to Related or Relevant Conceptual Models

Facets of the emergent theory share features and have similarities with many conceptual models or conceptual frameworks that have been developed to explain how participation in general or patient participation in health care can and/or should be enacted in practice. By way of example the present study like many of the classic models of participation (Szasz &Hollender, 1956; Arnstein, 1969; Richardson, 1983) and the more recent conceptualisations in the health care arena (Cahill, 1996; Hibbard et al., 2004; Henderson, 2002; Entwhistle and Watt, 2006; Thompson, 2007) discussed in Chapter 2 describes the nature of participation as a developmental process. Earlier models also categorise levels of participation in a similar way that the phase labelled *Shaping Work* describes the range and variation in participatory behaviour and the levels at which patients engage in their own care throughout their surgical experience. However, while there are some similarities between the emergent theory and existing models of participation, particularly those within the health care context, earlier models have often focused quite narrowly on particular aspects of participation most notably single behaviours such as treatment decisions, health care consultations or planned one-off activities. The present study's contribution is that it provides insight and rich understanding of the total experience of patient participation. The complexity of patient participation in the acute surgical care context has been explored as opposed to narrow or discrete acts of participation.

Key distinctions between the levels of participation that emerged in the present study and those apparent in existing models of participation do exist. In the present study, the levels of participation were not seen to be hierarchical in nature. The metaphor of a linear hierarchy was rejected in favour of levels of participation that ranged from restrictive to inclusive patient work. Both patients and nurses also asserted that there is no ideal form of participation. The emergent theory makes explicit that there is no archetype of participation as the level of participation assumed by the patient is context sensitive. Contextual determinants discussed later in this chapter (Section 6.7 page 218 refers) had a significant impact on patient interaction and behaviour throughout both the pre and the post-operative period. Indeed the level of participation assumed by the patient varied throughout their surgical experience.

Existing taxonomies of participation such as Hickey and Kipling (1998) and Cahill (1996) developed within the context of health care while being usefully simplistic to assist professionals to respond appropriately did not take full account of the complex and dynamic nature of participation. As Abelson (2001) and Collins et al. (2007) reported, there is a dearth of evidence that places attention on the specific conditions and contexts that impact on participation. According to Larsson et al. (2011), only a few empirical studies have discerned the contextual forces that impact on participation from both the patient and nurse perspective. With a few significant exceptions (Henderson, 2002; Sahlston et al., 2007; S. Parsons et al., 2010; Larsson et al., 2011) consideration of the infrastructures to support effective participation was somewhat limited in the literature. The very complex set of variables that in the present study impacted on levels of participation at any point in the patent's journey were not always considered in the development of earlier conceptual models associated with patient participation. The present study has therefore advanced the work already published on the driving and restraining forces associated with participation. It has through rigor of method, namely interviews with patients and nurses and observation of *real* practice, been able to capture the determining characteristics and impact of the general, specific and immediate context on patient participation in nursing care.

In the present study, it was difficult for patients and nurses to make sharp distinctions between the levels of participation a patient may desire or enact. Earlier linear conceptualisations of participation such as that of Thompson (1997) failed to place significant emphasis on the dynamic nature of a patient's work. In the present study levels of participation existed but they did not represent a position of patient power between the extremes of restrictive and inclusive participation. Furthermore, inclusive forms of participation were not seen to be dependent upon having undertaken restrictive acts of participation. All patients and nurses recognised that engaging in acts of participation waxed

and waned in synchrony with varying contextual dimensions. Patient control or full autonomy was also not seen to be the ultimate goal of participation. The idea that patients even seek ultimate control was refuted strongly in the present study, as such a view did not always align with a patient's own reasons for engaging in their care. In the present study, ultimate control was something that could not necessarily be achieved in acute surgical care practice. Many of the earlier models report that not achieving full control implies some automatic failure of the participatory process, even though those engaged may be content with whatever level has been attained. This viewpoint was contested in the present study. Comparing the present study to earlier taxonomies of participation it is apparent that in the present study a passive position was often adopted by a patient because of a deliberate act of detachment, illness acuity or lack of interest rather than a desire to be a passive victim of ill health or a non-participant. It was not associated with a form of failure or non-participation as many patients were firmly of the view that apparent passivity was a subtle articulation of participation.

While the present study provides evidence that there are some parallels between the levels of participation that emerged and those prescribed by some of the existing models, the levels prescribed by earlier models with a few other notable exceptions (Christensen, 1993; Henderson, 2002) reflect a normative perspective that originates from professionals rather than patients and/or the view of informants who were asked to *project* themselves into an illness situation. Many of the earlier models discussed in Chapter 2 have also been derived from unsubstantiated conclusion as opposed to empirically grounded research. Furthermore, many were developed within the context of primary care, general practice or the business arena, which does not readily allow for comparisons regarding degrees of participation to be made across different settings. Existing models, although useful, lack the level of specificity to formulate principles that will allow them to be applied in the surgical care context. Consequently, it could be argued that there is a substantial gap and/or lack of congruence between levels prescribed by many of the earlier models and modern day practice. The present study, through an analysis of the experience of patients and nurses and direct observation of practice, has narrowed the gap in the literature and facilitated improved understanding of the levels of participation in which patients engage in current surgical practice. In the present study, the emergent conceptualisation focuses on the *totality* of the patient's experience in the surgical environment and has generated a rich, narrative understanding of how participation in nursing care is viewed and enacted in modern day surgical practice.

When compared with recent empirically tested conceptualisations of patient participation within the context of nursing care (Henderson, 2002; Sahlston et al., 2007) the nature and

breadth of the sampling in the present study has allowed greater insight and deeper understanding of the levels and complexity of patient participation. Being able to discern a wide variety of viewpoints from patients and nurses, including those opposed to patient participation has generated a more sophisticated delineation of the shape of participation. More specifically the phase *Shaping Work* indicates that participation within the context of surgical nursing care must be seen as a dynamic process from admission to discharge during which patients develop their ability and desire to participate in care over time. Participation in nursing care is also not necessarily incremental in nature. Levels of participation fluctuate according to the circumstances that exist at the time. In the present study, no hard and fast rules emerged to indicate when a patient should move from level to another. The patient's experience was not without complication nor was progression necessarily linear in nature. There was recognition that patient progression in terms of level of participation is a very complex process. Since the context of the surgical care environment is often characterised by vigorous activity and unpredictability the level of work assumed by both patient and nurse was shaped or reshaped in response to the complexities inherent in the present and on-going circumstances of each patient's journey through the pre and post-operative period.

Finally, while most existing theoretical models relating to patient participation ascribe work of some kind to the health care professional, not all come up with the concept of a working patient. In the present study, patient participation was associated with work, explicit or implicit being undertaken by the patient. The concept of a working patient that emerged in the present study supports the earlier work of Christensen (1993). Christensen's conceptualisation of the nursing partnership did see the patient and nurse as two fully engaged participants in practice. Both the emergent theory and Christensen's model for nursing practice did assume that patients have or can develop the resources to be participants in their care and influence the course of their care experience if so desired. The process of *Engaging in Nursing Care* and Christensen's model also prescribe an on-going journey comprising different phases. Both conceptualisations acknowledge there is no linear progression through each phase however the changed behaviour of the patient and the nurse confirms the presence of each phase. Key distinctions between Christensen's model of nursing partnership and the emergent theory are however apparent. The context of Christensen's data collection was narrower in comparison to the present study as interviews with patients were limited to those patients undergoing only elective surgery. Christensen's study was also limited to particular incidents, such as pre-operative teaching or a wound care procedure, and only the total nursing activity of two patients over a seven-hour period. By Christensen's own admission, this yielded far less data than anticipated and the nature of many nurse-patient encounters not being captured. Christensen's conceptualisation did also

not reflect on the work of both patient and the nurse from the point of admission to hospital. Only the work of the patient at the time of entry to hospital was made clear. The nurse's preparation or role in preparing for their surgical experience was not addressed until the patient had 'settled in' the ward. This limitation was however addressed in later refinement of the model.

In the present study the role and work of both the patient and nurse from admission to discharge is made explicit. Indeed the nurse was found to have a key role in establishing a patient's readiness for participation in their care. Since the sources of data collection also included patients admitted for elective or emergency surgery and observation of a number of patients over a 72-hour period, it could be argued that a more in-depth picture of participation in the day-to-day surgical practice in the United Kingdom has been gained in the present study.

6.5　　Summary

In summary, no conceptual model exists currently to facilitate the effective translation of patient participation from theory to practice. The realisation of the process of patient participation specifically in the surgical care context from the point of admission to discharge has not been explored sufficiently in the literature. The exploration of the implementation of patient participation in every step of the care process remains a neglected area of surgical nursing practice. Even though patient participation is a central concept in the consumer driven health care approach of today as a *continuous process* as opposed to dichotomous variable it remains conceptually and empirically underdeveloped (Hibbard et al. 2004, Mockford et al. 2012). In contrast to earlier conceptual frameworks, this study provides a more complete picture of the *process* of engaging or patient participation in nursing care in the United Kingdom. It addresses the process from admission to discharge, the interactions, actions or behaviours to be employed by both patient and the nurse and the impact of the immediate, general and specific context.

6.6　　Relationship of the Emergent Theory to Empirical and Scholarly Literature

One of the key strengths of the present study is that the overarching emergent theory extends knowledge, provides a fresh perspective and new insights into the process or totality of patient participation. As discussed in Chapter 2 previous published work relating to patient participation in care has in the main focussed on clinically distinct patient groups, discrete features of participation and has in the main been undertaken within the context of chronic illness and primary care using quantitative methods of data collection. In the present study, a

fresh methodological perspective using a combination of naturalistic data collection methods has captured the complexity of the phenomenon and provided an in-depth understanding of the process of patient participation in modern surgical nursing practice, previously not explored. However, some of the assumptions or tenets that underpin the phases (*Establishing Readiness*, *Shaping Work* and *Incurring Rewards and Costs*) are supported and/or challenged by the findings of previously published literature. For ease of presentation, each conceptual category associated with the theory will be examined separately to make explicit how the underpinning assumptions of each are embedded in pre-existing literature. The contribution that has been made to the knowledge base for nursing will also be made explicit.

6.6.1   Establishing Readiness

The key underpinning assumption associated with the phase *Establishing Readiness* is that for effective and meaningful participation to be a reality certain conditions need to exist. Emphasis is placed on the *engaging* elements or conditions that form the backbone or foundation for patient participation. No matter how the data were sliced, whether by age, gender, experience, condition, illness or ethnic origin, certain antecedents were seen as key to effective patient engagement in nursing care. This view was expressed in the present study by both patients and nurses alike and is supported by the work of Cahill (1996); Rycroft-Malone 2002; Gallant et al. (2002); Sahlston et al. (2009); the European Patients Forum (2010) and Larsson et al. (2011). Clearly, the literature shows a remarkable degree of convergence in the elements considered critical for the successful engagement of patients in their nursing care.

In the present study, importance was consigned to the interpersonal relationship that developed between the patient and the nurse throughout the patient's surgical experience. A positive connection was at the heart of the establishment of the engaging process. The relationship evolved over time and was dependent significantly on trust, confidence, respect, disclosure and exposure of beliefs, interpersonal sensitivity and interactional ability, a finding reminiscent in the work of Henderson (2002). Over the last 20 years, the importance of relationship cultivation has been studied by many and across a range of health care contexts (Morse, 1991; Glaser, 2003; Coulter, 2006; 2011). In the present study while trust in the nurse was deemed significant to the establishment of patient participation critical was that nurses were also able to trust patients. Related to the need to *Establish Readiness* for patient participation and connect to the patient was the nurse's capability of trusting the patient and the patient's ability to instil trust within the relationship. Clearly, both patients and nurses

shared a vision that mutual trust and respect was important within the context of *Establishing Readiness* for participation. Both also stressed the need for an astute ability to analyse levels of trust, a dimension not addressed in earlier work.

The development of trust in the present study was linked to technical and interpersonal competence and continuity of care, a factor few have considered (Hall et al., 2002; S. Parsons et al., 2010). Patients and nurses, in attempting to develop trust, often set up trials to test the waters, one such example being the use of the call bell to see if a nurse would actually respond to it. A trusting scale was found to exist within the context of participation, the scale being similar to the model developed by Leisen and Hyman (2001) which included two dimensions: benevolence and technical competence. In the present study, levels of trust were associated with the dimensions of interpersonal and technical competence. Interpersonal sensitivity, skill and practice competence were crucial requisites for a trusting relationship, which in turn facilitated patient participation in nursing care. As found by Caress et al. (2002) and Kraetschmer et al. (2004) trust was an important element of participation, regardless of the precise role patients wished to assume.

In the present study, the use of humour was also found to facilitate the development of a positive connection. The exposure of such humaneness had a positive influence on the closeness of the nurse-patient relationship and thus the engagement process, a view supported by (Kralik et al., 2006). However, use of such a strategy has not been promoted by all. According to McCreaddie and Wiggins (2008), humour is a phenomenon, which is influenced by culture and is considered by some to be a controversial strategy that could result in disengagement between patient and nurse and little or no participation by the patient in their care. Many avoid the use of humour, as the risk of participation rupture through patient misinterpretation is too great (Spiers & Wood, 2010). In the present study, humour was not considered a 'risk' behaviour as both patients and nurses indicated that the judicious use of humour promoted positive energy flow and was found to be helpful in establishing and promoting patient participation.

While in the present study, most nurses employed linguistic interaction and non-verbal behaviour to create openings for participation some nurses did adopt strategies or actions to disengage or inhibit patient participation. Strategies such as closed questioning, monosyllabic responses and engagement in task-orientated care were often consciously and/or unconsciously employed to limit the scope of participation. Use of such behaviours or actions to restrict patient interaction or activity was reported to enable nurses to cope with the demands placed on them in the same way that the seminal work of Menzies (1970) found

that nurses deliberately employed strategies as a defence against the demands or pressures of hospital environments.

The accounts of both patients and nurses in the present study revealed strong convictions about the issue of interactive competence. Communication skills specifically those associated with listening, recognising verbal and non-verbal cues, reflective and open questioning and the use of eye contact were found to be factors that could facilitate a positive connection between the patient and the nurse and thus greater patient engagement in care. In the present study, recognition of interpersonal competence was deemed a critical attribute of participation, a view reached by Ashworth et al. (1992).

Brooks (2008) in her ethnographic study, which explored user participation in strategic level health care decision-making and planning, found, a pre-requisite for successful participation is that both patients and nurses should be equipped with the interpersonal skills to communicate in a position of interactional equality. Similarly, the present study illuminated the significance of interactional competence most notably because nurses in promoting participation needed to act as an educator, promoter, supporter and coach for different patients at different times. Interestingly while both patients and nurses in the present study reported that skills of communication to establish, promote and maintain desired levels of participation were critical both asserted that not only should such skills be taught and developed but also assessed in programmes of education. As recommended by Tew et al. (2004) and Reeper and Breeze (2007), it would appear that users of the health care services need to be placed at the centre of under-graduate and post-graduate curricula development, implementation and evaluation to enable nurses to develop the necessary engagement behaviours, understand the patient's story and make patient participation a reality in mainstream practice.

In the present study, the need for interpersonal skills to be learnt and enhanced through a process of role modelling or a support system such as supervision was also made explicit. Redfern (1996), Lundh et al. (2006) and Suhonen et al. (2010) reported comparable findings as they all established that a nurses' skills and knowledge level were positively related to their ability to engage patients in their care but that the development of participation could also be enhanced by the effective leadership and management of nursing including adequate supervision. As the present study makes explicit committed and engaged leadership from senior staff in the organisation is needed to incentivise and sustain desired levels of patient participation, a view also supported by Coulter (2011).

In order to establish readiness for participation there was also the need for both patient and nurse to be attuned to each other's views. In the present study participation in any form depended on a certain sharing of assumptions and presuppositions. The process of engaging required that each party identifies conscious desires, expectations, capabilities and limitations and then attempts, through compromise, to achieve a common understanding that would guide future encounters and roles. The need to gain an understanding of the often competing and conflicting nature of discourses, values, and assumptions between nurses and patients is reminiscent of the findings of Repper and Breeze (2004) and Brooks (2008), who asserted in attempting to promote participation nurses and patients need to remove the masks of anonymity and mutually acknowledge and recognise each other as persons. In the present study, the notion of reciprocity was key. Disclosure of personal and professional self and exposure of expectations about roles to be assumed provided a firm foundation for participation in care, a finding consistent with the work of Henderson (2002). Halldorsdottir (2008) also reported how mutual disclosure and the reciprocal exchange of views and beliefs about participation enable a strong connection to develop between the patient and the nurse. Such exposure and knowledge then forms a 'hook' for the engagement process.

In the present study in E*stablishing Readiness* for patient participation both patients and nurses were required specifically to be attuned to each other's views of the meaning of patient participation in nursing care and specifically the goals, roles and responsibilities that each wanted to assume. Exposure and exploration of views was deemed critical if patient participation was to be established, facilitated and maintained effectively and authentically. The present study makes explicit that no authoritative view or consensual opinion about participation existed between nurses and patients. There was among many a degree of incompatibility and/or dissimilarity in the meaning of participation. The lack of clarity and multiplicity of definitions of patient participation at the level of the individual patient was also a common theme in the literature discussed in Chapter 2. The present study, like the literature, suggests that patient participation, despite being a central theme in health care policy, is still one of nursing's most amorphous and ill-described concepts. However, despite the lack of clarity of meaning that emerged in the present study the study advances the existing body of knowledge in that it makes explicit the distinct dimensions of patient participation that are enacted by the individual patient in surgical practice previously not reported in the literature. There was common discourse regarding the fact that participation was a dynamic process comprising different forms of patient and nurse work or activity. The study contributes to an understanding of how patients perceive their role, what significance it has for them and makes explicit the dimensions of participation or more specifically the work patients' can and

do engage in throughout their surgical experience. It also depicts how roles and contributions can vary according to context and thus that participation is dynamic in nature.

To initiate or enable patient participation in nursing care another distinctive antecedent was that patients require access to relevant information, resources and expertise. In the present study, there was a need for patients to narrow the appropriate information, knowledge and/or competence gap between themselves and the nurse using suitable modalities. The desire for information was independent of any demographic factor. No factor such as ethnicity, age or illness influenced whether a patient wanted to receive information regarding their illness or care. The present study and the literature show a remarkable convergence with respect to information and expertise being key to successful patient participation. Clear parallels can be drawn between the present study and the work of Thompson (2007) who in examining the views and preferences of patients in the context of primary care practice found receptivity to information was a vital ingredient of participation. In the present study understanding of the presenting illness, care options and likely outcomes and knowledge of what the patient could do to help themselves was considered a basic building block for participation as it provided a means by which a patient could achieve some control over their life and move between different levels of participation. Patients who were coached to interpret and understand their own illness and care participated more inclusively in their care. The need for the patient to develop expertise supports the earlier work of Biley (1992), Henderson (2002) and Coulter (2006), who maintained that a lack of knowledge could leave the patient very dependent on the health care professional or in a situation where all they achieve is an illusion of participation. The seminal work of Rier (2000) supports the importance of information exchange and acutely ill patients developing an appropriate knowledge base. However, as found in the present study Rier found that *full* disclosure of information is of minimal relevance to the critically ill patient. He, like nurses and patients in this study, maintained that the level of information provided and the educational strategies employed needed to be relevant, appropriate and related to the learning needs of each patient.

In the present study, the importance of patients being provided with individually adjusted information using different modalities was an essential attribute of patient participation, a finding also evident in earlier work albeit related to very specific acts of participation or self-management such as health literacy, clinical decision-making and patient safety (Weiss, 1986; Coulter & Ellins, 2006). In a review of 129 studies evaluating the effectiveness of interventions to strengthen patient participation Coulter and Ellins (2006) found that key to effective engagement was the concept of personalising which related to providing the right information content, in the right way, at the right time.

In the present study nurses themselves were also required to possess a specific skills set to enable and encourage patients to engage in their care in both the pre and post-operative period. The message was clear, the nurse's manner, interpersonal sensitivity, competence, and skill in developing patient knowledge and expertise contributed significantly to the level of participation assumed by the patient. Despite this underpinning assumption there was an apparent lack of skill among many nurses, a finding reported by Meyer (1995). Meyer in an action research study discussed in Chapter 2 reported that a nurse's lack of understanding about patient participation, the lack of interpersonal and teaching skills to fulfil an educative role and being unable to break away from the tendency to be prescriptive in advice and authoritarian in manner contributed to an inability to facilitate patient participation in nursing care. While it could be argued that the findings of Meyer are now dated it would appear from the present study that professional training has still not been adapted sufficiently to meet the changing needs and expectations of patients and new patterns of health care delivery. As Frank et al. (2010) and the Prime Minister's recent review on the future of nursing and midwifery in England, (Prime Minister's Commission on the Future of Nursing and Midwifery in England 2010) reported despite advances in professional education over the last few decades health care trainees are still not equipped with the skills or competencies required for patient engagement. The present study echo's these views as nurses reported that the skills required to facilitate patient participation are still not central to their basic education. However, further research is necessary to confirm the extent to which nurse education curricula address or neglect the engaging behaviours required of a nurse.

6.6.2   Shaping Work

In the present study, a key premise associated with *Shaping Work* was that the scope of patient participation and the role that was assumed by patients could not be predicted. In the present study the work of most patients' waxed and waned in synchrony with the general and specific context. Patient participation in nursing care was not seen as a homogenous process. Many factors affected the manner in which participation was shaped. There were drivers that shaped patient participation and factors that threatened its form, development and continuity. The range and variation in participatory behaviour and the level at which patients participated or engaged in work associated with their own care throughout their surgical experience varied. The literature on patient participation is replete with discussions that focus closely and analytically on professional work (Collins et al. 2007), yet the specific work of the patient particularly in the context of acute care is not made explicit or defined. In the present study, the conceptualisation of the process of engaging makes explicit that both the patient and most nurses view participation as a collaborative endeavour that demands

patients *and* nurses engage in a specific form of work. Patients and nurses are involved in different types of work at different times during the patient's surgical experience. The work of the patient in particular was found to be explicit and/or or implicit by virtue of their thoughts and feelings about their care.

Support for a conceptualisation that ascribes work to both patients *and* nurses in the context of health care is gleaned from the earlier work of Strauss et al. (1984); Berry and Metcalf (1986) and Christensen (1993). In their work in the health care arena, they all identified that patients assume different modes of immersion in a ward's division of labour and that to deny the presence of an actively working patient is to deny reality. In examining the shape of a patient's work within the context of participation the impression gained from the literature is however of a normative perspective driven by professionals. In contrast, the present study describes a patients' own understanding and experience of the shape of participation within the surgical context. It makes explicit the work that patients may engage in but makes clear that a taxonomy of participation cannot be constructed for all patients as patients aspire or want to engage in particular forms of work at particular times and in particular situations. As Guadagnoli and Ward (1998) concluded "participation can only be defined by whatever level the patient is most comfortable with" (p. 337).

A further assumption underpinning the phase *Shaping Work* is that all patients do have a desire to engage meaningfully at some level in the delivery of individualised, high quality, safe care through interaction with nurses and/or participation in worthwhile work. What was particularly evident in the present study was that patients wanted to engage in their care in some way even if they were incapable of continuous self-care and particularly if care was ineffective or incomplete. Many patients wanted also to engage in work as a form of trade-off for the care given to them during their stay. There were different forms of immersion in the ward's division of labour. *Shaping Work* illuminates specifically that patients have a desire to actually engage in cognitive processes such as problem-solving, reasoning and decision making and physical work if they possess the necessary level of knowledge, interpersonal and technical competence. While most aspects of participatory behaviour and action were recognisable, some elements of a patient's work did go unrecognised or was hidden from immediate notice. Some activities were also taken for granted and not recognised by nurses as patient work or participative activities. They included the reporting of untoward symptoms or tasks relating to personal hygiene or ambulation.

In the present study some patients' did not however want to participate in their care in an inclusive manner due to vulnerability, lack of interest, apathy or dissatisfaction with the

outcome of an operation and/or the post-operative care process. Such disengagement often also represented a deliberate or assertive articulation of participation or even defiance in the face of perceived exclusion, a view not considered in earlier work on participation (Lupton et al., 1998; Cook & Klein, 2005). The shape and scope of the work assumed by patients in the present study makes explicit that patient participation is dynamic in nature and that a patient may wish to participate in their care at different levels in relation to different circumstances and that levels may change over time for the same person in the same context. Patient participation was seen as a dynamic, process, which could not be disaggregated easily into discrete levels of activity. Activity varied and was context-sensitive.

6.6.3   Incurring Rewards and Costs

In the present study, the shape of a patient's engagement in varying kinds of explicit and implicit work had a significant influence on the individual patient, the nurse, surgical ward performance and resources. The theory through the phase *Incurring Rewards and Costs* (Section 5.5 page 172 refers) describes the impact of such a form of practice. The outcome of patient participation although unpredictable was in the main reported to be associated with objective and subjective measures of gain such as a positively evaluated patient experience, safer care, early discharge and for the nurse increased levels of job satisfaction and energy. However, the impact of participation did on occasion require considerable strength to overcome many of the challenges such an approach to care generated like the confrontation of traditional attitudes and practice paradigms.

Although Coulter (2011) argued there is no perfect method to obtain patients' views about participation in care in the present study the use of both interviews and observation towards the end of a patients' episode of care enabled me to probe deeply and obtain rich information about the impact of the process of participation rather than just discrete events. A combination of both interview and observation enabled me to interact personally with informants in practice and capture and evaluate the complex impact of context, interaction and all levels of pre and post-operative participation activity generally and specifically. The combination of such methods of data collection enabled me to conclude through in-depth questioning and observation of patient work as it occurred in practice what specific returns and costs could be attributed directly and reliably to patient participation in nursing care, a factor rarely considered in earlier studies. As Entwhistle et al. (2004) pointed out, in assessing patients' participation in decision-making and investigating how people respond to structured questions about participation in their health care, responses to simple structured measures of participation must be interpreted with caution, as behaviour can be attributable

to factors not presented as a course of action. Measurement of a practice as complex as patient participation needs to go beyond that of a one-dimensional concept such as that of satisfaction or listening. The range and detail of indicators relating to a positive experience of patient participation cannot be limited, as insufficient information about the patients 'real life' experience will not be captured. Attempts to measure and evaluate the outcome of patient participation need to begin with, and remain sensitive to, an understanding of the contextual influences and interactional processes that influence its form.

Mockford et al. (2012) in a systematic review on the impact of patient participation reported on the positive impact of patient participation in terms of employee retention rates, improving a health care organisation's reputation and hospital performance. However, the broader more organisational areas of reward were not calculated or quantified in the present study suggesting further research on the rewards and costs incurred by health care providers is required. In general, the literature does not speak directly about the benefits of patient participation in terms of quality and effectiveness of service and economic cost (Crawford et al., 2002). The evidence base needs to be significantly strengthened to ensure the full impact of patient participation in NHS healthcare services is fully understood. Despite the lack of quantifiable evaluative data gathered in the present study, some gaps in the literature have been 'plugged'. The present study presents some evidence from the perspective of the patient and nurses that patient participation in the form of question asking and challenge resulted in a decrease in medication errors and improved patient safety. In the present study, the rewards associated with patient participation extended to the delivery of safe care. However, key to active patient orientation were knowledge acquisition, confidence and assurance of the legitimacy of such participation. In one case, it was perceived vulnerability and anxiety about potential medication error that triggered participation in the administration of medicine process.

In the present study, patient participation enhanced the delivery of safe care, a finding evident in much published literature. Coulter and Ellins (2006) found that patients could make a significant contribution to patient safety by participating in distinct activities such as infection control initiatives and the checking of the accuracy of records. The work of the National Patient Safety Agency (2004) and McGuckin et al. (2004) reported how patients in assuming an active role encourage staff to comply with practices such as those associated with hand hygiene a finding corroborated by the present study. However, the challenging of staff was still observed to be a rarity in practice for fear of causing offence. Clearly, the present study provides insight into forms of participation that can contribute to an improvement in distinct aspects of patient safety. However in essence there is a need for further research on the

impact of patient participation on patient safety. As Gysels et al. (2007) maintained, evidence of the likely effect of patient contribution on patient safety is sparse.

Although a significant majority of patients alleged that patient participation led to an overall positive experience, the benefit of participation was on occasion suspect and did on occasion lead to unwarranted costs such as emotional burden and stress. Some patients reported that participation did little to improve the quality of the eventual decision and the quality of care. This corroborates the work albeit very specific of Bergal et al. (2010). In a study evaluating the impact of patient participation on surgical site marking Bergal et al. found that patient engagement in pre-operative site marking did little to help decrease the chances of wrong-site surgery. Compliance with correct site marking was also reported to be only 68.2%. However, given the sample size (n=200) and the low prevalence of wrong-site surgery it is difficult to defend a claim that patient participation in surgical site marking can decrease the chances of wrong site surgery. In the present study no patient was afforded the opportunity to be involved in pre-operative site marking as the complication of wrong-site surgery was considered too rare to require such preventative action to be taken.

In the present study, it was evident that patient participation did not always have a positive outcome and expectations of participants were not always met. A significant cost associated with patient participation was the burden of responsibility felt by both patient and nurse. In some, there was an air of scepticism, defensiveness and resistance to engage with each other in the course of nursing care delivery. According to Simpson and House (2003), casting a patient into the participant role often results in an undesirable burden on the patient and consequently leads to patient distress.

Another particular cost incurred because of patient participation was that of conflict which emerged primarily from individual differences in attitudes, expectations, personalities and perceptions about patient participation in nursing care and the patient's role specifically. Conflict because of patient participation is reported in many of the concept analyses that have been undertaken in an attempt to demystify the phenomenon (Cahill, 1996; Gallant et al., 2002). However, the potential for conflict between patient and nurse and the negative consequences associated with such 'battles' is largely ignored in the research based literature on patient participation.

In the present study, some nurses were overtly reluctant to encourage patient participation throughout a patient's hospital stay on account of being locked into routines and traditional patterns of work. According to Thorne (1993) a nurses prejudicial attitudes towards an active

patient orientation are inevitable, inescapable and often unspoken and subtle as was the case in the present study when behavioural strategies were employed unconsciously to limit patient participation. Such behaviour often resulted in conflict between nurse and patient. Some staff most notably the more junior and non-permanent staff 'clung on' to tasks to cope with the uncertainty associated with the engaged patient. This finding supports again the work of Menzies (1970) who made explicit how health care professionals cling on to routine tasks as a social defence mechanism against high levels of anxiety and stress. In the present study it can be seen that in some quarters patient participation was particularly threatening to some nurses, as it required them to form a close relationship with their patients and challenged professional boundaries and practices. This often contributed to a degree of conflict and led to patients feeling undervalued, exposed and/or vulnerable. Gillies (1989) reported how conflict between individuals has the potential to lead to feelings of anger, hostility, a sense of helplessness and temporary withdrawal, patient behaviours observed in the present study.

Some patients also reported experiencing helplessness and emotional distress because of the negative behaviours of some nurses. In the present study the lack of consistent care by the same nurse also created distress mainly due to role ambiguity. Working with many different nurses all giving various directions with respect to forms of patient participation also caused confusion and uncertainty about role, an outcome congruent with the findings of Mackay (1993) who found that for patients and nurses role conflict commonly emerged when a patient was exposed to a transient workforce. Conflict because of a reluctance to facilitate patient engagement in the process of care was also compounded by professional conservatism created through a fear of litigation and a view that patient participation was a threat to professional practice. Consequently, some nurses reported feeling safer maintaining the status quo rather than taking personal risks by engaging patients in their care. Review of published literature revealed no study that has evaluated the impact of a health professional's fear of litigation on patient participation.

In the present study patient participation also resulted in what some patients and nurses referred to as a failure to provide sufficient services. For some patients participation was considered a government conspiracy to continue to reduce professional services. As Brearley (1990) pointed out, patient participation is in some quarters considered a euphemism for cost cutting and an exclusive alternative to professional care. Wanless (2002) more recently reported that patient participation is seen as a strategy to keep health care spending within manageable limits. Lott et al. (1992), albeit in the context of acute care in North America, found that patient participation did contribute to cost reduction from decreased length of stay but, at the same time, it improved utilisation of human resources,

improved job satisfaction for unit staff nurses and increased enthusiasm and morale, a finding evident in the present study, although not quantified in the quantitative sense.

Despite the claims in the present study and the literature that patient participation has a positive influence on financial resources, published empirical studies examining the cost-effectiveness of patient participation during the patient's period of hospitalisation are relatively rare, pointing to a divide between theoretical ideas and empirical indicators. A few studies, albeit specifically in the context of self-management, have indicated that patient participation may reduce health care costs; however, the findings are inconclusive, as they have focused on disease specific programmes, discrete patient groups and/or distinct patient activities such as self-monitoring of oral anticoagulation and diabetes (Garcio-Alimo et al., 2010, Gillet et al., 2010).

In the present study the cost implications associated patient participation were outlined by a few informants but no quantitative measurement was undertaken to enable firm conclusions to be drawn on the cost-effectiveness of such an approach to nursing care. Effective patient participation as an approach to care placed demands on resources, most notably at the outset of its implementation, although the amount was not quantified. To establish, promote and maintain participation during a patient's episode of care it was evident that expenditure was needed to ensure that nurses were appropriately trained and appropriate resources were readily available. Nurses were firmly of the view that without the necessary emotional, practical, educational and financial support effective and meaningful participation could not be enacted. What emerged is that further research into the cost-effectiveness of patient participation in general is needed particularly as such an approach to care could result in an elimination or curtailment of professional services.

6.7   Contextual Determinants

The emergent theory makes explicit that there is a context that is best suited to provide a meaningful and authentic participatory experience for patients. The immediate, specific and general context is important as it generates both drivers for and barriers to attempts by patients to become engaged in their care. Specific contextual determinants within the patient, nurse and hospital, influenced patient and nurse action and interaction during each of the three conceptual phases of the engagement process. The determinants exerted a specific influence on the shape of participation from the point of admission to discharge. Cognisance of this context by the patient and nurse was deemed necessary for meaningful patient participation.

In the present study, it was apparent that individual, organisational and structural factors all had an impact on patient participation. Both patients and nurses reported that organisational or more specifically ward practices needed to be such that they prevented marginalisation. Clearly, the influence of the hospital environment on patient participation extends well beyond ward policy and mission. Key organisational factors, such as the employment of permanent staff appropriately trained, educated and supported, the enthusiastic leadership of the ward manager and the quality of the ward environment had an impact on the extent to which patients engaged in their care. Indeed one of the most inescapable and unequivocal conclusions of the theory is that the impact of patient participation is largely determined by the individual patient and nurses quality of effort, level of knowledge and skill and the climate of the ward environment. In the present study, patient participation was incredibly context sensitive.

The importance of context or those factors within the patient, the nurse, surgical care environment itself that exert a specific influence on the shape of participation have largely been neglected from previous studies and most notably those undertaken in the context of acute care, a view supported by Henderson (2002); Sahlston et al., (2007); Collins et al., (2007) and Coulter (2011). There is a remarkable lack of empirical research assessing the driving and restraining forces that promote and impede the implementation and promotion of such an approach to care. In examining the impact of context on participation insights can however been drawn from evidence gleaned from the field of primary care and chronic illness. S. Parsons et al. (2010), in a review of the quality of patient engagement in primary care, reported on the impact of workforce skills, practice orientation, time and fragmented pathways. The findings of the present study corroborate the work of S. Parsons et al. as both alert to the fact that the disconnect between patient and nurse will occur if health professionals do not have a sufficient skill set to elicit and understand a patient's views, values and preferences and thus be able to develop a conscious philosophy or practice mentality that brings patient participation to the fore and focuses on its achievement.

In the present study, a nurse's skill was seen as an important driving force for patient participation, a finding that supports the earlier work of Redfern (1996), and Perry (2006). Although the present study makes explicit that nurses in promoting patient participation in nursing care need to possess a repertoire of skills such as interpersonal sensitivity and competence many were ill equipped to engage patients in participation initiatives, a finding supported by Brookes (2008). Curry et al. (2000) identified albeit in the context of elderly care that a nurse's lack of knowledge and skill limits the successful provision of patient participation. However, the researchers did not specifically reveal the content of the

knowledge and skills required, but refer to knowledge and competence in general. As the present study illuminates nursing curricula need to be reviewed to ensure nurses are enabled to meet the expectations of patient's and facilitate patterns of nursing care delivery that promote patient participation throughout a patients hospital stay. Current education provision as reported by nurses in the present study does not appear to have kept up with the challenges presented by patient participation, a view mooted recently by Coulter (2011) and Frenk et al. (2010). Little evidence has emerged from the present study to indicate that nursing curricula have been developed to ensure that nurses reach and maintain competent standards in communicating with patient's, sharing care delivery and supporting self-care activity. However, caution in drawing firm conclusions about nursing curricula needs to be exercised, as the content of curricula in the context of pre and post registration nursing was not reviewed in the present study.

Interestingly, national and local health care policy was not a factor that drove the patient participation agenda at the bedside. Despite the increasing emphasis that has been placed on patient participation throughout the duration of the present study the potential for patient participation was in this study predicated only on the interest, commitment and skills of patients and nurses and in particular the ward manager. The ward manager assumed a pivotal role in creating a work environment in which patient participation was the expected norm. As Evans (1994) over almost two decades ago asserted it is the nurse manager who clarifies the vision of participation, practices as a role model for participation, inspires others to achieve this difficult goal, manipulates the environmental resources and facilitates the self-confidence of staff to engender such an approach to care. Indeed accounts from nurses in the present study made explicit the need to provide nurses with a supportive culture in their endeavour to promote patient participation in mainstream practice. A facilitative manager was required to decentralise the authority to act and empower individual nurses to promote patient participation in nursing care. Berg et al. (1994,) on reporting on a study undertaken in the context of mental health, found that, to support patient participation, there is a need for a support system, such as clinical supervision to be in place to enable nurses to develop not only the skills but the confidence to promote such a form of practice as the norm. Such support was generally lacking in the present study, the exception being the support offered to staff on Ward A.

The lack of support to new, inexperienced and task-orientated nurses in their endeavours to change traditional practice was reported in the earlier work of Meyer (1993) and Redman (2008) suggesting little has changed over the last twenty years. While the present study illuminates a need to develop a more supportive culture in which nurses can develop and

foster change, other factors in the ward environment that were found to mitigate against the introduction, promotion and maintenance of patient participation need also to be addressed. Such factors included demanding workloads, inadequate staffing made worse by a transient workforce and lack of time, energy and resource.

Review of the literature illuminated that a lack of time and resource and workload pressures are cited frequently as factors inhibiting nurses' ability to introduce patient participation as a model of practice. Curry et al. (2000) identified that if patient participation is to become a norm in clinical practice structures and processes of ward organisation need to be adequately resourced. Lundh et al. (2006) maintained that in promoting patient participation consideration needs to be given to resource allocation and flexibly working schedules. As Brooks (2008) found organisational and managerial processes create many barriers to nurses' engagement with public participation a view confirmed by both patients and nurses in the present study. The present study reports how a lack of time and an appropriate staffing resource particularly a permanent one affected the implementation of patient participation. Lack of time frequently due to patient acuity and the ward climate was such that nurses did not have enough time to acquaint themselves with patients properly and thus facilitate such an approach to care. Often a demanding ward climate including the need to attend to technological equipment during periods of acute illness resulted in a focus on task-centred routines as opposed to individualised care that promoted patient participation. This particular finding reinforces in part the outcome of a study by McConnell and Fletcher (1993), who in examining the views of 142 nurses about the use of medical equipment, found that they viewed the use of medical equipment as a double-edged sword, which either inhibited or enhanced patient participation. The need to focus during times of acute illness on technological or invasive monitoring often led to a form of practice that was task-orientated. Redfern (1996) however, while recognising that time, excessive workload, an impoverished skill mix and task-oriented care can have an impact on the extent to which a patient engages in their care, does assert that patient participation can be promoted using any model of nursing care organisation and that key is that nurses examine their care delivery practices to ensure they do not disempower the patient. This view was challenged by nurses and patients in the present study as most were firmly of the view that the provision of organisational structures and processes were key to effective and meaningful patient participation.

6.8 Summary of Chapter

This chapter has discussed the full grounded theory, which provides a vehicle for conceptualising and integrating the three categories. Through due consideration of existing

theory, conceptual models and empirical and scholarly literature, the extent to which the overarching theory and the underpinning conceptual categories define new theory or knowledge has been made explicit. Discussion has revealed that the emergent theory has contributed new knowledge and understanding to the area of patient participation. The theory has opened the door to the importance of engaging patient in their nursing care and how such an approach to care should be implemented. The critical role of nurses in implementing such an approach to care has been illuminated.

The following chapter proceeds to discuss the practical significance of the present study and its specific contribution to knowledge development. Recommendations for practice, education, policy and areas for future research are identified. The key messages from the study are outlined and how the results contributed to the study's overall aim and objectives are discussed.

CHAPTER 7   IMPLICATIONS OF THE STUDY AND CONCLUDING REMARKS

7.0   Overview of the Chapter

The purpose of this chapter is to illuminate the contribution of the present study to the advancement of knowledge and understanding of patient participation in nursing care. The extent to which the findings define new theory and add a new dimension to patient participation are made explicit. The implications of the findings for nursing practice, nurse education, policy development, and future research inquiry are examined alongside the extent to which the original objectives of the study have been achieved.

7.1   Overview of the Contribution to Knowledge and Understanding

The broad purpose of the present study was to develop a theoretical analysis of the nature of patient participation in nursing care to explain the process by which patients participate in their care within the context of an acute surgical care setting. The aim was also to create and interpret new knowledge through original research and extend the forefront of an area of professional practice. The present study through a rigorously developed grounded theory has made a significant contribution to existing knowledge in that it provides nurses in the field of acute surgery with new and dependable empirical evidence that describes how patient participation in nursing care is viewed and enacted in surgical care practice. As Larsson et al. (2007) asserted empirical studies that have examined the patient and nursing perspective of patient participation and have observed the real world of patients and nurses are limited. This theory goes some way to close the current gap that exists in the literature.

Although the development of an evidence base for nursing is largely underpinned by the belief in the application of evidence from randomised controlled trials or other quantitative approaches to research there is a need in the current nursing climate to generate and expand evidence which is based on research in the 'real' world. Whilst knowledge gleaned from a positivist creed has a significant role to play in a science based health service, for rich understanding of the process of patient participation more qualitative methodologies, which have a close association with the applied environment, need to be employed. The knowledge gained from this grounded theory study, which employed a fresh methodological perspective to explore the process of patient participation in a rigorous and in-depth manner, has advanced knowledge and understanding of patient participation within the surgical care context. The process of establishing, developing and maintaining patient participation in nursing care at the bedside has been made explicit.

The theory that has emerged from the present study contributes to the evidence base for nursing, in that it explains the whole phenomenon and dynamic process of engaging or patient participation in a way that is meaningful and relevant to not only nurses in acute care but also nurses for whom establishing relationships with patients lies at the foundation of professional practice. The validated theoretical conceptualisation provides nurses with a window into the world of patient participation and thus an empathetic understanding of the patterns of behaviour that exist between and among patients and nurses. It also provides understanding of the impact of patient participation on the patient, nurse and ward environment.

The present study has opened the door to the importance of patients engaging in their care in modern day surgical practice. In turn, such understanding carries implications for action. Nurses, health care managers and policy makers will be enabled to develop substantiated strategies and initiatives for implementing and coping with the impact of patient participation on practice, the nurse-patient relationship and more importantly patterns of authority and deference. Clearly patient participation has been the central theme of many health care policy changes in the United Kingdom over the last thirty years however the intricacies of such polices have not yet filtered down to the bedside within the context of acute surgical care. The findings of this study provide insight into how patient participation can become more of a reality within the acute surgical care environment.

The knowledge, skills and attitudes that are necessary or that need to be refined in order to exercise professional power in a way that is amenable to such an approach to care are made explicit. Thus, the benefit of participation to the individual patient, the nurse and the health care organisation can be maximised and the incidence of token participation minimised. The emergent insights and understanding of the nature of patients' and nurses' roles and responsibilities within the context of patient participation in nursing care will not only inform clinical decision making and role function but also the professional education and training of nurses. Such education is imperative if the rhetoric of patient participation is to be translated into practical action. The emergent understanding of the intricacy and complexity of both role taking and role making within the context of acute care promises to provide clear directives for nurses and other health care professionals as they plan individualised care. Finally, the outcome of the present research provides a means by which both the general public and the profession can achieve understanding and become educated about their future roles in health care.

7.2   Contribution to Practice Development and Enhancement

Whilst there are limitations on how generally the findings from a study, which used data, collected from three surgical wards in one acute hospital can be applied, the emergent theory has been developed to a degree of abstraction that potentially lifts the conceptualisation beyond this single hospital setting. The findings of the present study contribute to the advancement of professional nursing practice by making explicit how patient participation is and can be executed in both the pre and postoperative period. The findings explain the process of establishing, developing and maintaining a level of desired participation throughout the patient's hospital experience.

Specific recommendations can be made to: enhance how patient participation can be implemented meaningfully in clinical practice; demonstrate how the gap between policy regulation and mainstream practice where it exists can be narrowed and how the role of the patient within the context of surgical nursing care can be advanced. The recommendations are presented in Table 18 overleaf.

Table 18	Recommendations for Practice Development and Enhancement

- **Patient participation should, from admission to discharge, be an integral part of modern surgical nursing care practice**.
  Patients and most nurses affirmed that patient participation in nursing care irrespective of level should not be seen as peripheral to the main business of nursing care. The direction of travel should be on ensuring patient participation even at its basic level is the norm throughout the patient's total surgical experience. Both patients and nurses were firmly of the view that ward infrastructures such as the system of care delivery used and the nature of the nursing workforce employed need to be reviewed to ensure they are conducive to the promotion of patient participation in nursing care throughout both the pre and post-operative period.

  Ward managers need to ensure staffing resources permit continuity of care and the development of a positive connection between patient and nurse. There is also the need to ensure all levels of staff including members of the transient workforce and students are committed to and supported in the process of engaging patients in their nursing care. Nurses themselves need to make a conscious effort to extend time spent with patients to assess willingness and capacity to participate in care. Nurses should work with patient's to develop a plan of care that meets jointly their needs and accords with their values, preferences and circumstances.

- **Ward managers and senior nurses need to be equipped with strategies and have a desire to empower and support staff in engaging patients in their nursing care.**
  Both patients and nurses asserted that the ward manager has the unique opportunity to influence and create an environment in which patient participation in nursing care can flourish. They recognised that a supportive leadership style with coaching and supervision as core values is needed. The ward manager was seen to have a key role in the facilitation of the ward's staff support and development programme. Senior staff need to acknowledge the importance of their role and role modelling behaviour and serve as a role model in providing effective experiences that impart appropriate values, beliefs, behaviours and skills to staff in order that they can empower patients to engage in their nursing care.

  Nurses themselves need to focus, where appropriate, on the development of specific behaviours in patients in order that they develop expertise, competence and confidence to participate in their care. A patient's knowledge, expertise and skills need to be harnessed in order that the resource of professional expertise can be deployed more effectively and patients can become the entrepreneurial force in nursing care delivery. Nurses need to be encouraged to promote dialogue that is more conversational in character, interactionally balanced and allows for forms of patient expression and elaboration. Plans of care need to make explicit what responsibilities the nurse and the patient will assume during a patients period of hospitalisation. Patients and nurses affirmed this was essential to avoid role confusion and conflict.

7.3   Contribution to Pre and Post Qualifying Nurse Education

Findings suggest there is an expectation that nurses in establishing and promoting a practice paradigm that has patient participation at the centre of all activity are required to possess a number of practice competencies for effective patient engagement. For this reason, the present study can contribute to pre and post-registration nurse education particularly in relation to curriculum design, assessment and evaluation. The specific recommendations are detailed in Table 19.

Table 19   Recommendations for Pre and Post Qualifying Nurse Education
• **The process of patient participation should be a core part of all curricula in nurse education**. Nurse educationalists require a through grounding in the evidence base that supports patient participation at an individual and bedside level. As both patients and nurses asserted there is a clear need to invest in nurse education in general to enable nurses to develop an appropriate skill set which will promote patient engagement in nursing care. There should be a strategic tailoring and targeting of the skills required. There needs to be a definite focus on interpersonal knowledge, skill, attitude, sensitivity and relations. Training to develop skills to deal with scepticism, defensiveness, challenge, inappropriate role models, practice variations and resistance to change is needed. In attempting to change traditional attitudes and mind sets an attempt should be made to make nurses aware of the potential strength of the patient role and the reality of engaging patients in their health care. As suggested by patients and nurses assessment of the practical application of such skills is needed to ensure nurses are competent and confident in meeting the expectations of patients and participating in a patient-centred health care system. Involving patients directly as teachers and assessors may help to promote such a practice paradigm and give real insight into the perspective of patients and the skills expected of the nurse. This would support the Nursing and Midwifery Council (2010) requirement that all programme providers must make the needs of service users their first priority and ensure their involvement in the design, delivery and assessment of the curriculum. Patient participation activity should also be incorporated into accreditation standards associated with the learning environment in order that students are exposed to such a practice paradigm and witness the skills required to promote it. Where possible there should be exposure to positive role models.

7.4   Contribution to Policy Development

The study has illuminated that to assist nurses in the process of engaging patients in their nursing care there is a need to determine the best way to go about it. Policy initiatives need to be designed at different levels of the organisation to translate rhetoric into practical action and

strengthen the impact of such an approach to care. The specific recommendations for policy development that have emerged from the present study are outlined in Table 20.

Table 20 Recommendations for Policy Development
• **A culture that promotes patient participation at all levels of the health care organisation is needed.** There needs to be senior commitment and leadership for patient participation. Implementation of a patient participation strategy should be incremental to ensure all staff are appropriately prepared and the necessary infrastructures are in place. The strategy should make all recognise their responsibility in establishing, shaping, promoting and maintaining patient participation in nursing care. As most patients stressed, patient participation should be seen as an essential component of modern nursing policy rather than an optional extra. It should pervade all operational practices including, patient surveys, interview practices, staff appraisal and clinical documentation such as the nursing assessment pro-forma, which was reported by both patient and nurse to constrain patient participation in the assessment process. • **Resources need to be ring fenced to promote patient participation throughout the patient's total surgical experience.** The necessary resources to support an integral form of patient participation in nursing care and the development of the competencies required of nurses to engage patients need to be identified and ring fenced. As both patients and nurses claimed to establish and sustain patient participation as a model of care within the context of surgical nursing resources need to be deployed appropriately. • **The monitoring of patient participation activity should be on-going to promote learning from achievement**. Data about what patients and nurses do and do not do could provide valuable information about the size and scope of the problem and to what extent nurses are performing specific actions that are linked to effective and meaningful patient participation. This will also enable strategic tailoring and targeting of efforts to support the capacity for all staff to engage patients in their care. Outcomes should be fed into ward planning, training programmes, appraisal, decisions, service delivery and priorities at a local level. • **Robust strategies of evaluation to gain feedback from patients about their experience of patient participation at a local and individual are needed**. Context specific evaluation tools should be developed. Patients should be involved in defining local quality measures of participation, which could then be translated into service standards.

7.5   Contribution to Future Research Inquiry

In reviewing the findings of the present study and where it is situated within the current body of published literature, patient participation could be considered to be an immature area of nursing practice that has relevance and potential for further inquiry particularly as the movement towards enhancing the patient's voice grows in health care discourse and practice. A number of research priorities have emerged from the present study. Findings from the study have the potential to shape future research activity. Some ideas for future research activity are presented in Table 21 overleaf.

Table 21	Recommendations for Future Research Inquiry

- **Development of a formal theory.**
  An extension of the present grounded theory study could be undertaken to raise the degree of explanatory power and develop a formal theory, which can be applied across a variety of care settings. By extending theoretical sampling to other contexts and cultural groups, the emergent substantive theory could be elaborated and refined further. It is acknowledged the study was undertaken in an affluent area of North London where the patient population was predominately English speaking. A more varied informant population in terms of biographical data and demographic characteristics may provide useful insights. The use of quantitative data to explore the impact of patient participation on factors such as resources, incidence of complaint, adverse events, symptom control, patient satisfaction and length of hospital stay would also be of value.

- **Research inquiry to evaluate the impact of specific contextual determinants on patient participation in nursing care.**
  A logical step would also be to evaluate how local organizational structures and processes facilitate or hamper the process of patient participation. For example a study to explore the impact that factors such as workload, patterns of work, methods of organizing and delivering nursing care, may singly, or in combination, have on patient participation would be illuminating. An evaluative study to examine the effectiveness of targeted and broad strategies that are used to support engagement behaviour in practice would be useful. Strategies may be evaluated at an individual, ward and institutional level.

- **Research inquiry to evaluate the impact of patient participation in nursing care on patient outcome and resource provision.**
  A study to delineate the 'real' value of patient participation on the patient experience would be attractive. Outcomes such as patient satisfaction, nurse satisfaction, quality of life could also be assessed in future research projects using both qualitative and quantitative data. Since the prevailing ideology of efficiency to achieve fiscal goals begs the question of whether patient participation is even feasible within the current health care system an evaluation of the 'real' cost of such an approach to practice would be of value. Whilst both patients and nurses in the present study have reported that adequate resources are needed in order to make patient participation a reality the present study has not quantified the resources needed. The added value of patient participation in economic terms could be evaluated in order that such a practice can be compensated adequately. Both the positive and negative consequences of patient participation require further examination. Given the lack of reporting on the impact of patient participation in general as opposed to distinct activities, a study to develop valid and reliable tools to capture the impact of such a model of practice would also be of value.

- **Review of pre-registration nursing curricula**
  An exploration of the effectiveness of pre-registration nursing curricula in preparing student nurses for the process of engaging patients in their nursing care would be valuable. This could involve the conduct of a large survey followed by focus groups with students from the four fields of nursing and an analysis of relevant curricula documents. From this could emerge recommendations for curricula content and methods of delivery and assessment.

7.6   Concluding Remarks and Reflection on the Original Intent of the Study

Despite the relatively advanced intellectual culture of nursing no one theory or study systematically grounded and pronounced as rigorous by the mantra of evidence-based practice exists to explain the process and practice of patient participation in the course of nursing care within the surgical care setting. The present study clarifies the existing state of knowledge and understanding about this form of practice and offers new insights into the process of patient participation in the context of the modern surgical care environment. The emergent theory illuminates the antecedents, attributes, consequences and context in which of patient participation can best be facilitated. The theory advances knowledge and understanding of patient participation in the context of a complex surgical care environment and provides a basis to enable both patients and nurses to articulate their purpose, assert, apply and evaluate their unique role and responsibilities. It also offers a platform for the review of pre and post-registration curricula, the development of health care policy and the conduct of future research enquiry.

Moving forward must involve engaging patients in the process of nursing care. Patients and nurses need to see each other as partners in care. The direction of policy is clear. Any strategy to establish and promote levels of patient engagement should encourage patients to raise their expectations of participation and to express their preferences more vocally. Strategy should also target the education of nursing staff at both an under and post-graduate level. Nurses need training in how to establish, promote and support patient participation at whatever level it is desired and agreed. Interpersonal, team-working and leadership skills need also to be enhanced. Opportunities to promote patient engagement need to be seized. Nurses, patients and policy makers alike need a better grounding in the evidence base that supports an engagement strategy. Strategy should also encompass professional leadership, management and financial and performance measurement. Without these basic building blocks the gaps, where they exist, between policy and mainstream surgical nursing practice will not be closed and strategy will fail. The direction of travel should be towards patient participation being seen as an essential component of a patient's total surgical experience rather than a discrete activity or optional extra.

Collectively the phases of the emergent theory make the antecedents and attributes of participation explicit. Many of the consequences of patient participation are also delineated however, further inquiry is needed to appreciate fully the impact of patient participation particularly the domains that require quantification and measurement. Areas that patients express satisfaction and dissatisfaction with have been revealed. The broad training and

standards required of nurses to establish, promote and maintain a desired level of patient engagement have been illuminated. Essentially the original aims of the study have been achieved albeit that there are limitations on how generally the theory can be applied as the study was conducted in three surgical wards within one hospital. The theory is however, developed to a level of abstraction that potentially lifts it beyond this single setting. Because of the duration of the study, it was possible to share the emerging theory with both patients and nurses in the field. Many confirmatory statements attesting to the rigor of the conceptualisation were gained; however, robust confirmation of the general applicability of the theory would come through the specific testing of the assumptions that form the basis of the theory using a broader data set, particularly with regards to culture and patient background. Data sources such as nursing documentation might also provide a richer and valuable database.

In conclusion, the originality of the emergent theory de-mystifies patient participation and provides unique insights into how it is and can be enacted in modern surgical care practice. The theory opens a window to how patients engage in their nursing care from admission to discharge and makes explicit that the patient is perhaps one of the most valuable resources in modern clinical practice. The theory offers a roadmap that will strengthen the patient's role in contemporary surgical nursing practice and will enable nurses to root patient participation in mainstream surgical nursing practice. Clearly there is a definite need in current service provision to advance doing things *with* people instead of *to* them. As the present study and Coulter (2011), a luminary in the field reveals, patient participation needs to become a reality in mainstream surgical nursing practice. Patients should no longer be viewed or treated as submissive recipients of care but as vital participants in the business of health care provision from the point of admission to discharge.

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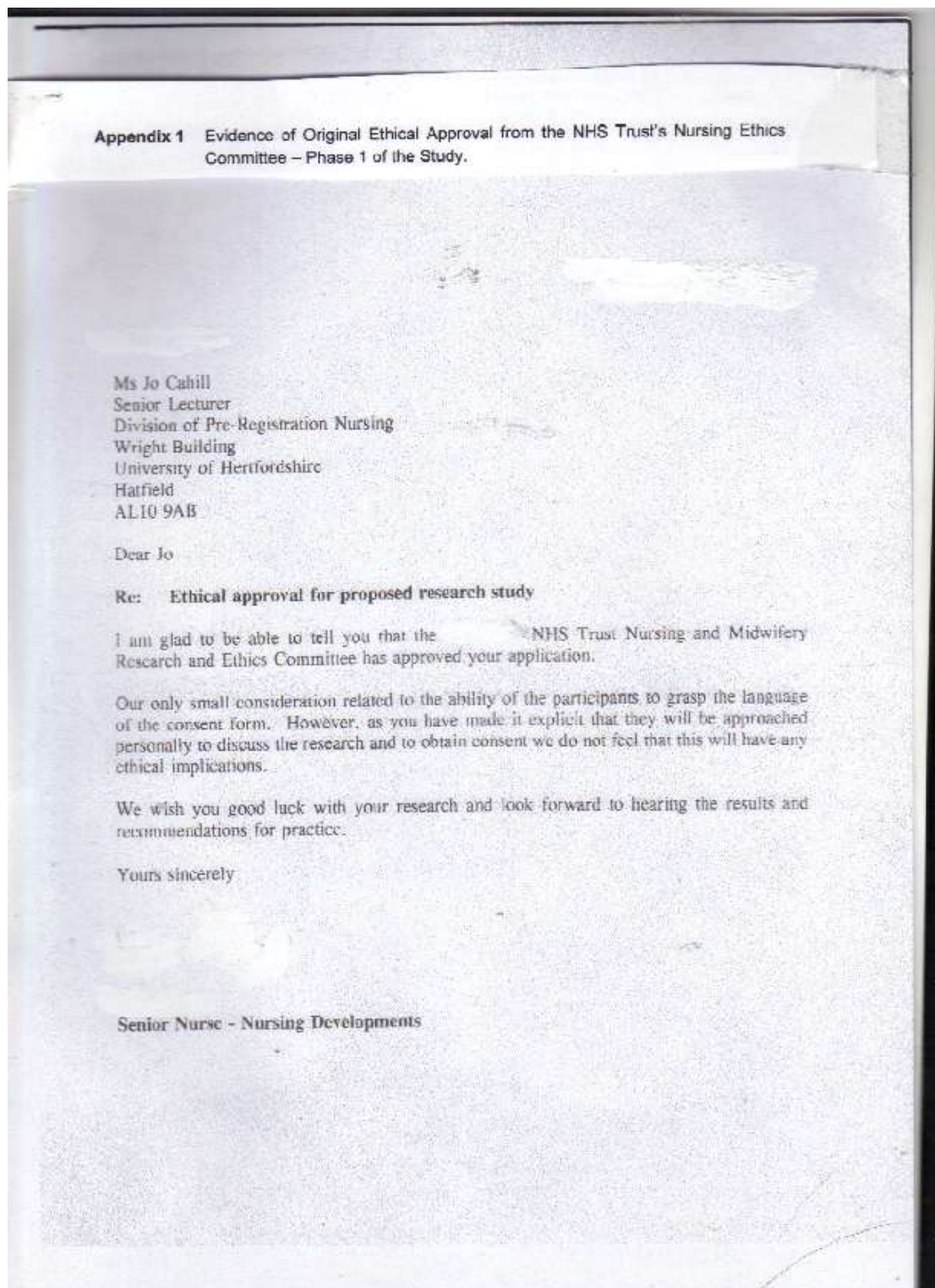
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Appendices

Appendix 1

Ms Jo Cahill
Senior Lecturer
Division of Pre-Registration Nursing
Wright Building
University of Hertfordshire
Hatfield
AL10 9AB

Dear Jo

Re: Ethical approval for proposed research study

I am glad to be able to tell you that the   NHS Trust Nursing and Midwifery Research and Ethics Committee has approved your application.

Our only small consideration related to the ability of the participants to grasp the language of the consent form. However, as you have made it explicit that they will be approached personally to discuss the research and to obtain consent we do not feel that this will have any ethical implications.

We wish you good luck with your research and look forward to hearing the results and recommendations for practice.

Yours sincerely

Senior Nurse - Nursing Developments

Appendix 2

Evidence of Subsequent Ethical Approval (in principle) from the NHS Trust's
Nursing Ethics Committee – Approval was related to changes to the method
of data collection namely the inclusion of a period of participant observation –
Phase 1 of the Study.

Ms Jo Cahill
Senior Lecturer
University of Hertfordshire
Hatfield Campus
College Lane
HATFIELD
Herts
AL10 9AB

Dear Jo

RE: ETHICAL APPROVAL FOR PROPOSED RESEARCH STUDY

Thank you for your recent letter regarding your proposed participant observation on

Your request has been considered and offered approval subject to your formally addressing
the amendments to your study. As your original proposal is being extended, we need to have
the distinct changes described formally. I am enclosing an application form to enable you
to do this and would like to stress that only the components which are being altered (i.e. the
methodology, consent etc) need to be addressed.

If you would like to discuss this condition further, please liaise with   (Acting
Director of Nursing and Quality) on

Yours sincerely

Senior Nurse – Nursing Developments

cc

Enc

Appendix 3

Evidence of Subsequent Ethical Approval (Final) from the NHS Trust's Nursing Ethics Committee – Approval was related to changes to the method of data collection namely the inclusion of a period of participant observation– Phase 1 of the Study.

Directorate of Nursing & Quality

Tel:

Our Ref:jocahill.eth
Your Ref:

Jo Cahill
University of Hertfordshire
Room LF285
The Wright Building
Hatfield Campus
College Lane
Hatfield
Herts AL10 9AB

Dear Jo,

Re: Ethical Approval for Extenson of Research Project

Thankyou for your letter of 13th December and the attached notes addressing the ammendments to your previous proposal. I am pleased to confirm that you are now able to go ahead with your research as planned.

I wish you luck.

Best wishes
Yours sincerely,

Acting Director of Nursing

Appendix 4

Directorate of Nursing and Clinical Services

Extension   or bleep

Dear Jo

Re: Extension of ethical approval for research study

Thank you for your recent letter regarding extension of your previously approved
research study.

The   NHS Trust Nursing Research Committee is happy that your informed
consent form has met with our criteria. We are therefore agreeable to your study
continuing within   ' in the way that you have requested.

We would like to wish you continued good luck with your work and look forward to
hearing of it's outcomes and recommendations for practice.

Yours sincerely

Senior Nurse - Nursing Developments

Appendix 5

Appendix 5   Evidence of Permission from the National Research Ethics Service for Phase 2 of the Study, namely further patient and nurse interviews and a period of observation.

National Research Ethics Service

24th August 2009

Jo Cahill
6 Riccat Lane
Stevenage
Herts
SG2 3XY

Dear Jo

Study title:	An exploration of the nature of patient involvement behaviour within the context of a surgical setting
REC reference:	(N/A Pre- RED:)
Amendment number:	2 (Minor)
Amendment date:	24 August 2009

Thank you for your recent emails, notifying the Committee of the above amendment.

The amendment has been considered by the Chair on behalf of the Committee

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

None.
(By email correspondence only)

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

An exploration of the nature of patient involvement behaviour within the context of a surgical setting   Please quote this title on all correspondence

Yours sincerely

Committee Co-ordinator

E-mail:

Copy to: Clinical Director   Hospital Trust

Appendix 6

Appendix 6 Evidence of Permission from the Department of Clinical Governance and Risk of the National Health Service Trust for Phase 2 of the Study.

Department of Clinical Governance & Risk

Jo Cahill
6 Ricent Lane
Stevenage
Herts
Sg2 3XY

Date: 29/10/2009

Dear Jo Cahill,

Study Title: An exploration of the nature of patient involvement behaviour within the context of a surgical setting
REC reference: (N/A Pre -
Amendment number: 2 Minor
Amendment number: 24 August 2009

Thank you for informing us of the amendment to the above study.
I am happy to acknowledge this amendment and for the trial to proceed in the modified form.

If you have any further questions please do not hesitate in contacting our Research Administrators on:

Tel:
Email:

Tel:
Email:

Yours sincerely

Associate Medical Director and Trust Lead for Research

Appendix 7

Directorate of General Surgery   Consultant in Charge
            NHS Trust
        General Hospital

RB/hm

25 March 1997

Jo Cahill RGN, RNT, Dip.N, BSc(Hons)Nursing
Senior Lecturer
University of Hertfordshire
Room LF285
The Wright Building
Hatfield Campus
College Lane
Hatfield
Herts AL10 9AB

Dear Ms Cahill

I am sorry to be slow in replying to your letter. It got
misfiled. I do not think there will be any problem about your
proposed research once Ethical Committee approval is obtained.

Yours sincerely,

Consultant Surgeon

cc

WZZ 431

Appendix 8

INFORMED CONSENT FORM FOR INTERVIEW - PATIENTS

Title: An Exploration of the Nature of Patient Participation within the Context of the Acute Surgical Care Setting

Researcher: Jo Cahill

The purpose of this research project is to discover what surgical patients feel about the nature of patient participation in nursing care during their period of hospitalisation before and after surgical intervention. Interviews will be tape recorded and last approximately 1-2 hours. During these interviews, questions will be asked regarding your feelings about participating in nursing care in the pre and post-operative period. The tapes will be made available to the researcher and her supervisor but will not be shared with other ward staff. The final report, containing anonymous quotations, will be available at the end of the study. There may be no direct benefits to the participants of this study but changes to nursing practice may be made following the completion of the study.

This is to certify that I _____(print name) hereby agree to participate as a volunteer in the above named study. I hereby give my permission to be interviewed and for those interviews to be tape-recorded. I understand that the tapes will be stored safely during the research and will be erased on completion of the study. I understand that the information may be published but my name will not be associated with the research.

I understand that I am free to deny any answer to specific questions. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty. I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

_____   _____   _____

Name of Participant   Date   Signature

_____   _____   _____

Name of Researcher   Date   Signature

Appendix 9

INFORMED CONSENT FORM FOR INTERVIEW - NURSES

Title: An Exploration of the Nature of Patient Participation within the Context of the Acute Surgical Care Setting

Researcher: Jo Cahill

The purpose of this research project is to explore and discover the nature of patient participation within the context of an acute surgical care setting. Ultimately, the aim is to generate an explanation that can account for and explain the process by which patients participate in their care within the context of an acute surgical care setting. Interviews will conduct with a range of nursing staff. They will be tape-recorded and last approximately 1-2 hours. During these interviews, questions will be asked regarding your feelings and experience of patients participating in their care during the pre and post-operative period. The tapes will be made available to the researcher and her supervisor but will not be shared with other ward staff. The final report, containing anonymous quotations, will be available at the end of the study. There may be no direct benefits to the participants of this study but changes to nursing practice may be made following the completion of the study.

This is to certify that I _____(print name) hereby agree to participate as a volunteer in the above named study. I hereby give my permission to be interviewed and for those interviews to be audiotape-recorded. I understand that the tapes will be stored safely during the research and will be erased 3 years following the publication of the study results. I understand that the information may be published but my name will not be associated with the research. I understand that I am free to deny any answer to specific questions and also that if I raise examples of poor practice and/or practice that contravenes the Code of Professional Conduct (Nursing and Midwifery Council, 2008), where appropriate, the researcher will be obliged to explore this further at the conclusion of the interview. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty. I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

_____   _____   _____

Name of Participant   Date   Signature

_____   _____   _____

Name of Researcher   Date   Signature

Appendix 10

INFORMED CONSENT FORM FOR PARTICIPANT OBSERVATION - PATIENTS

Full title of Project: An Exploration of the Nature of Patient Participation in the Surgical Care setting.

Name, position and contact address of Researcher:
Jo Cahill – Principal Lecturer
University of Hertfordshire
F316 Wright Building
Hatfield, Herts.
AL2 1AB
017070 28 5931

Please initial box

I confirm that I have understood the purpose of the above study and I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

☐

I understand that the researcher will make observations of care activities at various times during my hospital stay. I also understand that on-the-spot discussions about events, activities and interactions with other patients, nurses, medical and paramedical staff may be undertaken during each field session

☐

I agree to take part in the above study. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.

☐

I understand that this study has been approved by the relevant Ethics Committee and approved by the ward manager and my consultant.

☐

I understand there may be no direct benefits to the participants of this study but changes to nursing practice and infrastructures *may* be made following the completion of the study.

☐

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Name of Researcher   Date   Signature

Appendix 11

INFORMED CONSENT FORM FOR PARTICIPANT OBSERVATION - NURSES

Full title of Project: An Exploration of the Nature of Patient Participation in the Surgical Care setting.

Name, position and contact address of Researcher:
Jo Cahill – Principal Lecturer
University of Hertfordshire
F316 Wright Building
Hatfield, Hertfordshire
AL2 1AB
017070 28 5931

Please Initial Box

I confirm that I have understood the purpose of the above study and I have been given the opportunity to ask whatever questions I desire, and all such questions have been answered to my satisfaction.

[ ]

I understand that the researcher will make observations of care activities at various times during pre and post-operative period. I also understand that on-the-spot discussions about events, activities and interactions with other nurses, patients, medical and paramedical staff may be undertaken during each field session

[ ]

I agree to take part in the above study. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.

[ ]

I understand that I am free to deny any answer to specific questions and also that if I raise examples of poor practice and/or practice that contravenes the Code of Professional Conduct (Nursing and Midwifery Council, 2008), where appropriate, the researcher will be obliged to explore this further at the
Conclusion of the field session.

[ ]

I understand that this study has been approved by the relevant Ethics Committee and approved by the ward manager.

[ ]

I understand there may be no direct benefits to the participants
of this study but changes to nursing practice and infrastructures
may be made following the completion of the study.

[ ]

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Name of Researcher   Date   Signature

Substantive Codes	Extract of Raw Interview Data	Theoretical Notes
Tolerating disparity Crushing vulnerability Feeling uneasy Needing support Covert control Selective engagement	**Interviewer**: How do you feel about your degree of participation changing in accordance with the time of day? **Informant:** To be honest being able to be *active one minute and then inactive the next* was very frustrating. I felt quite *vulnerable* at times. When the *night staff* were on, I was *reluctant* to do my own dressing because they were *less encouraging.* They *say little and are reluctant to talk much in case they are caught spending time* with you. I needed a bit of *verbal encouragement or reassurance* and they didn't always give it me. I know *they are busy* but that is not the point	Is there a perceptual shift in participation behaviour? There is variation between night and day? Why? Are the staff different – Is the workload different? Is time an important element and if so why? Interpersonal dynamics are important. There is a power base here. Nurses appear to be very controlling. Patterns or styles of behaviour appear to give messages to patients about the degree to which they can participate in their care.
Covert control Feeling valued Needing support Mutual desire Controlling Nurse sovereignty Tolerating Disparity	**Interviewer:** I'm not quite sure what you mean. **Informant:** Well you have to *feel as if the nurse wants you to be active or have an active role* and that she feels you are *capable. Reassurance* makes you feel *your participation is important.* She needs to be *approachable and willing* to *let you* do things. You know whether a particular nurse is *willing to* let you get involved in activities just by the *look on her face. Each one lets you do different things*	The climate needs to be conducive to participation. What are the characteristics of a good climate, The climate appears to be associated with the nurse's demeanour. Nurses seem to control participation behaviour through their actions and interactions.
Controlling the agenda Looking for cues Hiding messages Surrendering power Maintaining a distance	**Interviewer:** Tell me more **Informant:** Well you can *tell by her face* can't you - you *get the look if she wants to do something herself*. You get an almost *dirty look* if you *take away their work.*	Patients need cues. There is no verbal invitation. Invitation to participate is discrete. Why is this? Why are nurses reluctant to surrender to the patient? Do nurses realise the impact of their behaviour?

Appendix 13   Template for the Microscopic Analysis of Data

Location Code:	FN 21
Extract from Field Note: Fragment No: 973	During the bedside handover the nurse who had been caring for Mr X that morning invited him to tell the oncoming staff about his morning. She sat smiling next to him with a hand on his shoulder while he reported. When he had finished she leant over to him and whispered well done. Not everyone heard this or even noticed what she had said. Mr X then turned and said 'no problem I quite enjoyed that – thanks'. . The nurse obviously had a good rapport with her patient. In addition, I am sure this participatory behaviour had been planned between the two of them. It was so natural and so expected. Mr X was just waiting to have his say and his smiling and general manner suggested he enjoyed being part of it all. During the next change of shift the reverse happened. Mr X was virtually ignored. Staff stood and talked at the end of the bed with little attention being paid to Mr X and interestingly he too did not attempt to interact with the nurses. He glanced up at them but on getting no response (not even a nod or smile!) he just knew he did not have a role to play. The situation was quite extraordinary. Nothing was said Mr X just seemed to sense instinctively that he should ignore the conversation. There was no attempt by the nurses to allow a participatory relationship to develop.
Substantive Codes:	Picking up cues Adapting to the setting Mutual Respect Sharing Roles Providing Reassurance Gaining Enjoyment Feeling Able/Valued Covert support Establishing rapport Focusing on the person Negotiating a role Feeling safe
Theoretical Notes:	The interaction dynamics between the nurse and the patient appear to have a marked influence on patient participation behaviour. It would appear that both linguistic and non-verbal interaction (the interpersonal experience) is important. Certain actions seem to encourage or initiate participation activity. In the first instance the patient felt confident and comfortable to report on his day. Why did this not happen on the later shift? Mr X. appeared to know 'instinctively' that he was not going to deliver his account. No verbal exchange took place - there was just this automatic knowing. It would seem that there are certain ingredients that need to be combined for the patient to feel able to participate in his care. Certainly, it would seem that both parties, the nurse and the patient, need to be prepared or willing to promote patient participation. There is an element of team playing here but at the same time an element of control. In the second handover, the nurses were simply not willing to surrender any of their power. In order for patients to assume a more active stance, I wonder whether it is essential for the nurse to surrender some of that orthodox power. Is there a recipe for success (patient participation) and for disaster (non-participation)

Appendix 14 Analytic and Self-reflective Memo Extracts

Analytic Memo

02.05.02: The data appear to be suggesting that there are many contextual and situational determinants that influence the participation passage. It appears there is a recipe for participation behaviour. A star best depicts the recipe.

The 'luminating points of the star' are the ingredients or lists of substantive codes from the data. If one or more ingredient were missing it would appear that the level of participation behaviour changes. The problem is trying to describe or define the ingredients. Some are quite explicit and thus more readily detected such as the 'verbal invitation.' (Albeit very rare!) Others are very implicit or covert and difficult to establish. I am thinking more about the non-linguistic behaviour; the use of verbal overtures like the patient's name and the ward climate in general. I certainly need to start exploring these ideas but I question whether I will be able to verify these assumptions using interviews alone. Interaction dynamics are surely best explored in the natural field - I think I might be heading towards a period of observation.

Self-Reflective Memo

02.05.02: How on earth am I going discover whether a nurse's covert behaviour really does have an impact on participation behaviour? How will I know? I cannot quite believe that a nurse's non-linguistic behaviour can be so powerful.

Analytic Memo

15.08.02: Patient participation is certainly dependent on a platform of ingredients. I have noted this from not only the interview data but also now some of the observation data. Both verbal and non-linguistic behaviour appears to be so powerful when it comes to participation activities. The micro behaviour of nurses is vital. Patients have suggested particularly in the immediate post op period that a nurse will employ certain verbal tactics to impede participation. One such tactic appears to be the use of superficial or brief dialogue. By keeping interpersonal encounters brief patients feel they are being deliberately neglected or inhibited from participating in their care.

Many nurses I note employ these tactics although what has struck me is the difference between those patients who have what I would call a terminal or chronic illness and those that have an acute or potentially curable illness. Patients who have surgery for cancer or surgery that will influence future life are treated differently. Nurses caring for these individuals employ tactics or strategies that facilitate patient participation right from the time the patient returns from the operating theatre. They do not attempt to 'control' even in the acute period. They give time, their approach is not hurried, and they were unusually friendly and cheerful. They call the patient by their name and genuinely appear to keep the patient informed of all progress and even deterioration. Their dialogue is peppered with comments like 'remember we talked about this before your surgery and we decided it would be best if you tried right from the outset'. It is almost as if they had already decided on the role boundaries. I must explore whether they actually negotiate some sort of contract with the patient. However I must admit 'these patients do appear keener to take on an active role as well. This must surely help the situation. Why though is it so different with the more 'straight forward' surgical patient or even the emergency patient? I wonder why with 'these' patients nurses feel they should have total control or divine rule throughout the whole of the post-operative period. It appears that unless they relinquish some of their power or control or are at least willing to do so, patients remain as one quoted idle objects (A3: 8)

Many of the substantive codes that have emerged to date appear to resemble 'ingredients' and when compared and grouped on the basis of similarity form a '*recipe or category*' - possibly *Getting Ready*, *Preparing a Place or Establishing Readiness.* The list of substantive codes (see below) clearly have a common element. They all seem to be describing the antecedents of patient participation action or interaction. Of note is the fact that the preparation or readiness business is a two way process. It requires that both the patient and the nurse exhibit certain behaviours or conduct themselves in a certain manner. The demeanour of the nurse and patient is crucial. An element of reciprocity is also needed. If equilibrium or a certain balance of power is not achieved one of two things appears to happen - patients become passive recipients of care or in some cases (A5: 17) active unpopular patients. I must explore this further. Why does the level of participatory behaviour vary throughout the hospital stay? What happens if a patient is only in hospital for a few

days? Does a short hospital stay allow for patient participation? Similarly what about the 'emergency' admission. How can the emergency patient be prepared for the participatory role? I must ask patients how they prepare for the participatory role – How do nurses facilitate such practice? Do they employ specific strategies? I must observe the admission process to see if the preparation starts right from the moment of initial contact. What so called ingredients can be left out – what are the essential elements? Literature might help me expand on the theory here.

Substantive Codes for *Establishing Readiness*

Self-Assertion	Accepting of responsibility
Establishing trust/confidence	Surrendering power
Relinquishing divine rule	Mutual respect
Perceived environmental harmony	Reciprocal trust
Receiving information	Closing the distance
Feeling at ease/valued	Willingness to share

Self-reflective Memo

15.08.02: Self-awareness - Gosh. Until I undertook this observation I did not realise how extremely powerful a nurse's non-verbal behaviour was. I honestly thought that patients were being overly sensitive and emotive - had a touch of the post op blues when they said they were ignored. Somehow, I thought they were imaging this. How wrong I was. - Just sitting and watching the ward handover really made me realise how manipulative nurses can be or is it a defence against anxiety rather than manipulation or "bad nursing". This sounds awful I know but I have seen it with my own eyes. I have also heard it.

Appendix 15

Patient participation: a concept analysis

Jo Cahill DipN BSc (Hons) Nursing Cert Ed RGN RNT DPSN
Senior Lecturer, School of Health and Human Sciences (Adult Nursing South),
University of Hertfordshire, Hatfield, England

CAHILL J. (1996) *Journal of Advanced Nursing* **24**, 561–571

Patient participation: a concept analysis

The purpose of this paper is to present an in-depth analysis of the concept of patient participation. The analysis was undertaken using the method described by Walker and Avant. Patient participation is defined and the critical attributes are identified. Model, borderline and contrary cases illustrate what the concept is and is not. The meaning of patient participation is compared with patient partnership, patient collaboration and patient involvement, three related cases. The antecedents and consequences of patient participation are investigated to further refine the critical attributes. Empirical referents are illuminated. The value of concept analysis in relation to precise communication, critical thinking and the advancement of the knowledge base of nursing is discussed.

INTRODUCTION

Concept analysis is widely recognized to be important for the development of nursing theory and practice (Hardy 1974, Norris 1982, Kim 1983, Walker & Avant 1988, Chinn & Kramer 1991, Rodgers & Knafl 1993). It is a highly creative, rigorous and intuitive process that can generate and clarify the meaning of a single concept. Wilson (1966 p. ix) proposes that conceptual analysis 'gives framework and purposiveness to thinking that might otherwise meander indefinitely and purposelessly among the vast marshes of intellect and culture'. Rodgers (1991) asserts that concept analysis is a method that can be used to make clinical decisions, improve communication, plan nursing care, facilitate clinical research and answer clinical questions, thereby enhancing nursing practice.

This paper will present an in-depth analysis of the overused, ambiguous concept of patient participation in order to provide a knowledge base that will describe, explain and give meaning to the concept within the context of nursing practice. Walker & Avant's (1988) method of concept analysis will be used as a framework for the analysis. Although many of the steps of the analysis process occur simultaneously and do not always proceed in a strictly linear fashion, for ease of presentation each step will be considered separately. By way of introduction two well-

established concept analysis methodologies, used frequently in nursing, will be critically appraised. Owing to the constraints imposed on this essay, an exhaustive review of the existing thought regarding concept analysis will not be presented, as the mere volume of literature available on the subject makes such a task impossible.

The rationale for selecting the approach to concept analysis proposed by Wilson (1966) and popularized in nursing by Walker & Avant (1988) will be discussed. The basis for selecting and analysing the concept of patient participation will also be addressed. Critical attributes occurring in the case of patient participation will be identified. A written narrative account of some paradigm experience of the case will be presented to elucidate the meaning, relevance and applicability of the concept to nursing practice. A borderline and a contrary case will also be formulated to exemplify the concept. Instances of concepts that are related to patient participation will be considered. Antecedents to patient participation and consequences of patient participation will be identified and justified. Empirical referents that demonstrate occurrence of the concept will be determined.

The final discussion concludes that concept analysis is a valuable methodology that can be used to clarify the meaning and nature of concepts such as patient participation. Indeed it is a rigorous process that needs to be encouraged amongst nurse practitioners as it is essential for precise communication, critical thinking and the advancement of the knowledge base of nursing.

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Knowledge development

Currently the professional discipline of nursing is energetically interested in developing its knowledge base and conceptual foundation. Concept analysis is considered by many to be centrally important to the development of knowledge and the evolution of nursing either as a science or as a professional practice field (George 1985, Rodgers 1989, Kramer 1993). According to Walker & Avant (1988) concepts are the foundation for all advances in nursing science. Hardy (1974) reports that they are the basic building blocks of all theory. Indeed, the diversity of definitions of the term 'concept' parallels the variety of methodologies available for concept analysis. Kramer (1993) maintains that there are as many approaches to concept analysis as there are concepts. However, Rodgers & Knafl (1993) contend that the extent to which different models of concept analysis have been applied by nurse scholars to the domain of nursing is limited. They insist that the limited applicability of concept analysis methodologies to the sphere of nursing reduces the menu of possibilities for a productive concept analysis.

Undeniably, it would be naive to accept all methods as legitimate or necessarily effective. The selection of a concept analysis framework should be contingent upon a variety of factors. The philosophical underpinnings of the approach, the analytical goals, the analytical steps and the practicality of the technique for furthering understanding of areas of nursing practice all warrant consideration if the method to be used is to be effective and of benefit to nursing enquiry.

Two of the concept analysis methodologies that have been applied to nursing have been developed by Walker & Avant (1988) and Rodgers (1989). Walker & Avant (1988) offer an approach to concept analysis that builds on Wilson's (1966) seminal work. Wilson (1966) described an effective easy to use 11-step method for discovering features of a concept (see below).

Wilson's (1966) eleven-step concept analysis methodology:

1. Isolating questions of concept.
2. Right answers.
3. Model cases.
4. Contrary cases.
5. Related cases.
6. Borderline cases.
7. Invented cases.
8. Social context.
9. Underlying anxiety.
10. Practical results.
11. Results in language.

Although relatively simplistic and uncomplicated, Wilson's (1966) approach to concept analysis is diffuse.

Even Wilson acknowledged this, as he asserted that in some concept analyses there is not much point in investigating certain phases of the analysis technique. However, he proceeded to point out that until the neophyte analyst 'develops or acquires a sensitivity towards concepts which enables him or her to select the most relevant technique it is always worth applying the technique to see whether it is likely to lead anywhere' (Wilson 1966 p. 39).

Walker & Avant (1988) provide a systematic, structured methodology for concept analysis based on Wilson's work. However, their approach differs somewhat in the nature and ordering of the analytical process (see below).

Walker & Avant's (1988) eight-step concept analysis methodology:

1. Select a concept.
2. Aims of analysis.
3. Identify uses of the concept.
4. Determine defining attributes.
5. Develop model cases(s).
6. Construct additional cases.
7. Identify antecedents and consequences.
8. Define empirical referents.

Refining and clarifying

Walker & Avant's (1988) analytical goals are also distinct in that a wider range of intentions is identified. They report that the basic purpose of their analysis is 'to distinguish between the defining attributes of a concept and its irrelevant attributes'. They too advocate that their approach to concept analysis serves the purpose of refining ambiguous concepts, developing operational definitions and clarifying over-used vague concepts that are prevalent in nursing practice. Furthermore, it could be argued that their rigorous approach enables the analyst to capture the richness and complexity of the concept under scrutiny. The recommendation for case development indicates that Walker & Avant's (1988) approach is clearly based on the entity view of concepts which emphasizes that concepts are constant, specific things or entities within clear and rigid boundaries. Indeed, the logical positivism movement provides the foundation for their popular approach, as value is placed on reductionism in an attempt to isolate the apparent essence of a given concept. Kemp (1985) asserts that such precise scientific inquiry is crucial for the development of a body of valid nursing knowledge that guides practice.

However, the basic tenet of Walker & Avant's (1988) framework has fallen into disrepute among contemporary philosophers with the demise of positivism and its emphasis on the context-free nature of knowledge. Rodgers (1989) criticises Walker & Avant's methodology for supporting a reductionist approach and for presenting a rigid, static view of the world. However, it would appear that Walker

& Avant's approach to concept analysis is not as inflexible or inert as Rodgers suggests, as interestingly Walker & Avant (1988 p. 35) report that 'the end result of any analysis should always be tentative as what is true today is not true tomorrow'. Rodgers (1989) contends that the adoption of a dispositional approach would surmount some of the difficulties associated with the predominant entity view, particularly with regard to the sharply defined boundaries of concepts and the lack of attention to any context. Rodgers (1989) proceeds to offer an approach to concept analysis that is an inductive, descriptive means of inquiry which has the singular purpose of clarifying the current status of a concept (see below).

Rodgers' (1989) seven-step concept analysis methodology:

1. Identify and name the concept of interest.
2. Identify surrogate terms and relevant use of the concept.
3. Identify and select an appropriate realm for data collection.
4. Identify the attributes of the concept.
5. Identify the references, antecedents and consequences of the concept, if possible.
6. Identify concepts that are related by the concept of interest.
7. Identify a model case of the concept.

PATIENT PARTICIPATION

Despite the criticisms proposed by Rodgers, and the provision of an alternative approach, the method of concept analysis propounded by Walker & Avant has been employed to analyse the concept of patient participation. The methodology has been selected because of its structured, systematic approach. It is anticipated that such a rigorous approach will eliminate vagueness and capture the intricacy and subtlety of the concept. Indeed, even Rodgers (1989), a firm critique of Walker & Avant's (1988) methodology, acknowledges that the use of such a structured approach has the potential to make a considerable contribution to nursing knowledge. Furthermore, since the intellectual underpinnings and the analytical goals of Walker & Avant's approach to concept analysis fit the purpose of this analysis and the initially desired outcome, it would appear that their methodology is best suited for this analysis of the concept of patient participation.

Selection of concept

The concept of patient participation has become a widely accepted tenet in contemporary nursing practice. It is now part of the vocabulary of professional nurses and has been heralded as a means of enhancing decision making and human dignity, and enriching quality of life (Clayton 1988). McEwen *et al.* (1983) assert that patient participation is widely recognized as a good thing as it results in

increased patient responsibility and a commitment to health and health-promoting behaviours. According to Meyer (1993) patient participation is a major thread of health promotion. Brooking (1986) and Batehup (1987) report that participation enables patients and their relatives to manage health problems more effectively.

Pressure for the promotion of patient participation has come from the belief that patients have a right and a responsibility to be involved in their health care (World Health Organization 1978, Audit Commission 1993). Its popularity is also associated with increased dissatisfaction with current styles of representative democracy, centralized bureaucracy and paternalistic professionalism (McEwen *et al.* 1983). Within the National Health Service, patient participation has been promulgated by government initiatives, most recently and notably *Working for Patients* (Department of Health 1989) and the *Patients Charter* (HMSO 1995). Indeed, nurses are now being actively encouraged to promote patient participation as a rule rather than as an exception. However, despite its current popularity the concept is elusive. It has not been adequately articulated or clarified and remains one of the least understood ideas used by nurses in clinical practice (Clayton 1988). The eclectic nature of the concept has also resulted in practitioners having only a cursory understanding of what patient participation is. Furthermore, it is clear that a diversity of opinions exists in the way both nurses and patients view the concept.

There is no clear consensus on what patient participation entails. Indeed, the lack of clarity associated with the concept has perhaps resulted in patient participation becoming a nursing rhetoric or even a cliché. Woods & Metcalfe (1980) report that the misconceptions about the meaning of patient participation have contributed to many negative reactions by health care professionals and patients alike. Clayton (1988) declares that the different orientations towards patient participation have resulted in role confusion and role conflict both for the nurse and patient, which in turn has contributed to inadequate nurse–patient communication and general nurse–patient dissatisfaction. Richardson (1983) maintains that the conflicting claims which have been asserted both in favour of and against patient participation in health care have arisen from an inadequate understanding of the concept. Indeed, the prevalence and over-use of the term, the ambiguity, the failure to appreciate the nature of the concept, and the lack of consensus regarding the meaning of patient participation, have been catalysts for this analysis. Certainly, it would appear that patient participation is a modern day icon in need of closer examination.

Aims of analysis

Since the concept of patient participation is elusive and under-developed (Clayton 1988) the overall intention of

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the analysis is to identify and explore the attributes of the concept, in order to clarify and elucidate the meaning and nature of the concept within the context of nursing practice. The analysis seeks to make the conceptual meaning of patient participation as explicit as possible in order to promote an understanding of what the parameters of patient participation are. It also aims to provide a single vocabulary for discussing the concept. Perhaps more importantly the establishment of the meaning of patient participation will provide a template for its challenge and critique within the context of nursing practice. Certainly, the concept has already aroused considerable passion among its advocates and critics. However, within the literature there is no consensus amongst nurses about what patient participation is, what form it should take, how far it should extend, and how it should be implemented by all interested parties.

This analysis will attempt to clarify and rectify the situation. It also intends to illuminate the role of the nurse in relation to patient participation so that any potential role conflict between the nurse and the patient can be curtailed. Finally, the analysis aims to highlight the numerous and complex skills, experience and knowledge that practitioners require to practice in this way. As McEwen et al. (1983) point out, if nurses are to extend their traditional role and become involved in promoting patient participation, they will have to clarify their own position with regard to the various nursing duties and functions they are prepared to perform. By offering some clarity to this somewhat complex concept it is hoped that nurse–patient communication and satisfaction may improve.

USES OF THE CONCEPT

Walker & Avant (1988) assert that this stage involves examination of the plethora of possible uses and instances of the concept. Although no explicit guidelines for sampling the literature are provided, Walker & Avant emphasize that an extensive literature review will yield rich meaning.

The *Oxford English Dictionary* (1989) states that the word participation is derived from the Latin *participare* which means to take part in (*pars* = part + *capere* = to take). According to Sinclair (1993) participation relates to the art of participating which implies that one 'becomes actively involved in or shares in the nature of something with others'. Stewart (1986) declares that participation involves a particular person or group of people actively taking part in a particular activity, action or system with others. Holloway (1993) suggests that participation is the involvement of people in decisions, giving them some feeling of control or responsibility. Viewing participation from a human relations perspective, Hill (1971) asserts that it is 'the involvement of subordinates in a task'. Maxwell & Deaver (1984) report that participation can imply involve-

ment in the decision-making process, sharing or undertaking activities with others, or heightened individual or communal responses and power. Brownlea (1987) contends that participation means 'getting involved or being allowed to become involved in the decision making process or the delivery of a service or the evaluation of a service or even simply to become one of a number of people consulted on an issue or matter'.

Participation within the context of professional nursing practice has most frequently been applied to the patients' role in the delivery of nursing care. Owing to increased consumer knowledge, an increased awareness of consumer rights, a general move towards all forms of self-help, accelerated health care costs and the changing role of nursing and health care professionals, patient participation has become a popular concept in nursing practice. Brearley (1990) and Biley (1989) affirm that it is commonplace today for patients to participate in many aspects of care. According to McEwen et al. (1983) patient participation in health care 'relates to the activities performed by an individual on behalf of others in the maintenance and promotion of health, the prevention of disease, the detection, treatment and care of illness and the restoration of health, or, if recovery is not possible, adaptation to continuing disability'. From this definition it would appear that patient participation occurs in many contexts. Furthermore, it is evident that the patient is no longer the passive client as suggested by Parsons (1957) but more the active consumer.

Saunders (1995) confirms that patient participation is an active process, as he advocates that it involves patients performing clinical or daily living skills, or partaking in the decision-making process from the time of admission until discharge. The value of patient participation as a way of enhancing decision making has been widely recognized (World Health Organization 1978, Council of Europe 1982, Audit Commission 1993). Clayton (1988) reports that giving patients improved opportunity to take part in the decision-making process is customary, as it is considered beneficial. Clayton reports that it improves self-esteem and mental health, reduces alienation, encourages a self-responsible attitude towards health and generally enriches quality of life. Patient participation has also been seen to focus on other aspects of care, such as patient compliance with treatment plans (Craig 1985), self-medication (Webb et al. 1990) patient education (Wilson-Barnet & Osborne 1983) and sharing information and taking part in physical care (Macleod Clark & Latter 1990). As Ashworth et al. (1992) maintain, it does not simply entail involving patients in care plans.

The degree of patient participation does, however, depend on a number of factors. Szasz & Hollender (1956) allege that patient participation is determined by the severity and type of illness the patient is experiencing. Biley (1989) reports that it is also influenced by the organiz-

ational structure, the amount of knowledge the patient has and the patient's desire to participate in care. Indeed, a patient's desire to participate is crucial. Some patients do not wish to participate in care and have only been coerced as reluctant collaborators (Waterworth & Luker 1990). According to Muetzel (1988), some patients derive security from passivity and 'the nurse knows best' stance.

Further examination of the nursing literature reveals that some nurse theorists have attempted to describe patient participation as an ethical ideal that can be realized within the nurse–patient relationship. Avis (1994) asserts that it is widely recognized as a principle of ethical care. Peplau (1988) sees patient participation as a psychosocial skill that is facilitated by a nurse who accepts and respects the patient as a person who can make decisions. Ashworth *et al.* (1992) declare that proper patient participation entails awareness of, and empathy for, the patient's personal investments. According to Pearson (1988), patient participation involves the adoption of a non-directive style, whereby nurses attempt to give patients greater choice, to promote activity in care to a degree which accords with the individual's negotiated needs. However, some professionals may have their own personal agenda when promoting patient participation. Clayton (1988) asserts that patient participation is frequently used to expropriate the power of patients and extend the already strong position of existing power holders so that only an illusion of influence, or frustration, is experienced. Brearley (1990) maintains that some professionals even see patient participation as a euphemism for cost cutting. Indeed, both views are summed up by a French students' poster of the 1960s which in translation reads: I participate, you participate, he participates, she participates, we participate, you participate, they profit (Clayton 1988).

Determine defining attributes

Defining attributes are those characteristics of the concept, which appear over and over again when the concept is defined or described (Walker & Avant 1988). The defining attributes, without which the concept cannot be said to occur, have been identified.

Defining attributes of the concept of patient participation within the context of nursing practice:

1. A relationship must exist.
2. There must be a narrowing of the appropriate information, knowledge and/or competence gap between the nurse and patient using suitable modalities in different contexts.
3. There must be a surrendering of a degree of power or control by the nurse.
4. There must be engagement in selective intellectual

and/or physical activities during some of the phases of the health care process.
5. There must be a positive benefit associated with the intellectual and/or physical activity.

The most distinctive attribute of patient participation that emerged from the literature is that 'there is a relationship with another'. Indeed, the definitions and uses of the concept appear to demand that a relationship exist as participation entails 'involvement, sharing or interaction with others' (Hill 1971, McEwen *et al.* 1983, Brownlea 1987, Sinclair 1993).

The second attribute originates from the fact that the uses of the concept demand a degree of knowledge, information or competence. Since the nurse in the relationship possesses an esoteric body of knowledge derived from years of training and education to which the patient is not privy, it would appear that for the concept to occur 'the appropriate information, knowledge and/or competence gap between the nurse and patient must be *narrowed* using suitable modalities in difference contexts'. Indeed if patient participation is to be seen as a means of enriching the individual and enhancing the prospects of decisions and outcomes, information and knowledge needs to be at the disposal of the potential and actual participant. Biley (1992) maintains that lack of knowledge can leave the patient totally dependent on the nurse or in a situation where all they achieve is an illusion of participation. Brownlea (1987) reports that without appropriate information and knowledge, patient participation is simply tokenism, an idea mirrored by Clayton (1988).

The third attribute that transpired from the literature is associated with the idea that patient participation is dynamic and tidal in nature. Patient participation appears to wax and wane in synchrony with a number of factors such as severity of illness (Szasz & Hollender 1956, Biley 1992) and a desire to participate in care (Waterworth & Luker 1990). Furthermore, it appears to be a highly individualized process as it manifests in a diversity of ways ranging from involvement in decision making (Manthey 1980, Mittler & McConachie 1983, Clayton 1988, Biley 1989) to the performing of clinical skills (Jacobs 1980, Saunders 1995). Indeed, it is the fluid nature of the concept that contributes to the third attribute being that there is an 'engagement on the part of the patient in *selective* intellectual and/or physical activities during *some* of the phases of the health care process'.

The fourth attribute that emerges from the literature is that 'a *degree* of power or control must be surrendered by the nurse'. Indeed, it would appear that when patient participation occurs, activities that were normally thought to be within the sphere of nursing are taken on by the patient. McEwen *et al.* (1983) report that this submission or surrender of control is otherwise called deprofessionalization. However, Berg (1983) points out that all that is occurring

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is that the nurse's role of empowerer and facilitator is being illuminated.

The fifth and final attribute that emanates from the literature is that there must be a 'positive benefit associated with the intellectual and/or physical activity'. This characteristic is illuminated repeatedly as the actual act of participation appears to be undertaken to achieve mainly positive outcomes such as: patient satisfaction (England & Evans 1992); a rewarding relationship (Glenister 1994); improved nurse–patient communication (Fry & Hassler 1986); improved patient adjustment (Wilson-Barnett & Fordham 1982); increased job satisfaction; and improved recruitment and retention of nurses (Lott *et al.* 1992).

DEVELOPMENT OF A MODEL CASE

Once the critical attributes have been defined, Walker & Avant (1988) suggest progress to the formulation of a model case. A model case serves to provide evidence of what the concept definitely is. It should include all the critical attributes. The model case shown below received careful consideration and testing on colleagues and patients, as suggested by Walker & Avant (1988) in order to refine the case to its purest form.

Model case of the concept of patient participation:

Nathan Thomas is a patient on a medical ward. He has recently been diagnosed as having diabetes mellitus. He has an understanding of his condition. However, due to lack of knowledge and competence, he is unable to administer his own insulin. In preparation for Nathan's discharge home his primary nurse aims to ensure he is competent in the administering of his own insulin injection.

Nathan has never administered his own insulin nor has he ever expressed an interest in doing so. Up until now the nurse has performed the task, an arrangement Nathan has been happy with. However, Nathan is beginning to realise that unless he learns how to undertake this procedure he will not be able to go home. He makes a decision to engage actively in the management of his diabetes. Nathan's primary nurse, on realising this, spends some time educating Nathan about his care. She explains how to obtain and store his insulin and necessary equipment, how to prepare and administer the insulin and how to dispose of the equipment on completion of the procedure. She also provides him with literature to read following demonstrating the technique. On reading, seeing and understanding the principles of the procedure, Nathan requests to practice the skill on an orange. This he does competently on numerous occasions and consequently asks to give his first insulin injection to himself. He does this and is discharged home within two days.

All five attributes are present in the case above. Firstly a relationship exists, as two people (the primary nurse and Nathan) are present and there is joint involvement in an activity. The appropriate information, knowledge and competence gap between the nurse and patient has been narrowed using suitable modalities (discussion, literature, demonstration and experiential technique). Engagement on the part of the patient in both selective intellectual and physical activities during parts of the health care process is evident (decision making and insulin administration). There is also evidence that the nurse has surrendered some power and control (the task of insulin administration and the shaving of knowledge). Finally, benefits have been accrued (the discharge home, self-care and nurse/patient satisfaction).

CONSTRUCTION OF ADDITIONAL CASES

The next stage in the analysis is the construction of a borderline, a contrary and a related case. Like a model case, these cases are developed to promote further understanding of the concept being discussed. In accordance with Wilson's (1966) suggestion, an invented case has not been used as sufficient instances are provided to clarify the concept. Similarly an illegitimate case has not been constructed as Walker & Avant (1988) assert that such a case is only necessary when a meaning of the term is completely different from all the others.

Borderline case

This is an instance that contains only some of the critical attributes of the concept of patient participation.

Borderline case of the concept of patient participation:

John has been admitted to the ward for surgery the next day. His named nurse spent time explaining all the pre-operative preparation that he would require. In particular she emphasized the need for a share of the operation site. The nurse told John that she would have to perform the shave as any slight abrasion could colonise bacteria and consequently increase the risk of a wound infection developing. Furthermore, she explained that it was customary for a nurse to shave a patient as only the nurse knows the surgeon's preferences with regard to preoperative shaving. John expressed reservations about this, saying he was a very shy person and would prefer to shave himself. The nurse declined his request and performed the shave.

This case demonstrates some of the attributes of patient participation. A relationship exists between John and his named nurse. The information and knowledge gap between the nurse and the patient has been narrowed using suitable modalities (explanation and discussion). There is evidence of engagement on the part of the patient in selective intellectual activity during part of the health care process (expressed reservation). However, there is no evidence that the nurse has surrendered any power or control or that John has accrued benefits, except perhaps that his risk of developing a wound infection might be reduced.

Contrary case

Walker & Avant (1988 p. 41) allege that this case illustrates 'what the concept is not'. An example which clearly does not demonstrate the concept of patient participation is described below. In this case a relationship does not exist. The knowledge and information gap between the nurse and the patient has not been narrowed as no dialogue about the forthcoming events has taken place. There is no evidence of engagement on the part of the patient in either intellectual or physical activity. Consequently the nurse has not surrendered any power or control. Finally, the patient has not accrued any benefit.

A contrary case of patient participation

An elderly patient in a very anxious state of mind was admitted to hospital for the first time for a cholecystectomy. She arrived on the ward and was shown to her bed by the nurse who was to be responsible for her care. No introductions were carried out. There was little interaction. The admitting nurse left the patient at the bedside and returned to the nursing station to complete the necessary assessment documentation. She used the patient's notes to do this and then formulated three pre-operative care plans for the patient without consulting her.

Related cases

Walker & Avant (1988) assert that a related case is an instance of a concept that is related to the concept being studied but which, on closer examination, is found to be different. In considering the concept of patient participation it is apparent that there are several concepts that are similar to, but not the same as, patient participation. The concepts of patient partnership, patient involvement and patient collaboration are often used interchangeably with patient participation. However, there are distinct differences. Examination of the literature reveals that a hierarchical relationship exists between the four concepts. This can be depicted in diagrammatic format in a manner

Figure 1 The hierarchial relationship between the concepts.

similar to that of Maslow's (1970) hierarchy of needs (see Figure 1).

Patient involvement and patient collaboration form the base of the pyramid and are the precursors to patient participation, which in turn is the precursor to patient partnership. To achieve the ideal of patient participation the lower 'needs', or in this case 'the concepts', need to be achieved first. The concept of patient partnership, like patient participation, is deemed to be a fundamental aspect of nursing care. It is regarded as an ideal, a goal towards which all practitioners should be working. However unlike patient participation, it is a goal which will not necessarily be achieved in practice (Mittler & McConachie 1983, Teasdale 1987). The concept is related to patient participation in that it also implies a reciprocal sharing or a closeness between the patient and the nurse. However, it is apparent from the dictionary definitions (*Chambers Dictionary* 1993), The Partnership Act 1890 (Barrister at Law 1971) and the nursing literature (Teasdale 1987, Robbins 1991, Stower 1992) that patient partnership, unlike patient participation, demands a working association between two people in a joint venture which is based upon a contract which may be verbal or written and which may have risks and benefits.

The presence of a contract requires that the relationship be obligatory, that there is commitment of all partners and that there is involvement throughout the processes of assessment, goal setting, planning, implementation and evaluation. This is not the case in patient participation as involvement only occurs in some of the phases of the health care process. Furthermore, as there is involvement throughout all the health care process when a patient partnership exists, full sharing of knowledge, skill and experience is necessitated to close, rather than to narrow, the information–knowledge gap. Finally, since patient partnership is based on equality within a relationship (Quill 1983) the nurse must abnegate all power and control as opposed to only a degree of it. Froland *et al.* (1981) confirm this by stating that within a partnership each partner needs to have equal control.

Patient involvement on the other hand is perhaps closer to the concept of patient participation. Indeed, within some of the American literature (Greenfield *et al.* 1985, Weiss 1986) the term 'patient involvement' appears to be used synonymously with 'patient participation'. However, close examination of a broader range of literature reveals distinguishing characteristics. Firstly, patient involvement is considered to be a one-way as opposed to a two-way process as the patient's voice is mostly ignored (Mittler & McConachie 1983). Secondly, a narrowing of the knowledge or information gap is not required for patient involvement as activities are undertaken in the form of delegated tasks. Furthermore, the tasks are of a very basic nature (Nethercott 1993) and do not extend to complex intellectual activities such as decision making. Jacobs (1980)

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endorses this point by asserting that patient involvement only 'involves eliciting the patients' perceptions of the situation'. Indeed, Brody (1980) reports that patient involvement is simply a precursor to patient participation.

Patient collaboration is one further related case. Like patient participation it is an important concept for nursing. It is similar to that of patient participation in that its essence is also sought after as a means of improving working relationships and patient outcomes. However, it does have definite differences. Whereas patient participation focuses on either physical or intellectual activities or both, collaboration only focuses on intellectual effort. Typically it is described as a process which stresses joint involvement in intellectual activities (American Heritage Dictionary 1983). Indeed, McEwen *et al.* (1983) report that it is a 'mental process' in which individuals are jointly involved for the purpose of decision making. This suggests that, like patient involvement, patient collaboration could be seen as a precursor to patient participation. Finally, the fact that collaboration has been described as a co-operative endeavour (Henneman *et al.* 1995) further distinguishes it from patient participation, as the latter does not necessarily result in co-operation. Indeed, Ashworth *et al.* (1992) warn that patient participation can result in disagreements about decision making and controversial suggestions. Suffice it to say that patient participation need not be a matter of perpetual consensus.

IDENTIFICATION OF ANTECEDENTS AND CONSEQUENCES

According to Walker & Avant (1988), antecedents are those events or incidents that must occur prior to the occurrence of the concept, and consequences are those events or incidents that occur as a result of the occurrence of the concept. The antecedents and consequences of the concept of patient participation within the context of nursing practice are identified in Table 1.

Justification for antecedents

Since Beyer & Marshall (1981) have identified that egalitarian communication has elements of respect, confidence, trust, open communication and freedom from threat, it would appear that an egalitarian communication system is a fundamental antecedent to patient participation. Muetzel (1988) reports that if patient participation is to occur, the nurse must provide an environment that is emotionally secure. According to Ashworth *et al.* (1992) the essence of patient participation requires trust and security so that one's identification is not under threat. Jewell (1994) acknowledges this requisite as she maintains that patient participation requires that the patient be seen as a worthy contributor.

Table 1 Antecedents and consequences of the concept of patient participation within the context of nursing practice

Antecedents

An egalitarian communication system
Respect for individuality
An element of reciprocity in the nurse–patient relationship
Competence on part of the nurse to manage with or without the security afforded by hierarchy
Recognition that a positive benefit will accrue
A desire on the part of the nurse to relinquish a degree of power, control and authority
A desire on the part of the patient to assume a degree of power, control and responsibility
Access for patients to an appropriate and comprehensible broad scope information and knowledge
Understanding on the part of the patient of appropriate information and knowledge

Consequences

A sense of contribution by patient
Improved nurse–patient communication and satisfaction
Better patient adjustment
Decreased number of complaints
Feedback about services provided
Patient empowerment
Enhanced decision making
Enriched quality of life
Increased understanding and better management of care at home
Diminished feeling of powerlessness, apathy and dependency
Loss of clinical independence on part of nurse
Emotional stress for both nurse and patient

Brownlea (1987) asserts that respect for individuality is also an essential antecedent as a patient may not want to participate in all aspects of care. Indeed, the tidal nature of a patient's participatory behaviour leads to a further antecedent being that the nurse requires competence to manage with or without the security afforded by hierarchy. Furthermore, the nurse must not only be flexible in his or her approach but will also need to have a desire to relinquish some power, control and authority and to act as an empowerer and facilitator of patients. If this desire is lacking, role conflict may result, with the consequence that the patient's voice will be ignored. Patient participation also necessitates that there be a desire on the part of the patient to assume a degree of power, control and authority. Indeed Bayntun-Lees (1992) asserts that if individual willingness on the part of the patient and an element of reciprocity in the nurse–patient relationship is not apparent, patient participation will not occur.

The final and perhaps most significant antecedent to patient participation within the context of nursing practice is the ability of the patient to access a broad scope of appropriate information and knowledge. Brownlea (1987) and

Biley (1992) both declare that a key requirement for patient participation is access to the appropriate information and knowledge. Wilcox (1995) contends that opportunities for participation will only occur if those involved have a common understanding and share a common language. Consequently, information and knowledge need also to be comprehensible. Busby & Gilchrist (1992), Feeley (1973) and Rintala *et al.* (1986) all found that where patients experienced difficulties with understanding information presented to them, patient participation did not occur.

Justification for consequences

From a nursing perspective, the concept of patient participation is widely recognized as a good thing (Brearley 1990). However, few empirical studies have been undertaken to test this hypothesis. Similarly there is a dearth of empirical work examining patients' perspectives of the outcomes of participation in nursing care. The literature available tends to focus on the consequences of patient participation within the context of medical care (Tuckett *et al.* 1982, Greenfield *et al.* 1985). Furthermore, it often only reflects personal opinion and anecdotal experience. Hence, the consequences of patient participation identified in Table 1 are primarily speculative.

According to Richardson (1983) the consequences of patient participation are highly unpredictable as one cannot assume particular results on the basis of the intentions of the participants. Pritchard (1986) identifies a range of consequences that may materialize as a result of the occurrence of the concept. He cites a sense of contribution, a feeling of some power or place in the system, improved communication and job satisfaction and a decreased number of complaints as examples. Clayton (1988) asserts that many of the consequences of patient participation can be subsumed into three broad headings: enhanced decision making, an enriched quality of life, and expropriation of patient power. Fry & Hassler (1986) report that as a result of the occurrence of patient participation the nurse–patient relationship and communication improve, patient dependency and apathy diminish, a patient's feeling of powerlessness lessens, and feedback for evaluating service to patients is provided. Furthermore, King (1990) maintains that the narrowing of the competence gap between the nurse and the patient improves a patient's understanding of his or her illness and consequently the patient is better able to manage care at home.

In summary, it would certainly appear that the consequences of patient participation are couched in arguments from a positive school of thought. Indeed, this may be due to the fact that an attribute of the concept is that a positive benefit must accrue. However, as Richardson (1983) points out, the outcomes of patient participation are unpredictable, therefore less favourable consequences such as loss

of clinical independence and emotional trauma may arise (Berg 1983, Biggs 1993).

EMPIRICAL REFERENTS

The final step in the analysis is to determine the empirical referents for the critical attributes. According to Walker & Avant (1988) empirical referents are used to 'diagnose' the existence of the concept. Owing to the multifactorial nature and complexity of patient participation within the context of nursing practice, empirical referents are difficult to define. Testing the extent to which patient participation occurs within the context of nursing practice would be best done by systematic observation of a sample of interactions between the patient and the nurse. Beside handovers offer an excellent opportunity to assess for the presence of patient participation. An observer could note whether an attempt was made to narrow the information and knowledge gap between the patient and the nurse and whether the nurse had abnegated power and control, and whether the patient had actively participated in the selected activity, and whether benefit had been achieved as a result of the activity. However, this would be a subjective measure of the presence of the concept as it would depend on the evaluator's perceptions and, as such, would not be the most reliable measure.

A more objective measure might be to examine the nursing records as they should clearly provide details and indicate the extent to which the concept occurred. However, as findings from the National Health Service Executive (1991) and Walker & Selmanoff (1974) emphasized that crucial information is often omitted from nursing records, or is even ambiguous, incomplete or contradictory, the use of nursing records as a means of measuring the existence of the concept might also be unreliable. Empirical referents relating to the use of patient participation might therefore need to include both the use of nursing records or observation schedules and data extracted directly from patients and nurses. On the contrary, a highly reliable patient participation practice scale, similar to that used by Tuckett *et al.* (1982), to measure the existence of patient participation in medical care might be a useful tool for measuring the existence of the concept within the context of nursing practice.

CONCLUSIONS

In conclusion, through careful analysis, the attributes of the concept of patient participation within the context of nursing have been identified and explored. This analysis has, it is felt, taken the first steps on the road to clarifying and elucidating the nature of the concept and the nurse's role with respect to patient participation. Furthermore, it is felt that a template for the challenge and critique of the concept within nursing practice has been provided,

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Indeed, patient participation appears to be a complex and sophisticated concept which is of extreme importance to nursing. However, it is acknowledged that the meaning and nature of the concept that has emerged from this analysis is only representative of the present state of the art. When new knowledge and experience becomes available the concept analysis will need to be developed further. As Rodgers & Knafl (1993) point out, a concept analysis is a never-ending process.

With regard to the concept analysis methodology employed, Walker & Avant's (1988) tool provided a useful guide for the systematic analysis of the concept. Indeed, it successfully accommodated the purpose of the analysis. However, for the neophyte analyst, the tool lacks distinct guidelines for carrying out certain stages of the analysis such as the literature review. Furthermore, it lacks an explicit validation phase to confirm the presence of the proposed defining attributes of the concept.

Finally, it would appear that concept analysis is extremely useful as a tool for clarifying potential concepts of interest. It has the potential to provide a solid basis for assisting critical thought and presenting arguments regarding the use or significance of a concept in nursing practice. Certainly, it is a process that should be encouraged to advance nursing knowledge, to guide nursing practice, and to facilitate clinical research.

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Appendix 16

Patient's perceptions of bedside handovers

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Summary

• The bedside handover is a universal phenomenon in nearly every type of care setting. It has become the chief arena for the intershift handover in contemporary nursing practice. Published literature investigating patients' viewpoints on the location of the bedside handover is sparse.

• The overall aim of this study is to describe and provide an analysis of patients' perceptions of the bedside handover.

• A grounded theory approach to data collection and data analysis was employed to capture surgical patients' views about the bedside handover.

• The analysis tentatively suggests the existence of three categories that describe the patients' perceptions of the bedside handover. 'Maintaining a Professional Distance', 'Establishing Professional Sharing' and 'Maintaining Patient Safety.'

Keywords: bedside handover, grounded theory, patients' perceptions.

Introduction

Thompson (1986) asserts that effective communication is perhaps the most important attribute of successful nursing. Certainly this is true with respect to the intershift handover, which is one of the most traditional and dominant forms of communication employed within the sphere of clinical practice. Johns (1989) perceives it to be the panacea for effective nurse and patient communication. The current emphasis on individualized patient care and lay participation in care has popularized the practice of the bedside handover. Indeed, it has become the central territory for the intershift report. However, despite its recognition, published literature pertaining to patients' perceptions of the bedside handover is sparse. Little empirical evidence exists that is based on patients' viewpoints of the bedside handover. Most of the literature pertaining to patients' per-

spective tends to be presented from the nurses' or doctors' viewpoint.

The professional perspective

The bedside handover is an integral part of the efficient running of wards, yet literature is deficient from an empirical point of view. Watkins' (1993) anecdotal report, like others on the subject of bedside handovers (Burns-Stewart, 1981 and Johns, 1989), fails to address salient issues. Firstly, there is no mention that the bedside handover has resulted in improved patient outcomes. Secondly, little evidence is provided to suggest that the bedside handover provides a report that enables the oncoming staff to provide safe holistic care.

MacMahon (1990a) states that the purpose of the bedside handover is to facilitate patient-centred care. He highlights that the pitfall of acting as though disease has an existence independent of the patient can be avoided. Indeed the

bedside handover lends itself admirably to a patient–centred approach as it provides a forum for the sharing of information between patient and nurse (Waight, 1992; Matthews, 1986). However, there is concern that in some cases the bedside handover is viewed as mere tokenism. This point is illustrated by MacMahon (1990a), who claims that some nurses just tend to stand at the end of the bed or in the doorway, with the patient feeling excluded.

Physical aspects of care rather than psychological aspects appear to dominate most nurse-patient communication during bedside handovers (Seers, 1986). Existing literature highlights that the bedside handover is frequently used to comment solely on activities prescribed by physicians. An examination of the thematic content of the bedside handover by Ross (1974) found 87.4% of the report consisted of physical care and tasks. Characteristics of patients including personality and emotional responses made up 4.8% of the report. Feeley (1973) found that 68% of the items reported were directly related to medical prescriptions. Nursing care comprised 37% of the content, although half of this category included biographical data.

Obsession with physical aspects of care during bedside handovers appears to resemble and may be seen to be modelled on the medical practice of ward rounds, reinforcing the hierarchy of power relations within the multidisciplinary team. In an analysis of verbal behaviour during a doctor's ward round Rintala et al. (1986) found a strong emphasis on physical aspects of care (65%) to the neglect of needs in the psychosocial area. Furthermore, patients contributed to only about 9% of the discussion. The predominant emphasis on physical aspects of care is perhaps due to the traditional biomedical model of health care (Whale, 1993). From a nursing perspective it might be that many nurses still see medical domination of nursing as the natural order of things. On the other hand, it may be that nurses are still in the process of adjusting to and developing care based on a nursing model rather than on a traditional medical one.

Neglect of the psychosocial domain of care may be a defensive strategy used to alleviate stress and anxiety (Walker & Selmanoff, 1974). Linfors & Neelan (1980) claim that emotional issues during bedside handovers are avoided for fear of being drawn on to intellectual thin ice. Such deliberate verbal blocking behaviours may even be employed by nurses to prevent patients unleashing strong emotions that the nurse cannot handle (Macquire, 1985). Neglect of psychosocial issues during bedside handovers may, however, be attributed to the ward management structure. In a laterally managed ward, such as one that employed primary nursing, MacMahon (1990b) found that a greater interest in nursing problems and patients as mul-

tifaceted biopsychosocial beings was apparent. On hierarchical wards nursing problems and subjective issues were rarely discussed. Instead they seemed to be ignored. This could be attributed to the increased accountability of primary nurses; alternatively, it may reflect the type of nurse who is currently attracted and appointed to wards implementing that structure. Jacobs (1980) believes that primary nurses have the ability to offer a truly patient-centred service as they have a genuine interest and skill in interpersonal relationships.

The dangerous consequences of careless public talk are a further thorny issue associated with the bedside handover. Since the tort of negligence and defamation allows a patient to sue if a breach of confidence results in injury, fear of malpractice or of litigation has been expressed by surprisingly few members of the nursing profession who practise handovers at the bedside. Indeed breaching the rules of confidentiality (UKCC 1987) is one of the most significant factors to consider when practising bedside handovers (Ward, 1988, Johns, 1989). Even though patients are often overheard discussing their ailments this type of discussion is not acceptable for nurses. Sensitivity to the disturbance of confidence is vital.

The nature of the bedside handover, apart from being guided by the rules of confidentiality, is also controlled by the limited time available. The bedside handover has been found to be time consuming when compared with office reporting initially and even after the practice was established (Pepper, 1978). Bedside handovers rarely fit into the allotted time as serendipitous and unanticipated observations are made (Burns-Stewart, 1981). Parker et al. (1992) observed that the bedside handover was inefficient in terms of time as the report often consisted of a simple recitation of facts, with little interpretation being made. Inefficient use of time during bedside handovers has also been reported by Mathieson (1984). He noted that the handover was often just a repeat of details that the next shift could obtain directly from patient documentation. Although such recitation and repetition during handovers can be criticized in terms of time, in an era of increased concern with accountability and litigation it may be seen as a theoretical safety net. However, inconsistencies in timing of bedside handovers do exist. Watkins (1993) reported that the bedside handover is efficient in terms of time as less time is spent sitting in the office chatting.

Beyond its official function in the communication of information for safe and holistic care Parker et al. (1992), in a pilot study of 12 handovers, observed that bedside handovers offered a forum in which nurses could gain mutual support and group solidarity. However, use of observation to collect data may have resulted in biased responses since

the extent to which professionals altered their behaviour as a result of an observer's presence could not be determined as the number of bedside handovers observed was limited. In contrast Pepper (1978) reports that within the current climate of holistic care the presence of patients during handovers has curtailed nurses' opportunity for personal expression, debriefing or abreaction of personal distress. However, Pepper's viewpoint has not been subject to empirical study.

Patients' perspectives

Current broad societal changes, such as the concept of consumerism, have been instrumental in directing attention to the patients' involvement in care. Waight (1992) affirms that the predominant reason for the translocation of handovers from office to bedside was to enable patients to become involved in their care.

Inherent in the philosophy of individualized patient care is the idea that each individual, when able, should be involved in their care (James & Biley, 1989). However, the picture from patients' perspectives differs markedly. It has been suggested that patients may not wish to participate in their care (Candy, 1991; Biley, 1992) and have only been coerced as reluctant collaborators (Waterworth & Luker, 1992). The severity of the patients' illness will, however, determine the extent to which they participate in care (Szasz & Hollender, 1976). Brearley (1990, p. 36) states that 'patient passivity is regarded as normal in very acute illness'.

Within the field of medicine, studies that examine patients' perspectives on medical ward rounds have been undertaken. They reveal mostly negative views about breaches in confidentiality (Payson & Barchas, 1975), a lack of interactive skills amongst doctors (Engel, 1971), intimidation and an undervaluation of information given (Sisson, 1976; Osler, 1988). In a study of 100 patients, Romano (1941) found disclosure of personal detail at the bedside led to resentment and humiliation in 33% of the patients. Social data, especially if they concerned prestige, also provoked resentment. However, 46% of patients in Romano's study received considerable satisfaction from hearing their care being discussed at the bedside. Romano reported that occasionally patients would take pride in correcting staff. On appraising the conduct of practitioners during ward rounds Steele & Morton (1978) revealed that the bedside ward round was a potent cause of embarrassment, anxiety and distress. Furthermore, bedside discussions often lead to loss of patient confidence in staff, refusal of treatment and self-discharge. However, Steele and Morton fail to rigorously define and explain concepts such as anxiety and

distress. An assumption is made that the reader shares with the researcher the meaning of these apparently objective phenomena. Particular elements of ward rounds that precipitated these behaviours were also not addressed. Boyle (1980) and Reynolds (1978) shed light on the situation by reporting that medical terminology used during ward rounds is often a common cause of alarm and despondency as patients worry and are embarrassed by their poor medical knowledge.

Research design

The overall aim of the study discussed in this article was to capture, describe and provide an analysis of patients' perceptions of the bedside handover. An attempt was made to capture and describe the bedside handover from the patients' frames of reference. The study also aimed to illuminate which elements patients express either satisfaction or dissatisfaction with. A qualitative research design was used that employed the grounded theory method of data collection and analysis (Glaser & Strauss, 1967). The advantage that grounded theory offered was that it allowed the complexity of bedside handovers in a surgical care setting and the richness of such an everyday life practice to be captured. Furthermore, as there is a paucity of research investigating surgical patients' perceptions of bedside handovers, a qualitative, inductive design was ideally suited to the study (Strauss & Corbin, 1990).

COLLECTION OF DATA

Unstructured, tape-recorded interviews were conducted one day before informants' discharge. In-depth interviews enabled the researcher to probe certain responses, pursue topics that had conceptual promise and thus obtain rich, in-depth data. To minimize the imposition of predetermined responses, both open and closed questions were used. Before each interview began the interview agenda was explained. This covered the purpose of the bedside handover, the content, timing and extent of patient involvement. Discussion of the agenda was the only part of the interview that was constant for all informants as the interview then proceeded in an informal, conversational style, with informants describing their personal experiences and feelings about the bedside handover.

Agreement to participate in the study was obtained in writing. No attempt was made to conceal the nature and purpose of the study. Confidentiality was assured. Informants were informed that a decision to withdraw from the study at any time would not jeopardize treatment or nursing care in any way. However, they were advised that

changes in the style of bedside handovers might occur following completion of the study. As theoretical sampling was employed no sample was predetermined before embarking on the study. The specific sampling decisions evolved during the research process. Emerging conceptual categories directed data collection and lines of inquiry. A total of 10 informants was recruited for the study.

DATA ANALYSIS: THE CONSTANT COMPARATIVE METHOD

The generation of grounded theory is achieved by concurrent collection, coding and analysis of data, a process known as constant comparative analysis (Glaser & Strauss, 1967). As suggested by Glaser (1978), coding of transcribed data was undertaken in two phases, a scanning phase followed by a more microscopic examination of the data. During the overview analysis, interview data were scanned in order to identify relevant themes and ideas and working hypotheses. This initial coding procedure served to develop theoretical sensitivity, that is an ability to 'see' with analytic depth what is there (Strauss & Corbin, 1990). A simultaneous in-depth or microscopic line by line analysis was undertaken to generate abstract concepts or substantive codes. Recurring themes, hypotheses, interrelationships and variations between substantive codes and potential categories were documented in memos throughout the analytic process. Ten potential categories developed quickly during the early stages but were then reduced to six preliminary categories which, in turn, when finally elaborated and refined, resulted in three major categories of a higher level of abstraction than the preliminary ones. A state of category saturation was not achieved as limited time was available for data collection and analysis. The analysis can therefore only tentatively suggest the existence of three categories that describe patients' perceptions of bedside handovers.

Discussion of findings

MAINTAINING PROFESSIONAL DOMINANCE

The category 'Maintaining Professional Distance' described patients' perceptions of their position during bedside handovers. Patients identified a clear divide between themselves and nursing staff. They spoke about how much they participated in the bedside handover according to how physically ill they were. 'In the early days' and 'being acutely ill' were regarded as reasons for not being involved in bedside handovers. It appears that traumatized patients are literally helpless to participate in bedside handovers. During acute physical illness nurses appear to act as patient advocates, with little or no responsibility being assumed by patients.

An improved physical status in the post-operative period signalled an increased desire to be involved in the verbal interaction of bedside handovers. Active participation was valued when a state of wellness was attained. Osler (1988) reports that active patient involvement is a positive feature of bedside handover as patients are able to see their health care as a collaboration between themselves and nurses. Furthermore, students can see nursing as something to do *with* patients not *to* them. Evidence from the present study suggests a significant deviation from the medical model where the patient is always treated as a passive object. Indeed there appears to be a definite move away from the traditional biomedical model such as that described by Parsons (1951). However, some polarized views were apparent. Different degrees of interaction occurred. The extent of nurse-patient interaction during bedside handovers was determined by a variety of variables, notably lack of assertiveness and confidence, previous experience, cultural background and even lack of clarity of role. Wolf (1986) claims there is a need for the function of the bedside handover and the roles of both patient and nurse during handovers to be understood before a collaborative relationship can develop.

It is significant that three informants did not appear keen to participate in bedside handover throughout the pre- and post-operative period. There appeared to be a preoccupation with 'not rocking the boat' and 'not upsetting anyone'. Being submissive, co-operative and accepting of the situation are patient beliefs that have been highlighted in other studies (Taliacozzo & Mauksch, 1979). Kelly & May, 1982 criticize the patient's role of passive recipient. They argue from an interactionist perspective that patients need to keep some power to influence and affect what is happening to them. One informant did however, reply in the following way:

> My nurse simply did not involve me in the bedside handover because she knew I was shy and got very embarrassed about talking in a group or even to someone I did not know very well. She relieved me of this great burden for which I am very grateful.

This challenges the view that the patient is simply ignored. To relieve patients of such overwhelming responsibility may have been the motive of many nurses. The concept of individualized care should therefore be foremost on nurses' agenda as active patient involvement in the bedside handover may not always be synonymous with individualized patient care. Indeed Waterworth & Luker (1990) claim a negative correlation between active patient involvement and individualized care. It is against this backdrop that the effort to treat patients as genuine human beings ought to be axiomatic to a profession widely understood to have interpersonal relationships at heart.

Analysis of findings also indicated that patients did not feel they had sufficient understanding of their illnesses to enable them to initiate dialogue or converse during bedside handovers. They happily accepted a passive role when 'technical issues' were discussed. Biley (1992) points out that the amount of information a patient possesses is an important determinant with respect to involvement in care. Patients in this study attempted to interact with nurses during handovers when they had enough information to justify an active role. Furthermore, knowledge contributed to assertive behaviour especially when it related to subjective and affective domains. The following scenario illustrates the point:

> I was determined to be involved and did get involved when I heard staff nurse X report that I was very anxious. I could not believe my ears. I was not anxious. I just wanted to know what to expect and consequently asked questions. It was this incorrect assumption that made me get involved. I certainly took the stance that I knew best here.

This supports the earlier work performed by Strull *et al.* (1984), who reported that clinicians were poor judges of patients' needs. Indeed, nurses' laissez-faire approach to psychological dimensions of handovers appeared so extreme as to support the observations of High (1989) that professionals are not sensitive to their behaviour during a ward round. Whale (1993) found that nurses commonly made inaccurate interpretations of the psychological status of patients to their colleagues during ward rounds. This suggests that nurses' interpersonal skills need attention and that it is necessary for nurses to objectively analyse how verbal and non-verbal communications affect patients. Furthermore, the human dimension of care needs to be considered. Burnard (1987) reports that the effectiveness of bedside communication is promoted by an atmosphere of warmth, friendship and comfort, which in turn allows discussion not only on factual information but also on feelings and emotions.

A daunting comment validates the need for a humanistic approach:

> All I wanted was for someone to actually ask me how I was feeling not how my wound was.

Informants also spoke of the professional jargon nurses used throughout bedside handovers. The language employed was varied, with colloquial and technical terms, acronyms and abstract words being used. In one recorded interview the following scenario was presented:

> I thought I heard them say this is Mr Y, he is a cabbage and is about to go down for surgery. Well I was stunned. I felt very insulted because I thought the staff thought I was stupid – you know like a

cabbage. I had asked lots of repetitive questions but I was scared. I laugh about it now but at the time I was very hurt – I did not know my previous operation was nicknamed a cabbage.

Four other informants highlighted that the language of bedside handovers was 'intolerable, dehumanizing, manipulative and controlling'. Such responses are worrisome as they imply psychological distress. Indeed House (1989, p. 229) asserts that 'no language is richer or more surprising than that heard in institutions where science and mercy meet'. On the other hand use of lay terminology may foster unwanted patient participation. Nursing jargon may therefore be used both consciously and unconsciously to exclude patients and as a means of ensuring control and authority (Wolf, 1986). Furthermore, it may be that jargon is used to ease the pressure of time. MacMahon (1990b) claims that nurses under pressure to complete reports direct handovers to become nurse orientated to ease the burden of their workload. Burke (1978) claims that jargon simply reflects a nurse's clinical ability.

The response of one informant illustrates that use of professional jargon can actually illuminate clinical expertise and thereby instil confidence:

> The mastery of clinical talk was reassuring to me. Such fluency reflected skill and the complexity of the work of nurses and moreover the competence of the nurse.

The divide between patients and nurses was also evident from informants' descriptions of the amount of time spent at the bedside during handovers. All informants identified that the handover never exceeded a time span of two minutes throughout their hospital stay. This refutes earlier claims that bedside handover is time consuming (Pepper, 1978; Parker *et al.*, 1992). Informants claimed that nurses appeared not to have time to act beyond superficial dialogue. They alleged that the 'business of the ward' prevented intimate interaction. This raises a question about the consequences of a bedside handover that is limited in terms of time. MacMahon (1990a) claims that if the interaction is short and characterized by little personal contact the relationship will also be like that. Consequently if more meaningful dialogue at the bedside is warranted for developing nurse-patient relationships and for increasing the quality of patient care and patient satisfaction, the time-span of bedside handovers needs to be subjected to reflective analysis most urgently.

ESTABLISHING PROFESSIONAL SHARING

This category seeks to describe patients' understanding of nurse to nurse interaction during bedside handovers. An important feature of patients' viewpoints was that bedside

handovers provided a forum for debriefing and catharsis. Patients commented that nurses were often confronted by their patients' crises, which might continue over several days or weeks and require consistent attention. Frequently it was reported that nurses were faced with difficult decisions and opportunities for personal expression are curtailed. One informant hypothesized that bedside handovers performed the function of debriefing and enabled nurses to deal more effectively with emotional overload. The following exert illustrates the point:

> The nurse looking after the man who was dying opposite me looked relieved to pass on the patient to the next shift. The report signalled an end to her traumatic shift.

This evidence supports the claim by Parker *et al.* (1992) that bedside handover provides a forum for peer support and the expression of personal distress. Furthermore, it highlights that bedside handovers may be used as a defensive technique (Menzies, 1970) to alleviate anxiety. The impact of personal expression at the bedside does, however, need to be considered. Improperly performed bedside handovers result in alarmed and anxious patients unable to cope with the surrounding environment (Burns-Stewart, 1981). Indeed whilst the bedside handover is used for gossip, it is hardly surprising that it is highly implicated in communication breakdown (Wiley, 1975).

Bedside handover was also seen as a means of ensuring a safe professional transfer of patient care. Sharing and passing on up–to–date information to oncoming shifts was seen as essential for planning and delivering efficient care. Patients believed that the ability of oncoming nurses to carry out their necessary responsibilities effectively and efficiently was directly affected by the comprehensiveness of verbal bedside handovers.

One informant stressed that the bedside handover was not always as comprehensive as it could be. Inconsistencies in information reported were found. Confusion was induced by inconsistent information. Omissions of important details of post-operative care were also stressed. This suggests that bedside handovers need to be streamlined so that information exchange is clear, concise and complete. Donaghue & Reiley (1981) recommend use of a problem solving approach as a means of streamlining the practice of handover, as it is second nature to professional nurses and enables thoughts to be organized in a logical manner. However, they do not indicate that this format has been tested in practice. Further studies to objectively evaluate such a handover format are needed. One informant did, however, question the value of oral information exchange during the bedside handover:

> I'm puzzled, I can't see the reason for it. They've got it all in the notes in front of them. I get fed up of hearing the same blurb all the time.

In one respect this patient is right as undoubtedly there is a degree of repetition. Patients can become tired of, and frustrated by, nurses coming to the bedside and repeating details at every shift change. Such practice would seem to be time wasting and counterproductive, especially in a climate where human resources are scarce. However, it could be argued that it is time well spent when the complexity and amount of information to be gleaned is considered. Oral bedside handovers may theoretically and practically function as a safety net. This is especially true in the light of inadequacies of nursing notes. By the same token inaccuracies in and omissions from verbal bedside handovers reinforce the value of a hybrid approach. Young *et al.* (1988), in a study aimed at improving the communication of patient information at changes of shift, found that a hybrid approach – a mini verbal report at the bedside, coupled with a silent report when patients' notes were read – facilitates the transfer of information necessary for safe and holistic care.

The value of bedside handovers in relation to group decision making was also noted by all informants. Mutual support, open communication and team effort towards goal achievement during bedside handover appears to be of paramount importance not only to nurses but also to patients. Unangst (1971) asserts that bedside handover has promoted professional growth and independence as a permissive atmosphere has encouraged nurses to reach decisions freely, to question and to experiment. In the same vein Burke (1978) claims that the bedside handover provides a venue for peer assessment and demonstration of professional competence to neophyte nurses. Most patients in this study expressed no objections to teaching students during bedside handovers. Indeed two informants stated that they had enjoyed the opportunity to learn about their illnesses.

Interestingly, most patients were not concerned about the number of nurses present at the bedside handover. This refutes the claim by Parker *et al.* (1992) that nursing dominance during handovers inhibits patient involvement. However, one informant did comment that he felt like an exhibit when he was the focal point of a teaching session.

Interprofessional relationships during bedside handover also received criticism from some informants, reiterating Brink's (1972) observation that a nurse's behaviour during a bedside round was often unprofessional and disconcerting. Student ignorance during bedside handovers also created concern as is evident in the following quote:

> When the student was asked if she had reported my poor urine flow she said no. The charge nurse ticked her off there and then. This student's incompetence

during the report worried me especially as later that same day she returned to look after me, albeit under supervision.

Indeed this extract of raw data substantiates the assumption that nurses are not aware of the messages that their behaviour conveys. Furthermore, it suggests that interpersonal competence is low. Sensitivity to interpersonal relationships is essential if patients' emotional well-being is to be enhanced. Criticism and correction of students should take place outside the bedside handover so as not to embarrass or worry patients and students. Finally, since evidence within this category suggests that nurses' behaviour during bedside handovers has a detrimental influence on patients' emotional well-being, it is perhaps an area worthy of further study. Undoubtedly, professional sharing holds considerable promise as a means of improving the transfer of essential elements necessary for delivery of safe and holistic care. However, in order to modify behaviour that negatively influences the practice of bedside hand-overs, further research that examines patients' specific viewpoints on nurses' interpersonal skills is urgently required.

MAINTAINING PATIENT SAFETY

The category 'Maintaining Patient Safety' describes what patients perceive the primary purpose of bedside handovers to be. An important feature involved the idea that it was undoubtedly a means of ensuring both physical and psychological safety.

Informants reported that handovers conveyed pertinent facts about their care and ensured continuity between one shift and another. They found it to be an essential and integral part of the effective running of the ward. However, varying opinions among patients about how bedside handovers could facilitate provision of safe care did exist. One informant felt that patient involvement was an important safety net, as misconceptions or incorrect information could be rectified. The same informant also felt that useful and accurate 'humanized' information could be passed on as a result of patient presence.

Diverse opinions were expressed about the quality of communication during bedside handovers. These viewpoints appeared to be associated with the technique employed for delivering bedside reports. One informant stated that:

> All the conscientious nurses used my notes. The others, well they just talked generally about my op and recited things like my name, age and doctor's name. They often omitted important changes such as me being allowed to eat and drink which one nurse had earlier written in my programme of care.

A consequence of alleged lack of interest in nursing notes during bedside handovers was a loss of trust and confidence in reporting nurses. One informant described how neglect of nursing documentation led to a feeling of 'insecurity', as some information was not passed on to the next shift. This finding echoes Ross's (1974) claim that neglect of nursing care plans during bedside handover contributes to a certain randomness and fragmentation in the delivery of patient care. Ross found that without a framework only 1.2% of the instructions and descriptions of patients needs were reported from shift to shift. On the contrary, reliance on patients notes during bedside handover can lead to misunderstandings, misinterpretations or even inaccurate accounts. Walker & Selmanoff (1974) speak of the ineffectiveness of nurses' written notes as a vehicle for communication, and they emphasize that crucial information is often omitted, ambiguous, incomplete or contradictory.

In order to ensure patient safety each nurse should devise an individual list in order to organize thoughts during the handover (Mezzanotte, 1976). However, such non-specific guidance could lead to confusion, ambiguous messages and unsafe practice. Indeed the general lack of clarification of the nurse's role during bedside handovers may contribute to reports composed of a simple recitation of facts with little interpretation or opinion being expressed (Mathieson, 1984). Use of a conceptual model as a means of streamlining the practice of handover is recommended by Riegel (1975). However, she does not indicate that this has been tested in practice nor does she highlight that critical to its success is nurses' familiarity with the model. On the contrary, over-abundance of data presented at bedside handovers contributed to feelings of anxiety in some informants. Payson & Barchas (1975) claim that over-valuation of technical information during bedside rounds is common. They advocate that information gained directly from patients or simple observation is often of more value as an unprejudiced view is obtained. The significance of professional interactive skills is therefore highlighted. The tools of both verbal and non-verbal communication need to be considered if maximum information is to be gleaned from bedside handovers. Secrets often emerge at the bedside if both eyes and ears are open (Federman, 1973).

In terms of psychological safety, only one informant commented that the physical surroundings of a Nightingale ward were inimical to safe bedside handovers. This informant felt the ward layout made private, intimate conversations between nurses and patients very difficult to achieve and quite impossible if a patient was hard of hearing. In contrast, confidential disclosure was not a concern for the

remaining nine informants. This supports Engel's (1971, p. 22) claim that 'patients for the most part appreciate the obvious attention being devoted to them by all concerned.' Engel, in a study of 100 patients, reported that no patient considered that bedside procedures had led to improper or confidential disclosure, although five did offer suggestions for improvement, one of which included being sensitive to individuals' preferences. The issue of sensitivity was also illuminated in the present study as it was found that disclosure of social data, especially if concerned with prestige, provoked resentment in some patients. The pervasive influence of social and cultural background needs to be considered with each patient (Jacobs, 1980). Indeed, diverse viewpoints about the bedside handover in terms of safety highlight the importance of not only interpersonal competence but also the need to fulfil each individual's requests regarding the practice. The following reflection indicates that there is a need for further interpersonal skills training:

> The bedside handover is all too often displaced from the bedside to the main corridor. Nurses do not always appear to be listening. They are looking out of the window or talking privately to each other.

Conclusion

The conceptual categories, 'Maintaining a Professional Distance', 'Establishing Professional Sharing' and 'Maintaining Patient Safety' are offered as a means of describing and explaining patients' perceptions of bedside handovers. Most of the findings appear to support the earlier conclusions of a considerable number of studies (Romano, 1941; Engel, 1971; Szasz & Hollender, 1976; Biley, 1992; Ross, 1974; Whale, 1993; Waterworth & Luker, 1990). However, some findings, such as the significance of interprofessional relationships and student performance during bedside handovers, have not been previously reported or discussed.

Since this study is no more than the beginnings of a more comprehensive grounded theory study, no definitive conclusions can be drawn. However, as the bedside handover is an issue of considerable significance, some important implications for professional practice and future enquiry emerge. Indeed since most patients wish to be able to hear and understand the discussion during bedside handovers they ought to have the opportunity to be involved. However, it must be acknowledged that there is lack of desire by some patients to be involved. By the same token, some patients adopt an active role even if they do not really want to. Individual needs and preferences should therefore be established and respected.

The significance of verbal and non-verbal communication behaviours for patients should be considered, especially in the light of the fact that interpersonal competence during bedside handovers appears low. Teaching interpersonal skills necessary for this everyday practice should therefore be a priority. Use of audio and video recorders or simulated bedside handovers may provide important insights and promote reflective analysis of an everyday ritualistic practice.

An understanding of the roles and responsibilities of participants in bedside handovers is essential if the quality of interaction and patient satisfaction is to improve. Each nursing care unit should identify the roles of participants in order to prevent role conflict and to promote collaboration in care if it is desired. Continuous systematic critical examination of bedside handovers should be encouraged to maximize the effectiveness of such a report style.

Acknowledgements

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Appendix 17

Patient participation – a review of the literature

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Summary

• This article presents a critical review of the concept of patient participation.

• The concept of patient participation has become widely accepted in contemporary nursing practice. It is now part of the vocabulary of professional nurses and has been heralded as a means of enhancing decision making and human dignity and enriching quality of life.

• Patient participation in care is emerging as a growing movement wherein patients are assuming more responsibility for the prevention, detection and treatment of health problems in a manner that supplements or substitutes for professional services.

• The review concludes with some recommendations for nursing practice, education and research.

Keywords: patient participation, patient role, practitioner role

Introduction

This review presents an overview of the research and scholarly literature surrounding patient participation in hospital care. More specifically it provides a global picture of the current state of knowledge regarding patient participation within the context of hospital practice in the UK. By way of introduction, the methods employed to identify and retrieve data will be outlined. The scope of the review will also be justified. Through an analysis of the literature in the field, the concept of patient participation will be defined. The plurality of meanings will be critically examined. Drawing on relevant literature from the foundation disciplines of social policy and sociology, an attempt will be made to illuminate how the concept of patient participation in care has evolved within the context of contemporary hospital practice. The significance of the trend in nursing policy and practice towards patient participation will be explored. Selective studies examining the phenomenon of patient participation will be critically evaluated. As patient participation in care constitutes a radical change to both health care and the role of the patient and practitioner, studies that have specifically explored patients' and practitioners' perspectives on the desirability and value of patient participation in care will be appraised. The strengths and limitations of the designs, methods of inquiry and instruments used in past empirical work will be considered. Since there have been few well controlled empirical studies of patient participation in hospital care in the UK, anecdotal accounts and theoretical discussions will also be included. Based on the findings in the literature, the review concludes by discussing some recommendations for nursing practice, education and research.

The review process

Patient participation in care is currently a modern day icon

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Table 1   Primary journals consulted during review process

1	*Journal of Advanced Nursing*
2	*Journal of Clinical Nursing*
3	*International Journal of Nursing Studies*
4	*Professional Nurse*
5	*Nursing Times*
6	*Nursing Standard*
7	*Senior Nurse*
8	*Social Science and Medicine*
9	*Journal of Health and Social Behaviour*
10	*Journal of Interprofessional Care*

that is widely used in the literature to describe various approaches to health care practice. It is a term that is conceptually similar and often used interchangeably with patient collaboration, patient involvement and patient partnership. Indeed, the distinct lack of consensus concerning the meaning of patient participation made the search for published papers using computerized databases (e.g. Medline, CINAHL and Psychlit) problematic. Data-based literature rarely used patient participation as a key term within the title or abstract, and therefore a manual search of a selection of recent journals (see Table 1) in which literature relating to patient participation was most likely to have been published was conducted.

The original intention was to search the publications of each journal identified in Table 1 over the last 10 years, as the concept has emerged over the last 15 years as a topic for debate (McEwen *et al.*, 1983) and as a new trend in nursing. The adoption of patient participation in care was most pronounced during the 1980s when the government recommended that views and wishes of consumers should be taken into account when planning and delivering health care (Department of Health, 1989). However, as nursing policy and practice reform accompanied government efforts to promote patient participation in care through the development of the nursing process, nursing models, primary nursing and a more patient centred approach, it seemed appropriate to consult both scholarly work and empirical literature from the 1980s to the present date. It is recognized that many journals, particularly those produced outside the UK, were precluded from the search and that those chosen do not include all potential outlets. Also it must be acknowledged that caution needs to be exercised when making generalizations about patient participation in care as distinct attitudes towards the concept are apparent within different health care systems.

In a multinational survey conducted by Kim *et al.* (1993) it was found that cultural heritage, social development and country of residence were all major structural variables that contributed to different patient and practitioner viewpoints about the nature of the phenomenon and how it is executed in practice. Indeed, Brody (1980) also found that different health care orientations influenced opinion about patient participation. She reported that patients in private as opposed to public sector health care organizations were more committed to the philosophy of participation in care as it was seen as a means of reducing the cost of hospitalization. Consequently, comparing studies undertaken in different health care areas could be problematic. Kron (1981), Marriner (1979) and Biley (1992) further illustrate the point as they found that attitudes towards patient participation within the USA were quite distinct from those in the UK. They attributed this to the fact that patient participation in care has been operationalized in the USA for a longer period of time that it has in the UK. Finally, as the purpose of the review was to develop a comprehensive picture of the state of knowledge on patient participation and to generate useful research questions for sound studies that will contribute to knowledge development for clinical practice and nurse education in the UK, it was deemed appropriate primarily to screen and review references of British authors, or studies carried out within the British health care culture. However, some international work has been reviewed owing to its seminal nature and frequent citation by British researchers. Study design was not used as a selection factor. The focus was on studies and literature examining patient participation in care in some way.

The concept defined

The *Oxford English Dictionary* (1989) states that the word participation is derived from the Latin *participate* which means to take part in. According to Sinclair (1993, p. 1069), participation relates to the act of participating, which implies that one becomes actively involved in or shares in the nature of something with others. Holloway (1993) suggests that participation is the involvement of many people in decisions, giving them some feeling of control or responsibility. Viewing participation from a human relations perspective, Hill (1971, p. 64) asserts that it is 'the involvement of subordinates in a task'. Brownlea (1987, p. 605) contends that participation means:

> getting involved or being allowed to become involved
> in the decision making process or the delivery of a
> service or the evaluation of a service or even simply to
> become one of a number of people consulted on an
> issue or matter.

Although these definitions have the advantage of brevity they do not embrace the complexity of the concept within the context of contemporary hospital practice. Further-

more, they appear to pay more attention to a collaborative approach to participation as opposed to an individualistic perspective of the concept. Within health care practice patient participation in care has most frequently been applied to the individual patient's role in the delivery of nursing or medical care. According to McEwen *et al.* (1983, p. 76) patient participation in health care relates to:

> the activities performed by an individual on behalf of others in the maintenance and promotion of health, the prevention of diseases, detection, treatment and care of illness and the restoration of health, or, if recovery is not possible adaption to continuity of disability.

D'Onofrio (1980, p. 274) suggests that patient participation implies:

> patient engagement in problem identification and prioritization, establishment of change objectives and the process of making decisions about how change will be accomplished.

Saunders (1995) asserts that patient participation is an active process which involves a patient performing clinical or daily living skills or partaking in the decision making process from the time of admission to discharge. However, it has also been seen to focus on other aspects of care, such as patient compliance with treatment plans (Craig, 1985), self-medication (Webb *et al.*, 1990), self-monitoring (Nelson, 1977), patient education (Wilson-Barnett & Obourne, 1983), goal setting (Janz *et al.*, 1984) and sharing information and taking part in physical care (Macleod-Clark & Latter, 1990). Indeed, the literature appears to suggest that patient participation is one of nursing's most amorphous and ill-described concepts.

It would appear that there is no clear consensus on what patient participation means or how far it should extend. No single term comprehensively describes this movement which is so widespread at present. Clayton (1988), in an attempt to clarify the nature of the concept, reports that the literature on patient participation can be subsumed into three broad categories: enhancement of decision making, enrichment of the quality of life and expropriation of client power. However, despite Clayton's attempt to illuminate the meaning of the concept, the present body of knowledge is somewhat fragmentary and incomplete. Conceptual clarification is needed to promote and apply the ideas implicit in the concept.

Meyer (1993) asserts that the incoherent or differing consensus regarding patient participation can be attributed to underlying philosophical and political persuasions. Van den Heuval (1980) suggests that there are two conflicting ideologies that have significantly influenced conceptual understandings of patient participation in care: one emerging from the humanistic perspective and the other from the bureaucratic view of consumerism based on controlling costs, outcome and efficiency. Indeed these opposing assumptions and the lack of analysis of the concept are unfortunate as there is a danger that the debate regarding what patient participation entails will remain at the level of rhetoric. However, in a recent study some effort was made to uncover the meaning of the concept. Jewell (1994), in an ethnographic study, examined the meaning of the phrase 'patient participation' with a group of four primary nurses from two elderly care rehabilitation wards. Tape-recorded unstructured interviews were used to collect data. Although the study provided a valuable emic perspective from those who considered patient participation as part of their practice, little effort was made to validate the findings. No tests of rigour, particularly in relation to neutrality, consistency and applicability (Guba & Lincoln, 1985), were reported. Therefore, albeit that Jewell reported that patient participation care meant involvement of the patient in clinical practice and decision making via the formal structure of the nursing process or informally through ongoing nurse–patient exchange, nurses' definitions of the concept are purely anecdotal. Indeed no firm conclusions can be confidently drawn. Furthermore, as the sample was small ($n = 4$) and the make-up of the sample could have had an impact on the investigation, the only conclusion that can be drawn is that further investigation is required for conceptual clarification. Certainly, a comparative study with a larger sample and using a combination of data collection methods such as interviews and non-participant observation might be of value, as verbal accounts could then be clearly validated. Indeed, such a study would be of worth as verbal accounts regarding patient participation in care often bear little relationship to the reality of nursing as practised on the ward (Glenister, 1994).

The historical perspective

Historically the accepted assumption about health care was that illness could only be effectively diagnosed and treated by expert professionals. Patients were regarded as passive recipients of care (Parsons, 1957) and decisions regarding their care were the domain of the physician (Roberts & Krouse, 1990). Traditional health care appears to have been based on a deterministic, mechanistic view of the nature of humans. The move towards patient participation in care has its philosophical antecedents in the opposing view that humans have free will and self-determination (McEwen *et al.*, 1983).

Many factors have been instrumental in the development of the concept of patient participation and the associated

undermining of the domination of the health services by providers. Steele *et al.* (1987) maintain that the concept has waxed and waned over the last 2 years in synchrony with broader societal issues. Brownlea (1987) also believes that patient participation has been 'tidal' in its behaviour as a result of changes in society in general. Hickey (1986) attributes the move towards a participatory approach to health care to increased consumer knowledge, an increased awareness of consumer rights, movements towards self help, accelerated health care costs and economic stringency, and an increasing awareness of the fallibility of health professionals. A modern view of the patient role is given by Reeder (1982), who describes a change in the passive sick role by defining a change from the role of the patient as a passive client to that of an active consumer.

Empirical evidence validates the assumption that the passive role of the patient and the paternalistic approach to patient care are changing. A survey of 193 physicians carried out by Oken (1961) illustrates the point as it was found that 10% of physicians preferred not to tell patients they had cancer or involve them in their care. However, an almost identical survey carried out many years later found that 97% of 260 respondents preferred to tell patients that they had cancer and invited them to participate in their care (Novack *et al.*, 1979).

Undeniably the entry of the consumerist ethos into the British health care system has led to consumers or patients becoming more actively involved in the provision of health care. Associated with this general socio–political trend has been the development of a new nursing philosophy which seeks movement away from biomedical domination towards a patient-centred approach to care (Beardshaw & Robinson, 1990). Salvage (1992) asserts that the ideology of patient participation is a central tenet of the new nursing paradigm. Indeed, nurses are now being actively encouraged to promote patient participation in care as a rule rather than as an exception.

Within the present National Health Service (NHS) patient participation has been further promulgated by government initiatives, most recently and notably *Working for Patients* (Department of Health, 1989) and the *Patient's Charter* (HMSO, 1995). Indeed market liberalism is clearly at odds with the paternalism inherent in the medical model of health care. The consumerist stance has undeniably constituted a challenge to the health care professionals' authority and power.

However, the extent to which the degree of power has been contested is an area which requires investigation. Hewison (1995), in an observational study using a modified grounded theory approach, found that nurses still exercise virtually total power and control over patients. Indeed, the power dimensions inherent in the nurse–patient relationship were found to constitute a definite barrier to patient participation in care. The findings of this study are, however, open to question as the study has many limitations. The length of data collection was limited to 37·5 h and therefore saturation of the emergent categories was not achieved. Furthermore, no attempt was made to verify the categories that emerged by taking the findings back to the informants of the study (Stern, 1980) or by having an independent expert examine them (Hind *et al.*, 1990). Since the study also took place in an elderly care ward where both patients and staff were female, increasing understanding of both the nurse's and the patient's role in other care settings would be valuable as differences in the dynamics of nurse–patient encounters may arise. Indeed, to assume that there has been a complete move away from a paternalistic philosophy of care to one in which patient autonomy and patient participation are promoted would be naïve, as a change of philosophy is often a gradual process.

The patients' perspective

Studies addressing the patients' perspective about the desirability and value of participating in care have in general drawn on positivist epistemologies. Data have primarily been derived from self-completed questionnaires and recall. No attempt has been made to observe what actually occurs in the reality of practice. Such data collection methods may not be the best way of obtaining data about the complex, elusive concept of patient participation, given that how people respond in theory may well be different from what they do in practice. Furthermore, it should be noted that the literature on the value and preferences of patients regarding a participatory approach to care has explored these in the context of medical care. Studies that have examined the value and desirability of participation from a patient's viewpoint within the context of nursing care are limited.

Calls for greater patient participation in care are based on the assumption that patients want and benefit from having a more active role in their health care. In a survey using structured interviews, Vertinsky *et al.* (1984) examined the role preferences of 200 citizens in Vancouver, Canada, with regard to consumer desire for participating in hospital care. The interviewer presented subjects with a vignette of a common medical situation (a patient complaining of a sore throat) and they were asked to project themselves into the role of the patient's adviser and to rate a series of possible actions the patient and doctor might take. The actions were rated on a scale ranging from 1 (unimportant) to 5 (very important). Following factor analysis the findings indicated that patients wished to employ physi-

cians as information sources and decisions makers but that they wished to participate in the decision making process. Although Vertinsky *et al.*'s study clearly indicates that patients have a desire to participate in care, the study is limited by the nature of the instrument developed for the research. The vignette presented a somewhat artificial situation and only one scenario was used to establish 200 preferences for participation in care. Furthermore, as the instrument was not used in the practice setting, subjects who were not in the patient role at the time of the research might have responded differently if they were receiving treatment.

In a study examining cancer patients' preferences for participation in care, Cassileth *et al.* (1980) found that patients often did adhere to the contemporary standard of active participation in the decision making process. This was particularly true of younger patients. Older patients and those more seriously ill preferred a less active role, a finding supported by Beisecker (1988). However, any attempt to generalize the findings of Cassileth seems inappropriate as the setting itself may have influenced preferences. Greenfield *et al.* (1985) support this assumption as they found that in the context of chronic or terminal illness a degree of patient participation is customary as the ultimate burden of care falls on the patient. In a more recent mail survey ($n = 459$) to examine a patient's preference for participation in care, Thompson *et al.* (1992) found that respondents expressed a desire to participate in care that did not require medical expertise, but had little preference for participation in care that required medical expertise. As found in earlier studies, younger and better educated individuals also reported a higher desire to participate in care. The limitations of Thompson *et al.*'s study should, however, be noted. The response rate to the mailed questionnaire was not reported, and therefore it is difficult to make a judgement about how representative the obtained sample was relative to the projected study sample. The vast majority of respondents were also white (87%). Indeed, it would be desirable to repeat the study using respondents from a variety of ethnic backgrounds to see if results generalize to other subcultures. Furthermore, as with earlier studies that tended to draw on a positivist epistemology, the use of a structured questionnaire did not enable the researcher to examine and understand why variables such as age and education were predictors of the desire for participation. Age and education may be markers of other variables such as deference to authority or confidence in one's own medical knowledge. Haug & Lavin (1981) reported that variables such as age, educational level and knowledge had a substantial impact on a patient's ability and desire to challenge a physician's authority and participate in care.

In one of the few studies examining patient preference within the context of nursing care, Brooking (1986) reported similar findings. She found that patients who expressed a positive attitude and reported the highest levels of participation were of a higher social class, had increased knowledge of their condition and were younger and more familiar with the hospital environment. Certainly, these findings have significant implications for nursing practice. It would certainly appear that patient characteristics need to be considered when participation is offered to patients.

However, Brooking's findings do have limited generalizability as the sample size was small ($n = 114$ patients). Furthermore, as acknowledged by Brooking, self-completed questionnaires may not be the most appropriate way of obtaining data about the complex subject of patient participation in care. Indeed, further study using a combination of quantitative and qualitative methods (observation and interviews) could increase confidence in some research findings such as those reported by Brooking and ensure that the concept is examined in the reality of practice.

In contrast to Brooking's discovery, some studies confirm the findings from medical sociology that the traditionally passive, acquiescent patient role is still accepted and wanted by some patients. Being submissive and accepting of the situation are patient beliefs that are still apparent (Taliazozzo & Mauksch, 1979; Taylor, 1979; Biley, 1995). It would appear that some patients derive security from the 'nurse knows best' stance. Strull *et al.* (1984) studied 210 patients who were receiving out-patient treatment for chronic hypertension and their 50 physicians, using questionnaires to discover what role patients preferred to play. Whilst it was found that 78% of the clinicians believed that patients would want to participate in their care, only 52% of patients actually wanted this. Sixty-three per cent of patients reported that they wanted the clinician to make decisions about their case using 'all that is known about medicine' (p. 24). However, since Connelly (1987) reports that participation in care for chronically ill patients is essential for the successful management of illness and avoidance of progression and exacerbation of symptoms, a direct comparison with acute illnesses cannot be made. Furthermore, as the study took no account of patient knowledge, the findings need to be treated with caution. As Brearley (1990) pointed out in her comprehensive review of the literature on patient participation, nonparticipation may be a self-fulfilling prophecy as patients cannot participate in care without the necessary information. Indeed, Brearley's assumption is validated by Avis (1994), who in a small scale ($n = 12$) exploratory study, found that all patients deferred to professional opinion. They allowed choices to be made for them because they lacked knowledge.

The degree of patient participation in care has also been attributed to factors other than age, education and knowledge. Szasz & Hollender (1956) contend that the degree of participation may vary in accordance with a patient's condition. Indeed patient passivity during acute illness was noted to be normal. Blanchard *et al.* (1988) examined the interactions between 439 hospitalized cancer patients and professional carers and found that the more physically sick were less likely to want to participate in care. Findings from a later qualitative study by Biley (1992) support this premise. Biley used a modified grounded theory approach to discover how patients felt about participation in decision making about their nursing care. Findings suggest that patients participated in decision making according to how well or how fit they were. 'Being too ill' (p. 416) was regarded as a reason for not participating in care. However, on a methodological note, it is difficult to draw any conclusions from Biley's study because, as he highlights, only a small number of informants were interviewed (n = 8). Also, saturation of concepts was not achieved and, although the interviews were conducted 7–10 days after discharge, no observation or comment was made about the nature of nursing practice or the organizational context of care on the wards where the informants underwent surgery. Furthermore, variables such as expectations regarding hospitalization, educational background, diagnosis and previous health care experience were also not reported. Therefore to assume that patients do not really want to participate in their care may be erroneous.

However, another qualitative study which explored the degree to which patients desire to participate in their care reported similar findings to Biley's. Waterworth & Luker (1990), in a small scale in–depth study involving a convenience sample of 12 patients from three medical wards and using informal interviews, collected information from patients about their perceptions regarding participating in decision making concerning their care. The authors drew from their 12 interviews one theme which they saw as throwing light on how patients view participation. They call this 'toeing the line' and argue that patients do not want to participate in care but reluctantly collaborate in order to comply with such an approach to care. However, it is with extreme caution that one should draw inferences from this study about the level of participation a patient desires as little information is provided by the authors about the way in which the interviews were conducted, where they were carried out or the patient variables which may have been significant. Reference is made to grounded theory (Glaser & Strauss, 1967) but there is little discussion about theoretical sampling.

In terms of the value of patient participation in care from a patient's perspective, there is some evidence to suggest that such an approach to care leads to improved outcomes and better adjustment (Wilson-Barnett & Fordham, 1982), patient satisfaction (Loughlin, 1993), compliance (Rost, 1989) and goal attainment (Langer & Rodin, 1976), and shorter hospital stays (Lott *et al.*, 1992).

In an experimental study Greenfield *et al.* (1985) studied the effect of patient participation on outcomes such as control, physical functioning and knowledge. Significant differences between the experimental and control groups were found in terms of knowledge, satisfaction and motor functioning. Identification of these outcomes followed tape-recorded interactions between doctors and patients, where those patients in the experimental group (n = 22) had been assisted by a researcher to identify questions and issues relating to gastric ulceration immediately prior to their encounter with the doctor. Those in the control group (n = 22) received no assistance. Analysis of the interactions revealed that the experimental group were significantly more in control of the interaction in terms of the number of patient utterances per minute and were better able to direct the flow of the conversation. Also the experimental group reported few physical and role limitations and demonstrated greater knowledge than controls after the encounter. However, whilst the significance of this study should not be underestimated, the findings must be treated with caution. The study clearly demonstrates that researchers can use the same words with entirely different meanings. Greenfield *et al.* concentrated on 'coaching' the patient prior to the encounter with the doctor rather than on training the doctor to elicit patient participation. Also, preparing a patient for an isolated encounter does not examine fully the concept of patient participation. Indeed, some patients may also have different preferences about participating when suffering from other diseases and their preferences may change over time. Finally, the study was limited by its quantitative approach to participation as the number of utterances by a patient gives little indication of the quality of utterances.

Overall it would seem that the literature examining patients' viewpoints regarding the nature of participation suggests that there is no clear consensus amongst patients about the desirability for, and the value of patient participation. Certainly no universal conclusions can be drawn. Indeed, it is against this backdrop that the effort to treat patients as individuals and genuine human beings ought to be axiomatic to a profession widely understood to have interpersonal relationships at heart.

If government and nursing policy and practice is to persist in emphasizing a participatory health care approach, there is a need to re-educate not only the public with

respect to their expected future roles in health care, but also health care professionals. Professionals need to learn and be better prepared for the more facilitative roles which are being advocated in current policies in the name of consumerism.

The practitioners' perspective

Studies which examine health care professionals' viewpoints about patient participation in care have similar problems to the studies exploring patient perspectives as they fail to explore attitudes in the reality of practice. Most seek practitioners' views through interview or questionnaire, and what actually happens in practice has not been observed. Furthermore, the empirical studies and anecdotal accounts suggest that both nurses' and doctors' sentiments of the value and desire to elicit patient participation in care are mixed. Findings provide some conflicting results. It would appear that, despite the widespread national and international commitment to patient participation in health care and the infusion of the concept into the nursing and medical profession, it is an approach to care that has neither been rejected nor welcomed as a panacea.

Numerous studies have found that, with few exceptions, health care professionals, particularly nurses, continue to see the patient as a passive recipient of care (Armitage, 1981; Bayntun-Lees, 1992; Saunders, 1995). Brody (1980) admits that clinicians are reluctant to elicit patient participation in care as they feel unable to relinquish any power or control over patients, an idea mirrored by May (1995). Indeed, it might be that such reluctance to encourage patients to participate in care is a defensive strategy (Menzies, 1970) employed to alleviate anxiety. Clayton (1988) reports that the techniques adopted in the name of participation often have the covert aim of legitimizing or extending the already strong position of existing power holders. However, to provide evidence of expropriation of power by professionals would be difficult as public justification for patient participation in care is usually couched in arguments of the enhancement and enrichment schools of thought and nothing is said about the less positive elements.

Meyer (1995) suggests that a clinician's lack of commitment to patient participation and reluctance to promote a participatory approach to care are due to the fear that such an approach is a governmental conspiracy to reduce professional services. In the same vein, Brearley (1990) maintains that some professionals avoid patient participation in care as they see it as a euphemism for cost-cutting. Indeed, the inclusion of patients in any form raises the notion of what Wilson (1987) refers to as 'pawns in a cost-cutting game'

and begs the question whether participation is being fostered for financial reasons. Woods & Metcalfe (1980), in an exploratory study of professional attitudes to patient participation, found that many negative responses towards the concept, such as loss of clinical independence, arose from misconceptions about the origins and function of such an approach to care. However, the extent to which these results can be applied to professionals in general is open to debate, as the study focused purely on general practitioners in 15 practices.

It has been reported that whilst most clinicians assume a dominant role and are reluctant to promote participation, some marginal differences between professional groups are apparent. Spears (1975) conducted a descriptive study of nurse practitioners' and physicians' interactions with patients and found distinct differences in verbal content and orientation during the provision of care. Nurse practitioners most frequently considered patients' needs and promoted patient participation in care. However, unfortunately levels of statistical significance and correlation were not assessed. Brooking (1986) also found nurses were particularly positive about patient participation when compared with other health care professionals. The findings do, nevertheless, need to be interpreted with caution as what people say they do may well be different from what they do in practice. As Waterworth & Luker (1990) point out, the writings of nursing theorists may bear little or no relationship to the reality of nursing as practised on the ward.

Saunders (1995) maintains that patient participation is avoided by nurses as they feel threatened by patients having a stronger role. He asserts that, whilst some nurses indicate that they perceive patient participation in care as valuable, they have reservations about certain patients' abilities to undertake that care. Similar findings have been reported by Goodwell (1979) and Jewell (1994). Eisenthal & Lazere (1977), in a somewhat dated study, found that many clinicians did not trust the nonexpert judgement of the patient and at the same time were fearful of being bombarded with unreasonable requests. In a later study similar findings were reported and Eisenthal et al. (1993) concluded that clinicians still do not find patient participation satisfying and much prefer to maintain a dominant role when in contact with patients. However, these findings are to be treated with caution as it could be that the results were influenced by the nature of the clinician's relationship with the subject. Indeed, Lloyd (1990) observed that for a rewarding alliance between professionals and patients to occur, trust and respect is vital. Muetzel (1988) and Ashworth et al. (1992) assert that if patient participation is to occur, an environment that is emotionally secure must be provided.

In conclusion, the literature focusing on the clinician's perspective of the concept seems to suggest that the health care professional's desire to encourage patient participation in care is dependent on the individual practitioner's values. Higgins (1993) believes that a practitioner's aspiration to promote patient participation in care is tempered not only by their beliefs about the concept, but also by the bureaucratic health care organization. Indeed, McMahon (1990) supports this premise as he found, in a ward where primary nursing was employed, that a greater interest in patient participation was apparent in comparison to the interest expressed on a ward managed in a hierarchical fashion.

In terms of value Pritchard (1986) reports that those health care professionals who facilitate patient participation at practice level see it as advantageous in a variety of ways. Pritchard asserts that such an approach is helpful for clarifying the aims of practice, providing feedback for evaluating services to patients, responding to change, improving communication and relationships, increasing job satisfaction and reducing or defusing complaints. Lott *et al.* (1992) speculate that patient participation is an under-used resource that is capable of decreasing burnout, increasing morale and increasing staff recruitment and retention. Indeed, the concept has been widely recognized by many health care professionals to be a good thing (Brearley, 1990). However, according to Richardson (1983), the consequences of patient participation are highly unpredictable. Therefore, until the outcomes are confirmed they must be considered to be merely reasonable hypotheses. Certainly, there is a dearth of empirical work which focuses on the value of patient participation from a health care professional's perspective. In fact, given the current political, social and economic situation there is an urgent call for hard evidence to show that patient participation is of value to the patient and the clinician.

Conclusion

This review has highlighted that the concept of patient participation is indeed extremely complex and multifactorial in nature. The concept has been defined and operationalized in a variety of ways, and it is therefore difficult to know if the apparent diversities in participation preferences of different patients and professional groups are genuine or merely reflections of different assessment tools. Certainly it would appear from the literature reviewed that patient participation cannot be assumed to be an approach to care that has been universally accepted by patients and clinicians alike.

Clearly efforts need to be made to formulate a standardized definition and to develop reliable and valid measures for assessing preferences, the value of the concept and the extent to which it is executed in practice.

As most of the findings in relation to the desirability and the value of patient participation are primarily anecdotal, there is also an urgent need to explore the concept in the reality of practice using more qualitative methods or a combination of both quantitative and qualitative research methods. Since Denzin (1970) advocates that a strategy of triangulation can counteract the threat to validity imposed by structured measurement tools and enables the researcher to explore the whole domain of a phenomenon, such a research approach could be of great value to future enquiry. Furthermore, since most of the research examining the concept has been based on the doctor–patient relationship, there is a need for further enquiry within the context of nursing practice. Generally it would appear that patients prefer to participate in their care while professionals, although acknowledging the potential value of patient participation, prefer patients to be passive recipients. Indeed, it is apparent that rewarding alliances are being developed yet the extent to which patient participation in care is actually carried out requires further exploration. Certainly if such an approach to care is to become the rule rather than the exception, nurses, and indeed all health care professionals, need to be adequately prepared for the more facilitative roles which are being advocated in the name of patient participation. However, not only is there a demand for professional resocialization, but there is also a call for patients to be re-educated about their future roles in health care. Or, as individual care is essential, and some patients prefer to assume a passive role, all clinicians need to ascertain how much patients want to participate in their care at the earliest point possible in their hospital stay.

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