

**THE EXPERT PATIENT: AN EXPLORATION OF
SELF-MANAGEMENT IN LONG TERM
CONDITIONS**

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DEDICATION

This thesis is dedicated to the memory of my parents whose love and example still lives on.

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This thesis would not have been possible without the very generous time and participation in the study given by all those living with a long-term condition and the clinicians who contributed to the study.

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ABSTRACT

Chronic disease is the major challenge facing global health care. In tandem there has been the emergence of active and informed patients in western society, with the contemporary patient increasingly involved in decisions about their treatment and care. However, while it is acknowledged that the vast majority of chronic disease management is via self-care and effective self-management has a potentially significant effect on reducing resource demand, there has been comparatively little research on the concept of the expert self-managing patient within chronic disease. The aims of this study were therefore to:

- Investigate how patient expertise is viewed, interpreted, defined and experienced by patients and clinicians.
- Understand how patient expertise is promoted and enabled through the self-management process.
- Discover how patient expertise is enhanced or impeded by other mechanisms.

Adopting a grounded theory approach underpinned by critical realism, the study commenced with three focus groups with patients and seven focus groups conducted with nurses and physiotherapists. Using the emergent themes as a starting point for constant comparative analysis, concurrent data collection via semi-structured interviews and observation was conducted. This included interviews with twenty two patients, twelve clinicians including doctors, nurses and physiotherapists and two Expert Patients Programme lay tutors. Observation was undertaken with ten consultant and nurse-led clinics, a six week Expert Patients Programme and an eight week Back Fitness Course.

A storyline is described that illustrates the journey of the expert patient and the thesis explores the barriers and enablers on this journey. A typology of the expert patient is developed in which it is shown that expert patients fall into four quadrants with overt acceptors as the idealized patient within medical consultations. The findings suggest that many expert patients learned characteristics of being succinct and non-emotional when communicating with clinicians, but at the cost of not being able to articulate the emotional consequences of living with chronic disease. Variance from this idealized type leads to conflict which is explored through theories of the medical division of labour.

It is concluded that the typology of the expert patient should be widely discussed and acknowledged as a framework for professional and lay practice. In particular, there should be explicit recognition of the emotional needs of people with chronic illness. Recommendations for policy and practice are generated that include acknowledgement of the expert patient beyond the medically idealised type.

It is suggested that within the Expert Patients Programme there should be a move away from the current rigid content and delivery style and a greater focus on the subjective experience of chronic illness. Lay tutors would benefit from developing skills to support the psychological needs of participants. Furthermore, it is suggested that the behaviours and working environment that characterised nurse specialists should be used as a template for good practice to enable clinicians to meet the needs of expert patients. Finally, recommendations are made for inter-professional education. It is suggested that the skills of a variety of expert patients beyond the idealized overt-acceptor type are utilised in order to expose clinicians to a fuller range of patient narratives surrounding the experience of chronic disease.

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CHAPTER ONE

INTRODUCTION

1.0 Setting the scene

This thesis explores experiences of a particular group of adults who have lived with a physical long-term condition over a number of years. It seeks to study the recently coined term of “expert patient” (Department of Health, 2001a) and unpick the reality of self-management in chronic disease. In doing so, the study investigated the health professionals and services that this group come into contact with; evaluating what enables or prevents people developing expertise in self-management of their condition. The purpose of this introductory chapter is fourfold. First the scene will be set for the reader with two areas highlighted; increasing prevalence of chronic illness and associated health care costs, and the concurrent rise of active patients. Second, the rationale for the research will be introduced; the tension between the rise of the active patient but continuing health professional and service responses being framed by the concept of a passive patient. Third, the specific research aims will be presented, and lastly the organization of the thesis will be described.

1.1 Rising chronicity against a background of finite resources

Medical and public health advances have resulted in a demographic transition towards ever increasing life expectancy and elderly people in the population. By 2031 it is predicted in the United Kingdom (UK) that although the population of all those under 44 years is set to fall, the 60-74 age group will rise by about 50% and the over 75 age group is likely to increase by 70% (Bootle, 2005). This changing pattern is echoed internationally and has resulted in a worldwide epidemiological transition from the predominance of infectious diseases to a predominance of chronic diseases (Harwood *et al.*, 2004).

Globally, approximately 35 million of the 58 million total deaths in 2005 were caused by chronic disease. Furthermore, as the major cause of adult death in

nearly every country the trend is expected to rise by 17% over the next 10 years (World Health Organization, 2005). The global response to chronic disease has included the development of a number of chronic disease management models with an exemplar being Wagner's Chronic Care Model (Wagner, 1998). The elements of the model include engagement of the community by the health system to tackle chronic disease, a health care system that is organized to improve care of people with chronic disease and a delivery system that has clearly defined and coordinated roles and tasks. In addition, the health system has support mechanisms that enable evidence based practice and mechanisms to facilitate self-management.

Whilst the human cost of living with a long-term condition can be immense (National Statistics, 2003; World Health Organization, 2005), so too is the financial cost to the state. If one takes the example of diabetes which has a globally increasing prevalence (Department of Health, 2006b), recent estimates suggest that it accounts for 10% of current UK National Health Service (NHS) expenditure (Roberts, 2006) with the Wanless Report estimating the total annual cost to the NHS as £1.3 billion (2002). If diabetic complications exist then this cost increases more than fivefold to the NHS and fourfold to social services (Roberts, 2006). Despite these costs diabetes is not the most costly disease, with CVD and respiratory diseases accounting for 50% of all General Practitioner (GP) consultations and 75% of hospital bed days. Elderly people with these conditions are the highest impact users of the NHS, costing £2.3 billion in 2003/04 (Dr Foster Intelligence, 2006). It is therefore unsurprising that the UK government, as with the rest of the developed world are now focusing on initiatives and models that seek to reduce this huge cost (Wilson, 2005; Wilson *et al.*, 2005). Many of the most common chronic diseases are preventable (Nissinen *et al.*, 2001) but the increasing trends towards obesity (Zaninotto *et al.*, 2006) suggests that attempts to engage the public in changing lifestyle behaviours have not been successful. In an attempt to enable a "fully engaged" public (Wanless, 2002), recent policies have focused on tapping into a concurrent trend; the active patient. The key exemplar of this is the Expert Patients Programme (Department of Health, 2001a), a lay-led

self-management programme for generic chronic diseases that seeks to harness and further enable self-management skills in people with long-term conditions (Wilson & Mayor, 2006).

1.2 The rise of the active patient

The active patient is not a new phenomenon, indeed up to the beginning of the twentieth century there was little choice for individuals but to actively participate in health care (Roberts, 1999). However, the rising success of the medical profession in the early part of the last century fostered an increasingly passive patient who was happy to accept advice and regarded the doctor with reverence (Association of the British Pharmaceutical Industry, 2002b). During the latter part of the twentieth century a sea-change began to occur, with a resurgence of active participation by patients in their health care. There were a number of triggers for this resurgence including better education demonstrated by an 80% rise in the number of UK undergraduates between 1971 and 1997, and increased access to information particularly through the Internet (Association of the British Pharmaceutical Industry, 2002a; Kivits, 2006). Linked to these changes was a concurrent loss of public confidence in the medical profession and NHS (Coulter, 2002). Coulter suggests that this loss of confidence resulted from a response to a number of UK medical scandals such as the excessive mortality rate of children undergoing cardiac surgery and subsequent cover-up at the Bristol Royal Infirmary. Coupled to this were the effects of globalization which enabled UK citizens to compare the NHS with other health care systems and judge that it appeared under-funded, and the increasing influence of the media on people's health attitudes and behaviour. Finally, these influences occurred against the backdrop of a cultural shift towards consumerism (Association of the British Pharmaceutical Industry, 2002a; Nursing Times, 2004b).

Coming to UK prominence within the Thatcher and Major eras, consumerism has continued to evolve over time from an emphasis on rights to the Blairite third way where rights are balanced with responsibilities and citizenship (Connelly, 1999). One of the rights that has been increasingly articulated is the right to active

participation in health care (Guadagnoli & Ward, 1998), indeed the right to participation is seen as an enshrining principle of Wagner's Chronic Care Model (Bodenheimer *et al.*, 2005). Nevertheless, the tension between consumerist rights and being a citizen living within a welfare state based on equity has been highlighted (Cayton, 2003). In response, some commentators argue that consumerism and citizenship have been merged into a new paradigm which now shapes the UK health arena (Sang, 2004). This paradigm is exemplified by numerous emerging models of patient-professional communication such as the informed model of decision-making (Wirtz *et al.*, 2006) and collaborative care model (Davidson, 2005). This paradigm is founded on the principle of patient/consumer as informed or indeed expert (Donaldson, 2003), and it is this group of people that the study focused upon. Whilst I will develop the concept of the expert patient within the dissertation, Jones (2003) provides a useful working definition of an expert patient as someone who will:

- Self-diagnose or offer suggestions to the doctor
- Actively seek out treatment options
- Ask about side-effects.
- Know what to expect and when to seek help.

However, whilst the policy rhetoric promotes the idea of the fully engaged, expert patient there are nevertheless a number of issues and tensions that this new paradigm brings and it is these that provide the rationale for this study.

1.3 The nature of the “problem” and research aims

There are indications that this new era of expert patient has not been accompanied by a corresponding paradigmatic shift in the health professions.

There has been some previous work in the UK on doctors' responses to active patients, and most notably Tuckett *et al.*'s (1985) seminal study on medical consultations suggested that GPs rarely pursued but instead inhibited patient initiated views. More recent work indicates that patients continue to be reticent in sharing their viewpoint within consultations (Barry *et al.*, 2000; Britten *et al.*, 2004; Stevenson *et al.*, 2003). Within nursing literature there has been a growing

acknowledgement that patient expertise within chronic illness should not only be promoted (Hughes, 2004) but also acknowledged (Fox, 2005; Wilson, 2002). Nevertheless, previous research suggests that there is some resistance from nurses towards the notion of active self-managing patients (Henderson, 2003; Thorne *et al.*, 2000). However, within the policy context of the paradigmatic shift towards expert patient and self-management, there has been very little previous research in the UK exploring nurses' responses towards active and informed patients, and little work investigating the responses of doctors towards active, self-managing expert patients. Therefore, as shown in box 1, the aims of the study were to explore these gaps in the research.

<ul style="list-style-type: none"> • How is patient expertise viewed, interpreted, defined and experienced by patients & health care professionals? • How is patient expertise promoted and enabled through the self-management process? • What mechanisms enhance or impede the development of patient expertise?

Aims of the study

Table 1

1.4 Organization of the thesis

The next chapter of the dissertation provides an overview of the nature of chronic illness. The demographic and epidemiological context of chronicity is first explored, with the main bulk of the chapter presenting the themes from a literature review on the experience of chronic illness. Chapter three continues the literature review but focuses on self-management in chronic disease. Drawn into this chapter is an analysis of policy surrounding long-term conditions.

The fourth chapter presents the research methodology and design. Critical realism as a philosophical foundation to the thesis is explored, as is the grounded theory design. It is in this chapter that I provide a reflexive account of where I am situated in the research, attempting to contextualise myself as researcher, nurse and someone who is affected by a long-term condition.

Chapter five presents the findings of the study followed by a discussion of these in the next chapter and development of a typology of the expert patient. It is within the discussion that I explore the relevance of a number of theorists in illuminating the concept of the expert patient. In particular, work surrounding the medical division of labour, power and emotion work are drawn upon.

The thesis is concluded in chapter seven with implications presented for the Expert Patients Programme and health care professionals. Finally a reflexive footnote is provided on my personal journey through this doctoral study.

CHAPTER TWO

THE NATURE OF CHRONIC ILLNESS

2.0 Introduction

This chapter seeks to provide an overview of the nature of chronic illness. There is a wealth of literature surrounding chronic illness but it is not the purpose of this chapter to provide an in-depth analysis of any particular issue. As Strauss and Corbin (1990) describe, the rationale for this review is to provide a technical background to the study arena rather than pre-empting themes that may emerge from the grounded theory. The aim of the review was to seek, map and contrast literature that provided examples of how chronic illness is perceived and described within the bio-medical, psychological, sociological, anthropological or applied perspective (Thorne *et al.*, 2002a). The context and biomedical definition of chronic illness is first presented. However, reflecting the changing pattern of research into the nature of chronic illness the chapter focuses on three broad areas that emerged from the literature; factors affecting the experience of chronic illness, the personal experience of chronic illness and responses subsequent to this experience. The chapter concludes by identifying recent moves away from the dichotomy of viewing chronic illness as an observable physical event versus chronicity as a purely socially constructed concept, towards understanding the experience of chronic illness as a tangible event inextricably placed within a constantly evolving and changing context.

2.1 Scope of the literature review

Literature was searched from 1970 onwards as it was during the 1970's that the seminal work of Strauss *et al.* (1984) on the quality of life impact of chronic illness created a sea change in the way chronic illness was researched and presented in the literature. Prior to this the medical perspective was seen as central but Strauss' work clearly identified the terrain for exploring the experience of living with a chronic illness (Conrad & Bury, 1997).

An electronic search within the PubMed, Cinahl, Assia and PsychLit databases was carried out using the key term “chronic illness”. The search was further refined by limiting the term to either the title or as a key word. All study types were included and papers were screened in terms of their potential for contributing a view of chronic illness in adults through a variety of perspectives. Pertinent references from the screened papers were also accessed. In total over 500 papers were screened from which 89 were used to form the basis of this review.

2.2 Definitions of chronic illness

Currently there appears confusion about appropriate terminology in the field of chronic illness. The terms chronic illness and chronic disease are often used interchangeably in the literature, whereas the former describes the effects of the latter. Definitions of chronic illness and disease are derived from the bio-medical perspective. The 1956 United States Commission on Chronic Illness definition includes the ideas of permanent pathological alteration, resulting in patients requiring a long period of supervision, observation or care (Strauss *et al.*, 1984). Miller also defines chronic illness as an “*altered health state that will not be cured by a simple surgical procedure or a short course of medical therapy*” (1992:4). Definitions within British health policy focus on the effects of chronic disease and illness (Ong *et al.*, 1999) with a theme of some degree of incapacity (Wilson, 2001). It is this latter theme that brings a plethora of negative imagery such as “in capable” and “in valid” that has spurred a move away from the terminology of chronic disease and illness. To reduce negative connotations “long term conditions” is the term promoted by patient organizations (LMCA, 2001) and in current use within Department of Health policy papers (Department of Health, 2005c). However, this term includes all diseases and illnesses which have an enduring nature such as cancer, and from a policy perspective covers too broad a range of conditions to all be suitable for a chronic disease management approach. Whilst experiences of having enduring conditions may have common themes between individuals, from a bio-medical or policy perspective chronic

diseases are those that are permanent, progressive if unmanaged, and where patient self-management is effective at improving prognosis. For the purpose of this review papers that illuminated the experience of any enduring physical condition in adults were included.

2.3 The demographic and epidemiological context of chronic illness

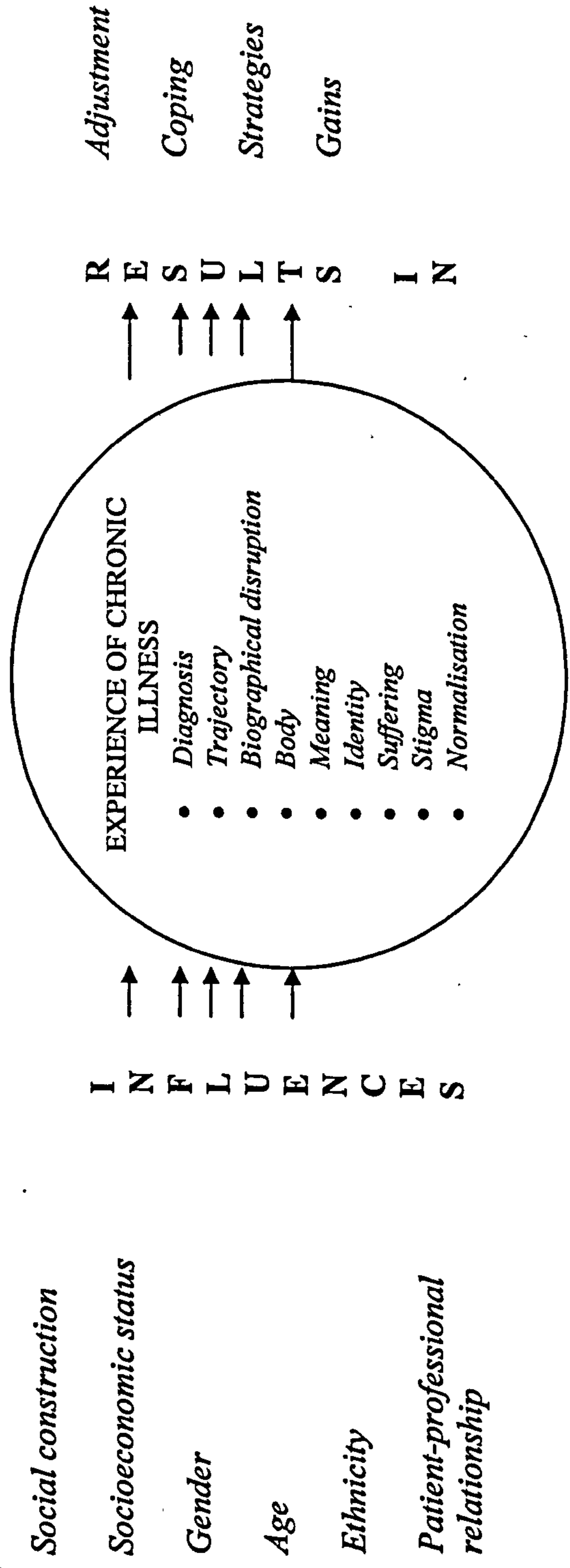
Chronic illness is seen as the most significant resource demand within the developed world's health care systems (Department of Health, 2004c; Harwood *et al.*, 2004), and is a critical indicator of need within local profiles (Ong *et al.*, 1999). In the United States just under one half of the population has some type of chronic disease, with the most common four (asthma, depression, diabetes and heart failure) being directly responsible for the generation of at least £108 billion in health care costs in 1999 (Rundall *et al.*, 2002). Within England and Wales one in three (17.5 million people) of the population has a chronic disease or disability (Department of Health, 1999a; Department of Health, 2005i) and with the elderly as the fastest growing segment of the population (Kalache, 1996) it is anticipated that these figures will rise. Within England and Wales life expectancy is currently eighty for women and seventy five for men, compared to forty eight and forty four respectively in 1900 (Department of Health, 1999a). Becoming older characteristically brings with it chronic disease and co-morbidity (Lorig *et al.*, 1996), with approximately sixteen years of a person's life expectancy being spent with a chronic disease (Department of Health, 1999a). Multiple pathology in the elderly is associated with increased morbidity (Ebrahim, 1996b). For example, osteoarthritis which affects eighty percent of the over sixty five age group (Badley & Rothman, 1996) may lead to inactivity and associated problems such as fractures (Campbell, 1996). Although morbidity in many chronic conditions is increasing, the mortality rates are falling. Whilst stroke is the seventh leading cause of premature mortality, disability and disease burden worldwide (Murray & Lopez, 1996), the standardised death rate (SDR) from strokes has fallen from one hundred and fifty in 1971, to one hundred in 1990 in the UK (Ebrahim, 1996a), with a 7% SDR reduction annually in Japan (Bonita & Beaglehole, 1995).

However, the incidence is rising with one hundred thousand first strokes annually in the UK. It is estimated that three out of four of these occur in the over sixty five age year group, with care and treatment taking up four per cent of the NHS total expenditure in 1990 (Ebrahim, 1996a) and 5.8% in 1995/6 (Stroke Association, 2006). Stroke care cost the NHS and social services £2.3 billion in 1995/6 and is projected to rise over £3 billion by 2023 (Stroke Association, 2006).

The concern over an aging population and ever increasing demand on health services is not unanimous. For example, Bury argues that current projections are based on a cohort generation and that future generations may have very different morbidity patterns (Bury, 2006; Bury & Pink, 2005). Another example of the problem in predicting future patterns is the current rise in childhood obesity which may not only increase prevalence of chronic illness but also mortality rates, for even at present approximately half a million people in North America and Western Europe die due to obesity every year (World Health Organization, 2002). Nevertheless, current evidence suggests that in the short to medium term, health service expenditure on chronic illness is likely to rise dramatically.

2.4 Findings of the literature review

A broad range of literature from the bio-medical to sociological perspective was reviewed. Three broad categories of literature emerged as illustrated in figure 1. Papers were organised into those that closely examined influences impacting on the experience of chronic illness, those that explored the actual experience of chronic illness, and lastly papers that focused upon the response to this experience from the perspective of the person living with the condition. As demonstrated by the research aims presented in the last chapter the study was particularly concerned with exploring the experience and construction of self-management in chronic illness, and therefore literature that illuminates the social construction of chronic illness will first be reviewed.



Conceptual map of the literature

Figure 1

2.5 Social construction of chronic illness

The social construction of chronic illness and disability has evolved with time. The religious construction of disability as a punishment for sins prevailed within the Middle Ages, but this was gradually replaced by altruism which culminated in the Victorian period with an array of charitable organizations helping “the less fortunate” (Hughes, 1998). Whilst voluntary organizations nowadays include those that promote a positive impression of the individual living with a chronic illness, victim-hood is a powerful and continuing image often used in fundraising. The stigma associated with chronic illness persists with, for example, the fitting and incontinence associated with epilepsy being particularly stigmatising in a society dominated by bodily control (Dilorio *et al.*, 2003; Sanders *et al.*, 2002). With the arrival of the twentieth century chronic illness was dominated by a medical construction and an accompanying sense of failure despite medical advances and the cultural emphasis on achievement (Bury, 1988; Lee-Treweek, 2001). With the western societal expectation of cure from illness (Kierans & Maynooth, 2001), there has been a tendency to relegate chronic illness from the medical sector to the care sector with a consequential reduction in state responsibility for resources (Twigg, 1997). The reconstruction of those with chronic illness as being innocent victims to culpable agents of their own misfortune (Pill *et al.*, 1999) fits with the negative view of chronicity as a burden and cost (Sanders *et al.*, 2002). Type two diabetes and cardiovascular disease are examples of chronic diseases that are often attributed to an individual’s lifestyle and there has been a growing move over the last two decades within the UK towards individual responsibility for health (Bury, 2006). The onus is now placed on the individual to maintain a lifestyle that prevents chronic disease in the first place, or at the very least prevents further deterioration and burden on the health services (Lee-Treweek, 2001).

The symbolic significance of chronic illness is highlighted by a number of authors. Bury (1988) argues that the effects of chronicity are not limited to biological functioning but also to cultural competence, which within western society includes being independent and self-reliant, hence there is a significant sense of frustration when autonomy cannot be reached (Williams, 2000).

One response to the negative societal dualistic modelling of chronic illness and disability (Kierans & Maynooth, 2001) has been the rise of a number of movements that resist the medicalised, problematised construction of disorders or disabilities. Examples include the Disability Rights movement (Sanders *et al.*, 2002) and on-line discussion forums that reject anorexia as a health problem (Fox & Ward, 2006). The dichotomy between the opposing schools of thought of disability as a product of social oppression versus disability as physical impairment is subject to a current critique and an ongoing search for a “middle way” construction particularly by critical realists (Williams, 1999). Critical realism is an emerging paradigm (explored more fully in chapter 4) which whilst acknowledging reality is interpreted and evaluated by social actors, also defines reality as existing independently of social actors’ descriptions (Bhaskar, 1978). Thus, whilst a social constructionist viewpoint may focus on, for example, diabetes type 2 becoming increasingly stigmatized as a symbol of an “unsuccessful” lifestyle, a critical realist perspective would take into account the experience of living with the disease, societal and clinician responses to the individual with the condition, but also acknowledge that there is evidence for contributing lifestyle factors affecting the body’s physiological status. A critical realist perspective would be interested in the reality of the changed physiological status for the individual, what has led to this change and the various contextual mechanisms that have influenced this change.

Nevertheless, the constructionist perspective is useful for examining how factors independent of physical state impact on the experience of chronic illness. While it is recognised that those with a chronic illness represent a marginalized group (Strauss *et al.*, 1984), the literature suggests that there is a double marginalization effect for particular groups resulting from social and economic disadvantage and it is to these that the review now turns.

2.5.1 Gender

A number of papers explicated the particular influence of gender on the experience of chronic illness. Women are more likely to suffer from a chronic illness than men (Macintyre *et al.*, 1999; O’Neill & Morrow, 2001) and are more likely to be diagnosed with medically unexplained disorders (Werner *et*

al., 2003). O'Neill and Morrow (2001) reviewed one hundred and ten studies of women's experience of chronic illness with one of the conclusions indicating that women tend to report more physical symptoms to medical practitioners and have poorer perceptions of health. However, although Macintyre *et al* (1999) acknowledge that women may be more socialised than men into confirming illness and are often attributed with being more atune to their body, their survey did not find any gender difference in the reporting of morbidity.

Nevertheless, women may have more difficulties in gaining legitimization of their illness, both from health professionals and family (Werner *et al.*, 2003). Tang and Anderson (1999) suggest that women are doubly marginalized in that they may be unfamiliar with the technical rational knowledge which underpins medical discourse and also the expectations of formal medicalised interaction. Thus although women are more likely to act on concerns about their health and consequently have more chance of preventing or getting early intervention in illness, their concerns are less likely to be acted upon not least because many are unable to voice them in the dominant rational discourse. In addition, women in particular have to deal with the chronic illness and maintaining roles such as motherhood from which it is hard to be relieved (Reynolds & Prior, 2003; van Mens-Verhulst *et al.*, 2004; Werner *et al.*, 2003). The literature suggests that for many women there is an ongoing struggle between maintaining cultural-social roles and coping with the chronic illness. As well as the obligations of being a wife and mother, the female body is perceived as a form of social capital (Kvigne & Kirkevold, 2003). Whilst stigma is discussed later on in this chapter it should be noted that when the body is affected or marked by a chronic illness or disability, the gaze of others can be particularly problematic for women.

In comparison to the literature on women, there was surprisingly very little to indicate any particular issues for men with chronic illness. However, Bates *et al* (1997) highlight the link between the inability to work with the loss of manhood and self-esteem. This lack of literature specific to men may indicate that the bulk of papers exploring the experience of chronic illness present a generic masculine voice, often ignoring the subjective experience of chronicity unique to women.

2.5.2 The older person

Older people also face a double marginalization in that chronic illness is accepted by both the individual and society as just part of old age (Lansbury, 2000). The consequence is that symptoms are discounted despite severity and there is a general lack of acknowledgment of being both elderly and disabled (Sanders *et al.*, 2002). As chronic illness is seen as a natural element of aging it is not legitimised as an illness, with both Lansbury (2000) and Sanders *et al.* (2002) describing how the older person feels pressurised into presenting a public face of “aging well” whilst suffering severe effects from the symptoms. Like women who must conform to the beauty myth, the older person is expected to deal stoically with the consequences of chronic illness. This lack of legitimisation is one barrier to older people accessing help, but Lansbury (2000) reports a number of others. Access to clinics and medical centres is often difficult for the older person due to decreasing mobility and cost implications of travel. Co-morbidity may also prove a barrier to obtaining help for one particular problem. For example, an individual with diabetes may find it difficult to access specialist help if they also suffer from severe osteoarthritis. Finally, Lansbury (2000) suggests that the fear of loss of independence may be a psychological barrier in the older person accessing professional help.

2.5.3 Ethnic minorities

The cultural background of an individual will affect the meaning of the chronic illness and the person’s reaction to it. A study comparing American Anglo and Puerto Rican patients in the United States (US) found that the former group were expected to be stoic and take responsibility for self-managing their chronic pain, whereas there was an expectation by professionals that the Puerto Rican patients would more readily express their symptoms (Bates *et al.*, 1997). Cultural health beliefs will also affect an individual’s response to chronic illness. A study comparing British Afro-caribbean and white patient’s beliefs regarding anti-hypertensive drug therapy found that the afro-caribbean group were less reconciled to long-term therapy (Morgan, 1996) than their white counterparts. The researcher suggested this

was influenced by the group's beliefs in herbal remedies and the availability of these. This belief was compounded in a preference to react to symptoms rather than to take a drug as a preventative measure. Most significantly for chronic illness, there was a general belief that conventional western medicine although vital in acute illness, was too powerful to take as a long-term therapy in chronic disease.

Ethnic minority groups are also more likely to have difficulties in voicing their needs to health professionals (Ali *et al.*, 2004) either because of language difficulties, cultural barriers or a failure of health professionals to understand the needs of individuals from differing backgrounds to their own. There is also some suggestion that the notion of active self-management in chronic illness may run counter to values such as fatalism (Griffiths *et al.*, 2005). Indeed, one of the major criticisms of the EPP is that it does not take account of such cultural sensitivities.

2.5.4 Socio-economic status

The socio-economic status of an individual will also have a significant effect on their response to chronic illness. O'Neill and Morrow (2001) suggest that those in poverty will focus on their economic survival rather than their symptoms and disease management. The links between chronic illness, social exclusion and poverty have also been explored. Burstrom *et al* (2000) analysed and compared this link in the UK and Sweden. The authors concluded that since deregulation of the British market in the early 1990's, there has been an increasingly negative impact of chronic illness on the less skilled occupation groups thus leading to a further rise in health inequalities. Although the literature highlighted specific groups that were doubly marginalized by chronic illness, the review suggested all individuals' experience of chronic illness was significantly influenced by the patient-professional relationship.

2.5.5 Health care professionals

The relationship a patient has with health care professionals has a significant impact on their experience of chronic illness and yet it is relatively under researched (Thorne *et al.*, 2005). It is suggested that within chronic illness a

collaborative relationship based on mutual participation is ideal (Coates & Boore, 1995; Watt, 2000) and appears an assumed given in much of the professional literature. However, this is often not the case with doctors questioning the very existence of patient reported symptoms (Koch *et al.*, 1999) particularly during the pre-diagnosis phase (Thorne *et al.*, 2005). Lay knowledge of the condition (Kelleher, 1988) such as the effect of anxiety in triggering exacerbations is also frequently challenged by health professionals. Despite the mantra of information giving, studies indicate that the quality of health education is poor to non-existent in chronic conditions (Gillibrand & Flynn, 2001; Koch *et al.*, 1999; Thorne *et al.*, 2005) despite an increasing expectation for patients to self-care (Coates & Boore, 1995). There is also a tension in the differing aims of patient and professional within the management of a condition, with patients' focusing on maintaining normality as much as possible within a complex life (Thorne *et al.*, 2004) often set against professionals' aims of maintaining optimal physiological response to treatment (Coates & Boore, 1995). Whilst there are common themes within the health professional and patient relationship, there also appears a distinct disease world within which this was encapsulated. Thorne *et al.*'s (2004) study suggested that diseases such as diabetes with an easily measured biochemical marker such as haemoglobin A1c (HbA1c) are prone to a coercive, punitive communication style from the professional. With improvements in biomedical analysis and the formulation of more rigid protocols with optimum biochemical markers, patients with these kind of diseases are more prone to victim blaming if their blood results are not within optimum range (Pill *et al.*, 1999). However, in disease groups such as MS, where traditional medicine has little to offer and is therefore less likely to adopt such a coercive style, patients highly value courtesy and respect not least in support of their choice to access complimentary therapies. In diseases with contested medical diagnosis such as fibromyalgia respect is valued highly as patients' often have a pervading sense of lack of credibility. Thus the "status" of the disease from a medical perspective influences health professionals' responses and what response the patient desires, with an inevitable tension if there is a mismatch between the two. Whilst the responses impact on the experience of chronic illness, the

review will now turn to the literature that explicated the actual experience of chronic illness.

2.6 The experience of chronic illness

There are a number of frameworks that have developed over the last twenty five years to facilitate an explanation of the experience of chronic illness.

Starting with Strauss and colleagues' ideas of an illness trajectory and the unending work of chronic illness, theoretical frameworks moved on to explain the significance of meaning, identity and erosion of self (Charmaz, 1990).

More recently work has focused on seeking out similarities and differences in both chronic illnesses and the differing health care contexts (Thorne, 1993; Wellard, 1998).

2.6.1 Pre-diagnosis phase

The first signs of a chronic disease are often sensations such as a mild skin irritation that an individual may rationalise as being caused by a new soap powder (Kierans & Maynooth, 2001). As the symptoms persist, often over a number of years (Sylvain & Talbot, 2002), the individual may make numerous visits to the doctor who might question the very existence of the symptoms (Koch *et al.*, 1999), with individuals having to manage the discrepancies between their own perceptions of what is happening to them and the clinician's (Thorne *et al.*, 2005). The literature suggests that there is a general belief by physicians that patients over-report symptoms (Kleinman, 1995), and there is often lengthy negotiation between doctor and patient regarding the necessity for further investigation (Robinson, 1988). The process of attracting enough attention in order for diagnostic tests to be undertaken is often the first challenge an individual with a chronic illness faces (Thorne, 1993), and consequently the actual confirmation of a diagnosis may come as a relief in legitimising an individual's health problems (Kralik *et al.*, 2001). However, generally the receiving of a diagnosis is a negative experience with feelings of utter devastation (Alonzo, 2000; Kralik *et al.*, 2001; Wiles, 1998) often leading to depression. The inappropriate nature of information given by health care professionals at the time of diagnosis is highlighted in the literature as

either being too little, too much, or timed when the patient was unable to make sense of it (Koch *et al.*, 1999; Thorne *et al.*, 2005).

2.6.2 The trajectory of chronic illness

The nature of chronic illness is that it is incurable and therefore will be with the individual for the remainder of their time (Thorne, 1993) with an inevitable restructuring of life (Pinder, 1988). A number of University of Chicago trained sociologists began researching illness from the patient perspective during the late 1950's, with Glaser and Strauss developing this work in the seminal exploration of dying in hospitals (Glaser & Strauss, 1965). They extended this work into an examination of the chronic illness experience, highlighting how people manage to maintain a normal a life as possible despite the disease. Stemming from this pioneering work (Strauss *et al.*, 1984), the experience of chronic illness is frequently described in terms of a trajectory or career (Wellard, 1998). Strauss *et al* (1984) argue that the trajectory model is based on the patient's personal perception of their illness which may be different to the physician or relatives' perceptions. The trajectory framework is based upon the idea that chronic conditions have a common course that varies and changes over time (Corbin & Strauss, 1992). Within the framework are eight phases (table 2) which are not necessarily linear and may contain sub-phases (Corbin & Strauss, 1992). Having a chronic illness means that an individual remains within the trajectory until the end of their life (Burton, 2000).

The trajectory framework is criticised as being a biomedical interpretation (Scott Dorsett, 1992), and indeed bears striking similarities to the sections of an individual's medical notes. It could also be argued that the phases post trajectory onset are not peculiar to individuals with chronic illness. People with or without chronic disease may have acute health problems, stable periods when they are in good health, times when they feel less well but not ill enough to seek medical help, deterioration towards the end of their lifespan and inevitable death. However, perhaps the strongest argument against the trajectory framework is that it makes the chronic illness central to an individual's persona. In reality, the illness may just be a small part of the

Pretrajectory	Before the illness course begins, the preventive phase, no signs or symptoms present
Trajectory onset	Signs and symptoms are present. Includes diagnosis period.
Crisis	Life threatening situation
Acute	Active illness or complication that require hospitalisation for management
Stable	Illness course/symptoms controlled by regimen
Unstable	Illness course/symptoms not controlled by regimen but not requiring hospitalisation
Downward	Progressive deterioration in physical/mental status characterised by increasing disability and symptoms
Dying	Immediate weeks to hours preceding death

The Trajectory Framework (Corbin & Strauss, 1992)

Table 2

person who has a number of other trajectories happening such as education, relationships and so on. For individuals' themselves, being labelled with an inevitable trajectory can be perceived as significantly disempowering (Thorne *et al.*, 2005).

2.6.3 Biographical disruption and the body in chronic illness

The trajectory framework provided the foundation for the development of the biographical paradigm; with Strauss *et al* (1984) suggesting that an individual's changing view of their trajectory profoundly affects their sense of identity. The concept of identity as a consequence of biographical disruption is identified extensively in the literature (Asbring, 2001; Bury, 1988; Charmaz, 1991; Conrad & Bury, 1997; Strauss *et al.*, 1984). Identity and biographical disruption are shaped by both the meaning attributed to the chronic illness (Thorne, 1999) and the changing relationship with the body in chronic illness. It is not the purpose of this section to provide an in-depth analysis on the wealth of sociological literature on the body. However, its significance as a

theoretical framework must be acknowledged and indeed the notion of the body in chronic illness is returned to within the discussion chapter. The duality but intertwined nature of the body as both a physical object and subjective lived entity forms the basis of much sociological work (Fox & Ward, 2006; Kvigne & Kirkevold, 2003). There are a number of historical critiques of medicine's focus or clinical gaze (Foucault, 1976) upon the body as a physical object, and the pervasiveness of medicine as controlling, defining and treating the body (Bury, 2001; Frank, 1990). Spurred on by the work of pioneers such as Strauss and Glaser (Strauss *et al.*, 1984), there has been a growing sociological interest in the lived experience of the body (Williams, 1999), and the problematising of the body when it fails (Corbin, 2003), is unpredictable or demanding (Kvigne & Kirkevold, 2003), or is a constant reminder of what one can no longer do (Ironsides *et al.*, 2003). The problematic nature of the body in chronic illness is emphasised by late modernity's celebration of the healthy or perfect body (Walter, 2004) and the rewriting of the chronically ill body as a failure (Frank, 1990). A person with a chronic illness has an increasing awareness of their body, and unlike others is unable to forget it (Davies, 2003; Price, 1996). Keirans and Maynooth (2001) highlight that this awareness is even more acute when what is normally hidden inside the body (for example, urine) is made visible outside (for example, in a catheter bag).

2.6.4 Biographical disruption and meaning in chronic illness

The literature suggests that people need to find meaning of a chronic illness to make sense of what is happening to them, often questioning why did I get this illness? Meaning is often symbolic (Baker & Noerager Stern, 1993) with people either attributing the illness to a life crisis or reframing it as being spared something far worse. Thorne (1999) argues that meaning in chronic illness is to be found at different levels of complexity such as the health care system, society as well as the individual's history. Bury (1988) separates meaning into two aspects. Firstly meaning as consequence of a disease, for example pain in arthritis that dominates an individual's life. Secondly, meaning as significance such as the inevitability of arthritis in old age

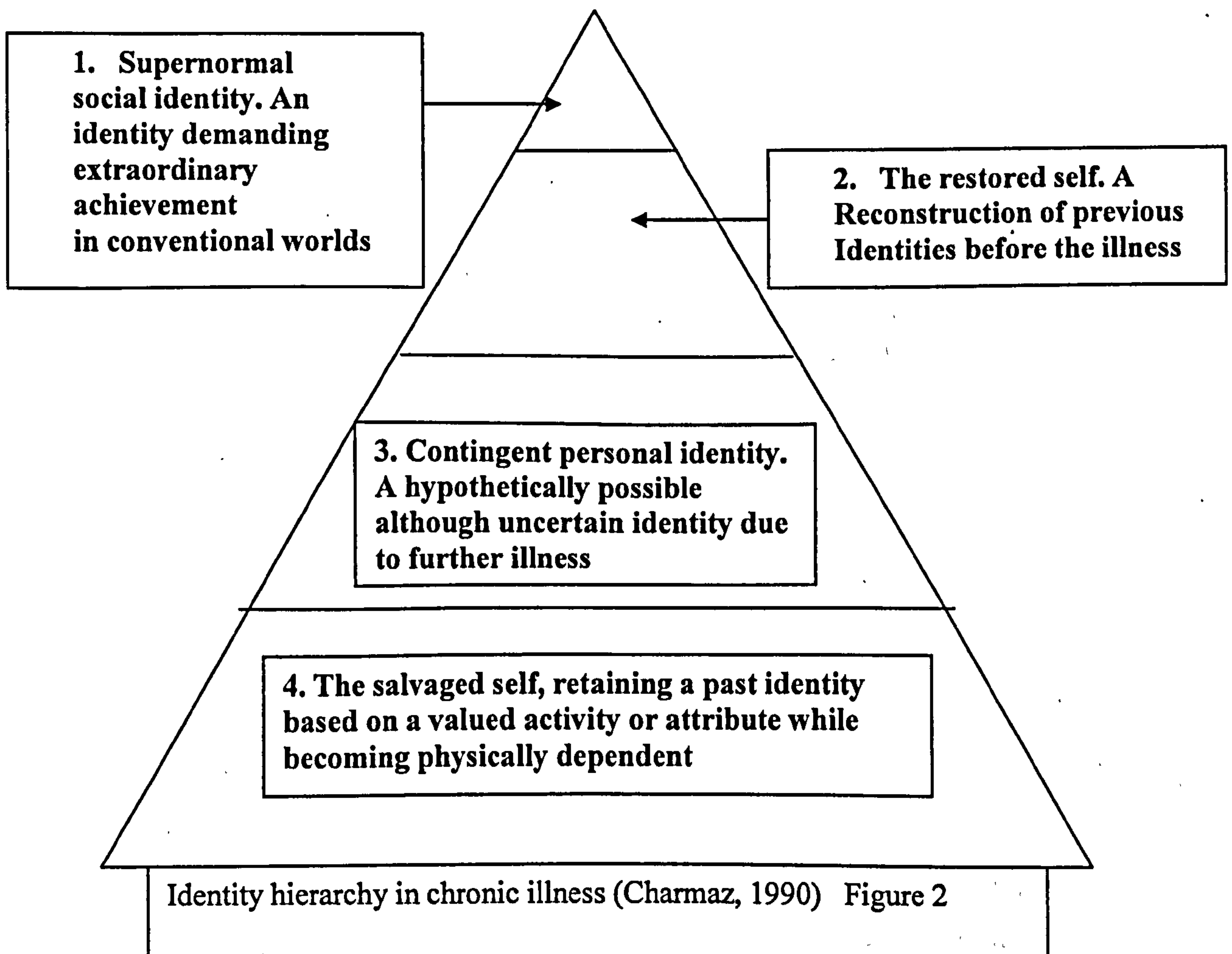
(Sanders *et al.*, 2002). Sanders *et al* (2002) point out that these meanings may be in direct conflict as in the case of the elderly with arthritis.

Meaning within chronic illness may be formed by contingent and moral narratives (Bury, 2001). Contingent narratives are based on the beliefs and knowledge a person may have about the onset of the illness whereas moral narratives introduce an evaluative element with accounts and justifications for the illness (for example, the disease was caused by years of working in a factory). Meaning also depends on the disease itself (Roberson, 1992) with a less intrusive disease such as hypertension having a different meaning than arthritis. Meaning also changes with time (Wiles, 1998). Wiles (1998) found that immediately after a heart attack people did not deem it serious as they had survived. However, the same individuals reframed it as serious if they did not make a full recovery with time. Meaning contributes to the struggle people with chronic illness have in attaining valued lives and selves (Charmaz, 1990).

2.6.5 Biographical disruption and changing identity in chronic illness

Several factors in the experience of chronic illness will impact on an individual's identity such as the isolation (Hodges *et al.*, 2001), limitations and compromises a person has to make within the social context (Koch *et al.*, 1999). Asbring (2001) ascribes identity change in chronic illness to loss of the past self, work and social life. This idea of biographical disruption which is mainly attributed to the work of Bury (1988) is critiqued as being inappropriate for those who were born with a chronic illness (Williams, 2000). However, for those who develop the condition later in life the challenge is to regain an identity. Charmaz (1990) suggests an identity hierarchy in chronic illness (figure 2). She argues that with disease progression people may have to reduce their identity goals and aim for a less preferred one – the restored self. In addition to coming to terms with a new biography (Asbring, 2001), the literature also highlights the concept of suffering as part of the experience. Suffering is often thought about in terms of physical symptoms such as pain from arthritis (Sanders *et al.*, 2002). However, Charmaz (1999) argues that psychological suffering is far more significant to the individual than physical distress.

Both Koch *et al* (1999) and Gillibrand and Flynn (2001) give the example of the constant worry involved in living with diabetes such as the fear of coma, future complications and death. Psychological suffering contributes to an individual's definition of self (Charmaz, 1999), and also provides a moral status. Suffering brings with it certain moral rights such as being deserving, dependent and in need. It can also bring an elevated moral status where people who suffer may be seen as heroes (Charmaz, 1999). However, Charmaz (1999) argues that this moral status wanes with time as people begin to tire of the individual's tales of their experiences, and so to maintain their moral status an individual may take risks in their health such as carrying on working or remaining silent about pain and other distressing symptoms (Charmaz, 1999). Whilst the biographical framework identifies the issue of changed identity as a major consequence of chronic illness, it focuses on the individual's perception



of their identity rather than the impact of society or others in shaping the individual's identity. Whilst undoubtedly, not being able to do the things one used to be able to, shapes the new identity, the way one is perceived by others is a powerful influence on identity. Feeling under the gaze of others, feeling patronised or pitied, or feeling less worthy when asked by others what your occupation is (Galvin, 2005) all impact on the biography. The other may not be a stranger as biographies can also be rewritten by family members (Gregory, 2005), or indeed health professionals who rewrite the individual as a patient, with this latter aspect virtually ignored within the literature. The impact of outsiders on self-identity can be seen clearly when the notion of stigma is explored.

2.6.6 The stigma of chronic illness and the quest for normalcy

Moral status is affected by the stigmatising effects of the chronic illness. Wellard (1998) explores the fact that all long-term conditions are stigmatising not least because a patient will be labelled as the illness rather than as an individual. However, some diseases are particularly stigmatising either because of cultural taboos such as human immunodeficiency virus (HIV) (Miller, 2003) or due to visually obvious symptoms such as an epileptic fit. Pinder (1988) describes Parkinson's disease as potentially discrediting and argues that individuals use covering tactics in order to disguise the fact that they have the disease. Mental health issues within chronic illness such as depression have an inherent stigmatising element that may be more powerful than physical problems (Cohen *et al.*, 1995), and the level of stigma will also be affected by cultural interpretation (Bates *et al.*, 1997). Bates *et al* (1997) give the example of the Anglo American values of autonomy and remaining stoic with the greater perceived stigma if these values cannot be achieved due to a chronic illness. The literature reveals a recurring response to the stigmatising effects of chronic illness. Wellard (1998) describes stigma as the reaction to someone who does not appear "normal" to others. Therefore the response is to appear to be as normal as possible, a process described as

normalizing (Strauss *et al.*, 1984). Strauss *et al* (1984) describe normalizing tactics as hiding intrusive symptoms such as skin lesions, coaching friends and relatives, keeping up with usual activities and maintaining self-poise; part of the unending work of living with a chronic illness. Having a long-term condition results in a reframing by the individual of what is normal (Thorne, 1993). Thorne (1993) gives the example of the diabetic who measures “normal” by their blood glucose readings, whereas a non-diabetic may measure normalcy in terms of career progression. As the chronic disease progresses an individual may need to lower expectations of normalcy, a process identified by Strauss *et al* (1984) as renormalizing. Helping the individual to live a normal a life as possible pervades much of the literature (Bostrom & Ahlstrom, 2004; Wellard, 1998), but is a critiqued concept. Thorne (1993) argues that this quest for normalcy prevents many individuals in being realistic about their condition. The concept of “normal” is also contested as a social construction (Thorne, 1993), and is rejected as a concept by the Disability Rights Movement (Hughes, 1998; Williams, 1999). In conclusion, the exploration of the literature surrounding the experience of chronic illness often describes the individual almost as if they are living within a void with the disease. There appear to be gaps in work that explore how others, particularly health care professionals impact on identity and experience within chronic illness. Whilst this area has been neglected there are a number of papers that explore some of the responses to chronic illness; adjustment, coping, strategies and perceptions of gain.

2.7 Responses to chronic illness

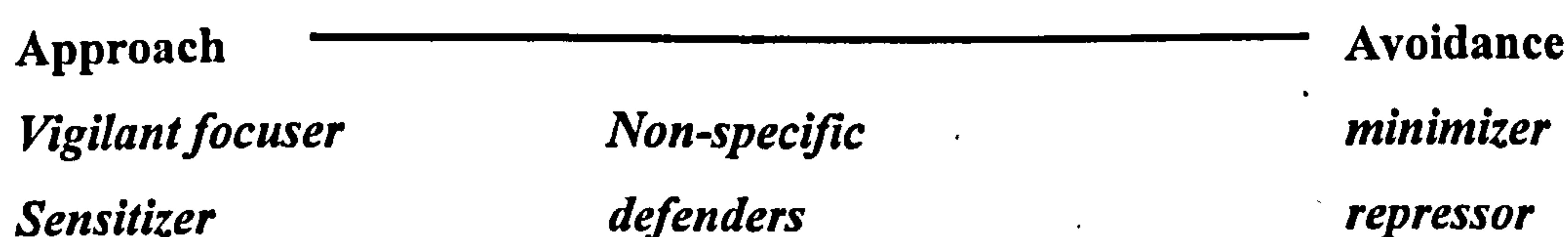
Adjustment to chronic illness is seen as a prerequisite for good quality of life, well-being, positive self-esteem and satisfaction with life. It is defined as “*a response to a change in the environment that allows an organism to become more suitably adapted to that change*” (Sharpe & Curran, 2006). However, developing my earlier argument that much of the work on chronic illness appears to assume the individual is in a void, the idea of adjustment to chronic illness also fails to acknowledge complexity of an individual’s life in adapting to a constantly changing environment not solely defined by chronic illness. One of the complexities of the adjustment is a persons relationship with

others, not least health professionals. Whilst there is a growing realisation that support from both family, friends and the wider community including professionals is a major factor in promoting resilience or effective adjustment (King *et al.*, 2003), there has been little empirical work on the impact of professionals on adjustment (Thorne *et al.*, 2005).

2.7.1 Coping with chronic illness

Part of adjustment is learning to cope with the illness within the complexity of life. Coping is described as being a mental process by which people seek to maintain a sense of self-worth despite the experience of the illness (Pound *et al.*, 1999). Various functions of coping are described within the literature such as adapting to the illness, helping decision making, maintaining autonomy and motivation, controlling potential stressors before they become a threat and avoidance of negative self-appraisal (Miller, 1992). Barnard (1995) encapsulates these functions into three themes; a search for meaning, an attempt to regain mastery over events in an individual's life and an effort to enhance self-esteem.

Miller (1992) develops a continuum of coping styles (figure 3), with a study by O'Neill and Morrow (2001) suggesting that women are more likely to use confrontive coping styles whereas men more commonly utilise avoidance coping styles.



Continuum of coping styles (Miller 1992)

Figure 3

2.7.2 Strategies

Although intimately linked with coping style, strategies are described as more practical responses of people in order to minimize the impact of the illness on their everyday life (Pound *et al.*, 1999). A number of strategies are described in the literature although they are often linked to specific groups. Lansbury

(2000) found that older people often prefer strategies such as home remedies and distracting themselves by keeping busy as opposed to professionally suggested strategies. Pound *et al's* (1999) study suggests that individuals who have had a stroke use a number of strategies such finding new ways of doing activities, methods of re-learning that had not been suggested by professionals, creating their own exercise programme, and particularly in the younger patients covering up any sign of the stroke. Research with people with back pain suggest that protecting oneself and taking great care are the individual's prime concern (Lee-Treweek, 2001; Shaw & Huang, 2005) which may differ from a physiotherapist's advice to take exercise. Many papers indicated that people develop imaginative and proactive strategies but often keep these hidden from professionals (Paterson, 2001). Resisting over- medicalisation of their life is a repeated theme within the literature and this would include denial of the illness to professionals, minimising disabilities and avoiding activities that would identify the individual as sick (Ong *et al.*, 1999), or seeking alternative therapies (Thorne *et al.*, 2005). However, although the bulk of the papers reviewed focus on the successful nature of the strategies employed by people with long-term conditions, Kelleher's (1988) study of diabetic patients suggests that people adapt to an illness rather than cope with it.

2.7.3 Gain in chronic illness

An emerging theme in the more recent literature is the paradoxical nature of chronic illness in that it brings suffering and loss but also some gains. As discussed in the previous section, suffering endows a certain moral status with people who maintain their personal dignity in the face of adversity being regarded as heroic (Charmaz, 1999). A qualitative study of chronically ill individuals' self-perception of their state of health revealed themes such as positive seeking and connecting with others, celebrating life, and a perception of acquiring a state of grace (Lindsey, 1996). People with even a debilitating chronic illness are often more likely to perceive their quality of life as higher than an outsider may judge (Barnett, 2005), again indicating that for many chronic illness is just a small part of a complex life. Asbring (2001) also suggests that having a chronic illness provides the opportunity for re-evaluating life and ignoring trivia, with half of the respondents in her study

feeling they had a deeper understanding of themselves, others and life in general. However, despite this more positive response to chronic illness the majority of literature links the event of chronic illness with significant loss (Asbring, 2001). It is perhaps more appropriate to view chronic illness as a mix of losses and gains, again reflecting the normal tapestry of life. Reliance by professionals on a theoretical framework such as the bereavement model to understand the experience of chronic illness fails to capture the complexity (Alaszewski *et al.*, 2004).

2.8 Conclusion

A generation of literature on chronic illness has been reviewed with the range suggesting a shifting perspective from a purely biomedical perspective to one that encompasses the nature of an inevitable enduring disease course, effects on self-identity, and more recently that the experience of chronic illness is intertwined with the milieu that the individual inhabits. This latter viewpoint calls for a middle perspective in chronic illness which moves away from the dichotomy of illness as a physical event versus a purely constructed phenomenon, to a philosophical stance that understands chronic illness as an identifiable event that happens in and is influenced by a constantly evolving and changing context; a critical realist perspective (Williams, 1999). To understand the context appears as important as understanding the individual with chronic illness, for although the rhetoric may have changed from a disease focus to enabling an individual to be in control of their long-term condition, it is understanding how this control is interpreted and influenced not only by the individual but also by other key actors and organizations. In particular, the literature search revealed gaps on how health professionals interpret and influence personal control in long-term conditions. Although papers were identified that explored interactions between health professionals and patients, there appeared less work on how clinicians influence patients in active and independent self-management of their long-term condition.

CHAPTER THREE

SELF-MANAGEMENT IN LONG-TERM CONDITIONS: POLICY RESPONSES & ANALYSIS OF THE LITERATURE

3.0 Introduction

The aim of this chapter is twofold. First, policy surrounding long-term conditions (LTC) is analysed with the current emphasis on self-care illuminated. Second, the literature surrounding self-management in health care will be explored. The review will demonstrate how there is currently a confused picture with the terms self-care and self-management often being used interchangeably or simultaneously. Therefore the chapter will attempt to define self-management and differentiate it from self-care. A number of theoretical models for self-management will be explored and drivers, strategies and outcomes of self-management will be reviewed. The chapter will be completed with a critical realist analysis of barriers to self-management, including health professionals' responses.

3.1 Policy responses to long-term conditions

In the previous chapter literature exploring the impact of chronic illness on individuals and their families was explored. However, whilst there is some acknowledgement of the impact of chronic disease on quality of life of the individual and their family (Department of Health, 2004c), this is often subsumed by the focus on resource issues within policy papers.

Paradoxically, it is the resource issue that affects all health care consumers, not just those with a LTC, that proved the major trigger for the plethora of policies on LTCs. Access, and particularly speed of access to services is the major concern for most users of health services (Coulter & Magee, 2003), and cutting of waiting lists for treatment was and continues to be a main priority for the current government (Hudson, 2005). People affected by LTCs make up 60% of hospital bed days, comprise two thirds of all emergency admissions and tend to be highly intensive users of health services. Not only do people affected by LTCs make up 80% of all GP consultations, but also make up a

small group of inpatients (10%) that account for 55% of inpatient days (Department of Health, 2004c). It is therefore unsurprising that the aim of the majority of policies is to cut the need and demand particularly for inpatient services in order to reduce waiting times for the remainder of the population. However, this focus is not without criticism with particular concerns about the effect that concentrating targets on elective care has on the care and management of people with LTCs (Kings Fund, 2004). Nevertheless policy makers would be likely to argue that their work is underpinned by the principles of patient involvement and choice, with a patient-led NHS (Department of Health, 2005a) the espoused aim. Whilst the current government's mantra of involved and active patients is explored in-depth in the discussion chapter (6.3), it is appropriate to note at this point that the challenge for policies is not only to develop mechanisms to ease the demand on resources, but also to enshrine the principles of public involvement, patient participation and choice.

3.1.1 An overview of the policies

The majority of systematic work on managing chronic illness has emerged from the US and current government policy leans heavily on this with the development of an Anglo-US approach (Hudson, 2005). Wagner's Chronic Care Model (CCM) (Bodenheimer *et al.*, 2002b) exemplifies current thinking. Developed by a panel of experts in the US the model is based on the premise that chronic care spans hospital, community and social care organizations and indeed the wider community (Lewis & Dixon, 2004). The model is made up of a number of interdependent components (table 3) with the aim of providing a coherent approach and seamless service (Hudson, 2005; Royal College of Physicians *et al.*, 2004).

Whilst in the past the Department of Health has focused on a disease specific approach as exemplified by the National Service Frameworks (NSF) such as the Diabetes and Coronary Heart Disease NSF (Department of Health, 2000; Department of Health, 2001b) the CCM is a generic approach for all LTCs. The current emphasis on generic rather than condition specific approaches stems from a realisation about the incidence of co-morbidity with the

associated problems of managing a number of health needs in one individual. For example, the adverse events associated with multiple medications is

<p>COMMUNITY</p> <p>Mobilising community resources to meet the needs of patients, for example encouragement of patient support groups.</p>
<p>ORGANIZATION OF HEALTH CARE</p> <p>Creating a culture and mechanisms promoting safe, high quality care, for example auditing and evaluation of diabetes service for the housebound.</p>
<p>SUPPORT SELF MANAGEMENT</p> <p>Preventing health deterioration and promoting a sense of empowerment for patients by using and encouraging effective self management support strategies such as the Expert Patients Programme.</p>
<p>DESIGN OF DELIVERY SYSTEM</p> <p>Assure effective delivery and efficient clinical care and self management support, for example by clearly identifying roles and responsibilities within the multidisciplinary team.</p>
<p>DECISION SUPPORT</p> <p>Promoting evidence based practice and patient choice by the use of clinical guidelines and the development of skills in facilitating concordance.</p>
<p>CLINICAL INFORMATION SYSTEMS</p> <p>Managing patient and population data to enable effective care, for example the use of disease registers to invite patients with diabetes for regular reviews.</p>

Chronic care model (Lewis and Dixon 2004)

Table 3

problematic and there may also be patient and professional differences in terms of outcome preferences (Tinetti *et al.*, 2004). This coupled with an acknowledgement that whatever the disease, individuals need to alter their behaviour in some way and deal with the psychosocial impact of the condition (Wagner & Groves, 2002), lends chronic disease management to a generic approach. The most recent NSF to be published illustrates this new approach (Department of Health, 2005c).

3.1.2 A generic approach - the NSF for Long Term Conditions

Although aimed for applicability to all LTCs, this NSF was built upon the specific needs of those affected by neurological LTCs such as epilepsy and multiple sclerosis and is indicative of the sea change to generic rather than condition specific approaches. By focusing on people affected by a long term neurological disease not only does the NSF identify the needs of this significant group who make up approximately 10 million of the UK population and comprise approximately 50% of all people accessing Social Services (Department of Health, 2005c), but also remains broad enough to be relevant to the needs of all those affected by a LTC. The underpinning aims are to promote equitable access to a full range of health and social care services such as rehabilitation, promote independence, autonomy and quality of life for users and their carers, provide choice and responsiveness for users and their carers, and avoid discrimination and enable diversity (LMCA, 2001). The NSF also took on a new style to previous ones with devolved responsibility and less targets and milestones (LMCA, 2001), with standards being replaced with quality requirements (appendix 1). Nonetheless, the very broadness of the NSF has not only been criticised for attempting to meet the needs of very diverse groups (Agrawal & Mitchell, 2005), and failing to be a useful vehicle to understanding the myriad of initiatives in current LTC policy (Wilson, 2005). In order to gain a clearer understanding of how policies have developed it is necessary to return to examining how the CCM is operationalised in the US.

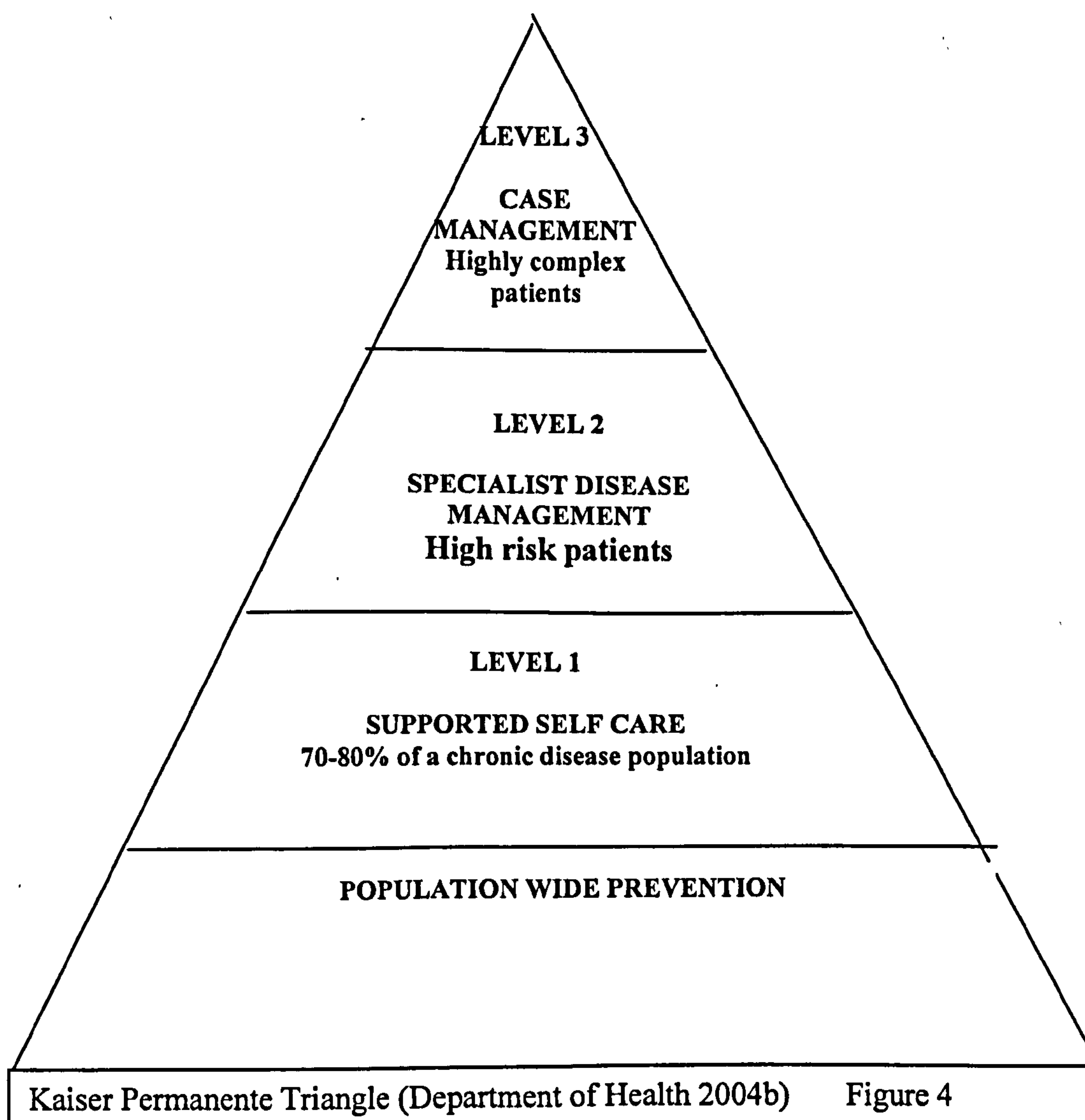
3.1.3 Operationalising the CCM. The example of Kaiser Permanente.

While Wagner's CCM has been globally adopted (Gask, 2004), it is most embedded within US managed care systems. A key exemplar is Kaiser Permanente (KP) and is particularly significant as the Department of Health has extensively explored how the KP system could be adapted within England. Despite the fact that the UK achieves better value for money in health care than the US (Ham, 2005), there has been great interest in specific US health systems such as KP. As a managed health care system, KP has more similarities with the NHS including not-for-profit status, an enrolled and defined population, and capitation (Lawrence, 1996). However, compared to

the NHS, KP achieves better performance, particularly in hospital bed usage. Ham *et al's* (2003) study exploring the reasons behind KP's efficiency uncovered a number of factors. Integration, particularly of primary, secondary and tertiary care was found important. There was also greater emphasis on prevention of illness, self-care, and active management of patients either to prevent admission or to facilitate hospital discharge to specialist intermediate care.

3.1.4 Kaiser Permanente Triangle

So that interventions could be targeted appropriately, the KP system involves stratifying the enrolled population in terms of risk, developing a conceptual model for this; the KP triangle (figure 4).



This model acknowledges that people affected or at potential risk of LTC have very differing needs varying from prevention of developing a LTC in the first place to the needs of highly complex and dependent patients. The levels of care provided in this model are termed stepped care, and is seen as providing a framework for using limited resources to the greatest effect (Von Korff *et al.*, 2002).

The KP triangle has been adapted by the Department of Health to organise LTC policy initiatives (Department of Health, 2005h). It is important to note that the triangle is built upon a foundation of population wide prevention focused upon in the white paper “Choosing Health” (Department of Health, 2004a). The rhetoric of this paper is to “reconnect” health with the general population by enabling informed choice, ensuring the choices are relevant for a community by personalisation and encouraging healthy choices by a process of working together. This latter principle of the citizen having both a right and responsibility for health (explored further in chapter 6) is a key example of current government thinking (Wilson, 2001) and can be found in the majority of health policies. An example of an associated initiative is the implementation of Health Trainers for disadvantaged areas (Department of Health, 2005b) which will be part of the “Fitter Britain by 2012” campaign (Department of Health, 2006d).

Whilst prevention of LTCs is the ultimate aim via public health initiatives, as described earlier the most urgent priority is to reduce emergency bed days by 5% by March 2008 (Department of Health, 2005h). In the shorter term strategies are focusing on levels 3 and 2. Because of the impact on resources of patients with highly complex needs an intensive case management approach is promoted. This involves the identification of the most vulnerable and intensive users of secondary care (Hudson, 2005) and then applying an individualised, whole person approach with interventions aimed at promoting maximum function, independence and quality of life (Department of Health, 2004b; Skills for Health, 2005). Nurses are seen as key in this approach (Department of Health, 2005i) and a US model – Evercare, has been piloted in nine English Primary Care Trusts (PCT) (Winstanley, 2004). Primary care nurses with advanced skills (Advanced Primary Nurse) (APN) (Department of Health, 2003) are now relabelled as Community Matrons and currently PCTs

are working towards implementing 7000 such posts by March 2007 (Department of Health, 2005h). However, the evaluation of the Evercare model in the UK suggests there has been no reduction in hospital bed days in this client group (Boaden *et al.*, 2006). Paradoxically, there is also the suggestion that identification of the target group has led to a number of patients being placed on the APNs caseload who were not previously known to the Health Services, hence increasing rather than decreasing demand (Boaden *et al.*, 2005).

However, albeit that homing in on those with complex needs may bear some short term gains in terms of efficient use of health resources, it is the “battle” to promote effective self-management in the vast majority of the population living with a LTC that is seen to be one of the most important ones to win.

3.1.5 Policy focus on self-care

The Wanless Report (2002) suggests that for every £100 spent on self-care approximately £150 of benefits can be delivered in return, such as a 40% reduction in GP visits. Wanless depicts three possible future scenarios of health service use, and argues that the Fully Engaged scenario is the cheapest long-term option. This would be exemplified by a high level of public engagement, a significant rise in life expectancy and health status, and an increasingly efficient health service.

The government have responded with a number of initiatives focusing on self-care. Following positive evaluations in North America there is currently development of on-line decision support in the UK to help people decide whether they need to consult the GP such as NHS Direct Online (Department of Health, 2005f). Initiatives are set to increase (Eve *et al.*, 2003) and are currently targeted on those most in need. For example, people with serious mental health problems are significantly more likely to have a physical chronic disease and there is now an impetus on addressing this group’s self-care needs via the Well Being Programme – an integrated programme generally led by a Mental Health Nurse focusing on promoting healthy living (Department of Health, 2006a).

However, perhaps the most cogent example of a self-care initiative that encapsulates the generic approach discussed earlier and principles of an engaged public is the Expert Patients Programme (EPP).

3.1.6 The Expert Patients Programme

The EPP is explored throughout the dissertation and the content of the EPP is dealt with in chapter 5 (5.4.9) and presented in appendix 2. I will develop a critique of the programme in the discussion chapter (6.3.1), therefore the purpose of this section is to trace the origins of the programme and its introduction into England and Wales.

The model for the EPP was developed by a US nurse, Kate Lorig. In 1978 she started work on an arthritis patient education research project at Stanford University, developing the Arthritis Self Management programme (ASMP). Early research showed a rise in health status in participants who completed the programme, however no association could be found between this improvement and any changes in behaviour or knowledge (Lorig & Gonzalez, 1992). A chance meeting with Albert Bandura, a Canadian psychologist based at Stanford University, led to further research to investigate whether self-efficacy was the key factor in the ASMP's success. Bandura (1986) who developed the concept of self-efficacy describes it as the belief in one's ability to achieve an action (the concept is explored in 3.3.3). In 1990 building on the ASMP's results and in collaboration with KP, Lorig developed the Chronic Disease Self-Management programme (CDSMP) (Sobel *et al.*, 2002). The CDSMP is based on the assumption that whatever the long-term condition, people need to develop a generic set of skills to self-manage successfully (Lorig *et al.*, 1996), and these skills form the content (Bodenheimer *et al.*, 2002a; Lorig *et al.*, 1999). Positive evaluations of this programme and the success of the ASMP which was introduced to the UK by Arthritis Care in the 1980's (Barlow & Barefoot, 1996; Barlow *et al.*, 1998a) added impetus to the development of the EPP, particularly by its adoption by the Long Term Medical Conditions Alliance (LMCA) as the LILL Project (Cooper, 2001).

Attracted by evaluative results suggesting it was an intervention that could reduce hospital bed days (Lorig *et al.*, 1999) and that it could be effectively delivered by volunteer lay tutors (Bury *et al.*, 2005), the Department of Health

set up a taskforce including members of Arthritis Care and the LMCA. Now a Professor in the Stanford Patient Education Research Centre, Lorig was heavily involved with the Department of Health in the development of the EPP. Personally championed by the Chief Medical Officer, the EPP was introduced in 2001 (Department of Health, 2001a) and piloted in nearly 300 PCTs over the next three years (Wilson & Mayor, 2006). The EPP is a six-week small-group intervention attended by people with different chronic conditions. It is taught by peer instructors from a highly structured manual based on self-efficacy theory.

It should be noted that the EPP is particularly cost-effective as it is delivered by a volunteer workforce. Via a standardised training day and assessed delivery of two programmes, suitable lay people who have a long-term condition themselves are taught to facilitate the EPP as lay tutors (Department of Health, 2005g). They are provided a manual and are required to adhere rigidly to the teaching material in it. In most cases, apart from travelling expenses the lay tutors run a number of EPPs a year without any payment, which considering that they are living with a LTC themselves is a significant commitment. Ideally there are 2 lay tutors running each programme which normally has about 10-20 participants. The lay tutors are supported by an EPP trainer who is paid to support the programme within a region.

It is also pertinent to observe here that whilst named as a self-management programme, the content (appendix 2) appears to be more closely aligned to the concept of self-care. This exemplifies the semantic muddle of self-care and self-management; a confusion that will now be explored.

3.2 Self-care and self-management: overlapping concepts

A useful, all encompassing definition of self-care is “...*the things people do because of ...*” a health problem (O'Hara *et al.*, 2000). This will include both self-care and self-management activities, and the differentiation between the two will be developed in the next sections. However, what will be discussed first is the overlap between the two, interfaces created because self-care and self-management are often mutually dependent and are underpinned by common theoretical frameworks.

A common theme in defining self-care and self-management is that it is a hallmark of the management of all chronic illness (Department of Health, 2002a), and requires the acquisition of new knowledge and skills (Watt, 2000). In diabetes it is estimated that 98% of the management is self-care (Toljamo & Hentinen, 2001) and much of the research carried out surrounding self-care is with this disease group.

Analysis of the literature reveals a large number of perspectives through which self-care and self-management are defined. From an individual's viewpoint self-care is a psychosocial response and part of everyday life, whereas health care professionals' commonly perceive it as an activity supplemental to medicine (Stevenson *et al.*, 2003). Whilst self-care and self-management are often defined as independence from professionals, the literature indicates a paradoxical but concurrent idea of self-care being the performance of professionally set behaviours (Baker & Noerager Stern, 1993). Baker and Noerager Stern (1993) also describe self-care as a mutual activity that is dependent on the individual's abilities. Despite the assumptions of many authors that self-care and self-management are a legitimate and expected patient behaviour (Coates & Boore, 1995), there appears to be a contrasting anxiety from the patient's perspective as to whether professionals see their self-care as legitimate (Stevenson *et al.*, 2003). The resulting barriers from these differing viewpoints will be discussed further in 3.7.

3.2.1 Defining self-care

Self-care consists of the ability to evaluate one's state of health and adjust one's behaviour (Makinen *et al.*, 2000). One of the most well known theorists on self-care is Orem (Orem, 1995), who defines self-care as the "*action of mature and maturing people who have developed the capabilities to take care of themselves in their environmental situations*" (1995:103). Orem describes six self-care activities that are learned behaviours (Ricka *et al.*, 2002) (table 4).

Despite Orem's work often being drawn upon as a foundation for nursing it is nevertheless open to criticism. First, she argues that self-care is conditioned by scientifically derived health knowledge and yet as I will argue there is a strong case for effective self-care being based on lay derived health knowledge.

Connected to this is my second criticism in that she argues that technical knowledge about self-care must be drawn from authoritative sources but fails to voice who defines “authoritative” source. Third, point five of table 4 above speaks of the need for acceptance and yet I will develop the case (see chapters

1. Seeking and securing appropriate medical assistance
2. Being aware of and attending to the effects and results of pathological conditions
3. Effectively carrying out medically prescribed measures to regulate or prevent pathological processes or compensating for disabilities
4. Being aware of and attending to or regulating discomfort
5. Modifying the self-concept in accepting one-self as being in a particular state of health and in need of a specific form of health care
6. Learning to live with the effects of medical diagnostic and treatment measures in a lifestyle that promotes continuing personal development.

Orem’s six self-care activities (Ricka *et al.*, 2002)

Table 4

5 and 6) that some active self-managers do not “accept” but fight for alternative views of health and health care from that defined by health professionals.

Nonetheless, if these activities are seen to form the basis of self-care and self-management then there are a number of ways that they can be enacted.

Toljamo and Hentinen (2001) describe four differing modes of self-care: flexible, regimen adherent, self-planned or neglect. Similarly, Chapple and Rogers (1999) put forward four types of self-care behaviour: regulatory, preventative, reactive, and restorative. What is interesting is that not all these modes are professionally set, and professional approval is unlikely to be gained by neglect, or in some cases self-planned self-care.

As in Orem’s work, other authors also closely link self-care with self-development. Self-care is seen as an active, responsible and flexible process that will result in personal development (Ricka *et al.*, 2002), and Corner (2001) sees self-care as cultivating oneself.

The literature discussed so far suggests that self-care is a series of activities that an individual must learn to manage their condition or to prevent further deterioration. There is also a wealth of literature that links self-care to activities in well people. However, to maintain the focus of the thesis, literature was only included that directly described self-management in chronic illness.

3.2.2 Defining self-management: how is it different from self-care?

A large amount of work in self-management as opposed to self-care is in the field of asthma (Lahdensuo, 1999), where it is described as the patient making therapeutic, behavioural and environment adjustments in line with professional advice (Partridge, 1997). Whilst behavioural and environmental adjustments are part of self-care activities as described earlier, it is the therapeutic adjustments that appear characteristic of self-management. In asthma this would involve adjusting inhaler medication or commencing oral steroids (Lahdensuo *et al.*, 1996). Diabetes also has a long history of self-management where patients are increasingly expected to adjust their insulin dosage (DAFNE Study Group, 2002; Toljamo & Hentinen, 2001), but a newer area of self-management is in anticoagulation where some patients self-test and self-dose (Fitzmaurice & Machin, 2001). Thus, the key difference between self-care and self-management is that in the latter patients are undertaking tasks that are the traditional province of professionals such as prescribing drug dosages. In view of the fact that many health care professionals would have years of training to undertake these tasks, it is unsurprising that the literature highlights the need to provide the means for patients to develop self-management skills (Corner, 2002).

Definitions of self-management (table 5) are more specific than self-care although there are several common features such as being a proactive process, complying with professional advice, close attention to one's body, and having the appropriate coping behaviour (Worth, 1997). The feature of self-surveillance as opposed to professional surveillance could be argued to be empowering for the patient (Corner, 2001), however this may simply be replacing one form of subjugation with another.

The chapter will now go on to describe some of the theoretical models underpinning self-management.

- Assessing and responding to signs and symptoms in line with professionally set rules (Fishwick *et al.*, 1997)
- Adjusting medications (Worth, 1997)
- Self treatment (Van der Palen *et al.*, 1997)
- Self-test, interpret results, change drug dosage (Fitzmaurice & Machin, 2001)

Definitions of self-management

Table 5

3.3 Theoretical underpinning of self-management

As described in the above sections there is considerable blurring of the boundaries between self-care and self-management. One reason for this appears to be that the theoretical underpinning of self-management is derived from that of self-care. This section will present the major theories but will conclude by critiquing these as professionally set and outlining an alternative lay theory model that provides a contrasting framework to underpin self-management.

3.3.1 Responses to self-care

A small number of theories pertinent to self-care and consequently to self-management, focus on the individual's responses. A study on coping strategies in the self-management of chronic heart failure (Buetow *et al.*, 2001) suggested that patients have four differing approaches in emotion-focused coping. The first response was typified by avoidance, with patients reluctant to face reality. Secondly, patients demonstrated disavowal or self-deception in the face of accurate perception, in other words – hope. The two other responses are characterised by either complete denial or acceptance. The authors conclude by arguing that disavowal provides more scope for self-management and improved outcomes, and connect this with these respondents self-description of a fighting spirit and proactive response to the situation.

Another example of a theory that relates to the individual response to self-care is learned resourcefulness (Boonpongmanee *et al.*, 2003). This is described as a set of personal skills to manage the undesirable effects of certain conditions (such as pain) in order to self-care effectively. In a study of HIV infected women, it was found that learned resourcefulness reduced depression and increased self-care abilities (Boonpongmanee *et al.*, 2003).

The interrelationship between personal characteristics and responses to self-management are explored further in 3.6.

3.3.2 Health Belief and Socio-behavioural Models

Whilst there are a range of other theories that attempt to explain health behaviours and service utilization, significant attention has been paid to the Health Belief Model (HBM) in relation to self-care (Hassell *et al.*, 2000) and therefore warrants some discussion. The HBM has been linked by a number of authors to self-care (Coates & Boore, 1998) and has five components (Hjelm *et al.*, 1999). These include an individual's readiness to take a particular course of action, perceived risks and benefits from taking an action which will be influenced by the individual's view of the seriousness of the condition, internal and external cues for action such as pain, self-efficacy, and lastly modifying factors such as culture and gender (Hassell *et al.*, 2000). Culture is seen as having a significant modifying effect. A study comparing Yugoslavian and Swedish diabetics suggested that being raised in an independent, individualistic society results in a more pronounced readiness for self-care than those raised in a dependent collective society (Hjelm *et al.*, 1999). However, the HBM has been extensively critiqued in failing to provide a significant correlation between health beliefs and professionally set self-care (Roberson, 1992). A study of the health beliefs of diabetic patients found that although the majority of respondents demonstrated that their attitude towards the disease, treatment and seriousness would imply effective self-management, the health outcomes were unsatisfactory from which the authors argue that neither health beliefs or perceptions of control have any demonstrable effect on the outcomes of diabetes self-management (Coates & Boore, 1998).

While the HBM has insufficient explanatory power in self-care, social cognitive theory, particularly self-efficacy, appears to provide a firmer prediction of self-care (Strecher *et al.*, 1986).

3.3.3 Social Cognitive Theory

Social cognitive theory (Bandura, 1986) is strongly linked to the health belief model not least because self-efficacy is a central construct, and as stated earlier, is the underpinning framework for the CDSMP (Lorig *et al.*, 1996) on which the EPP is based. The theory recognises that human functioning is explained in terms of the reciprocal relationship between behaviour, cognitive and personal factors, and environmental events. An individual is seen as having a number of capabilities that shape behaviour and have a direct bearing on self-care actions (table 6). Self-efficacy is defined as the belief in one's own ability to achieve an action (Bandura, 1986) and is a central construct within social cognitive theory. It is strongly linked to outcome expectation; the expected consequences of the action. The majority of people will avoid undertaking tasks such as self-management of a disease if they believe it is beyond their capabilities, or if the expected outcome does not provide sufficient reward for the amount of effort put into the activity. Thus, although a person with diabetes may know the consequences of poor glycaemic control, they may still feel incapable of self-managing, or in contrast may feel able to self-manage but do not perceive the outcomes as outweighing the effort required. Many professionals underpin their relationship with the patient on these theoretical constructs, and often there is a focus on the outcomes of the prescribed self-care and self-management. However, professionals are more likely to articulate outcomes as a negative consequence of non-adherence to self-management. Studies of clinicians' talk with diabetic patients illustrated the frequent use of fear as a tactic to promote self-management (Broom & Whittaker, 2004; Loewe *et al.*, 1998) and the literature reviewed for this chapter had a predominant focus on the consequences of poor self-management. Professionals and self-management programmes in general aim to increase self-efficacy by a number of means. Repeated failures are likely to decrease self-efficacy

<p><i>Symbolizing capability</i></p> <p>People use symbols to transform experiences into internal models that serve to guide for future action. For example, a walking stick is seen to symbolise infirmity and people may go to great lengths to manage without one despite the risk and possible consequences of pain.</p>
<p><i>Forethought capability</i></p> <p>People are able to calculate likely consequences of an action not just based on previous experience. The individual may decide that even though they have never had a fall, the likely consequences of falling without their walking stick are too great when they are fatigued.</p>
<p><i>Vicarious capability</i></p> <p>Learning through observing other peoples' experiences and actions. The individual may know of someone with a fractured neck of femur because they had not used their walking stick.</p>
<p><i>Self-regulatory capability</i></p> <p>Much of peoples' behaviour is motivated and regulated by internal standards and self-evaluative reactions to their own actions. A fiercely independent individual may resist the use of a walking stick as they perceive it as capitulating to the condition.</p>
<p><i>Self-reflective capability</i></p> <p>By reflecting on varied experiences the individual gains generic knowledge and understanding which may lead to altered thinking. Thus, a person may gain insight into their resistance to the use of a walking stick and reframe it as a tool to promote their independence.</p>

Basic capabilities in social cognitive theory (Bandura, 1986) Table 6

(Bandura, 1986) and so self-management education will promote small positive steps (Buchmann, 1997). Vicarious experience is also seen to increase self-efficacy (Bandura, 1986) and thus small groups are seen as effective in developing self-management skills (Barlow & Barefoot, 1996). Although less effective than the two previous tactics, verbal persuasion is also seen as a useful tool in raising self-efficacy (Bandura, 1986; Sigurdardottir, 1999).

Professionals may also actively address fear and anxiety which may be reducing self-efficacy in an individual (Bandura, 1986).

3.3.4 Constructed by professionals: a critique of the theories

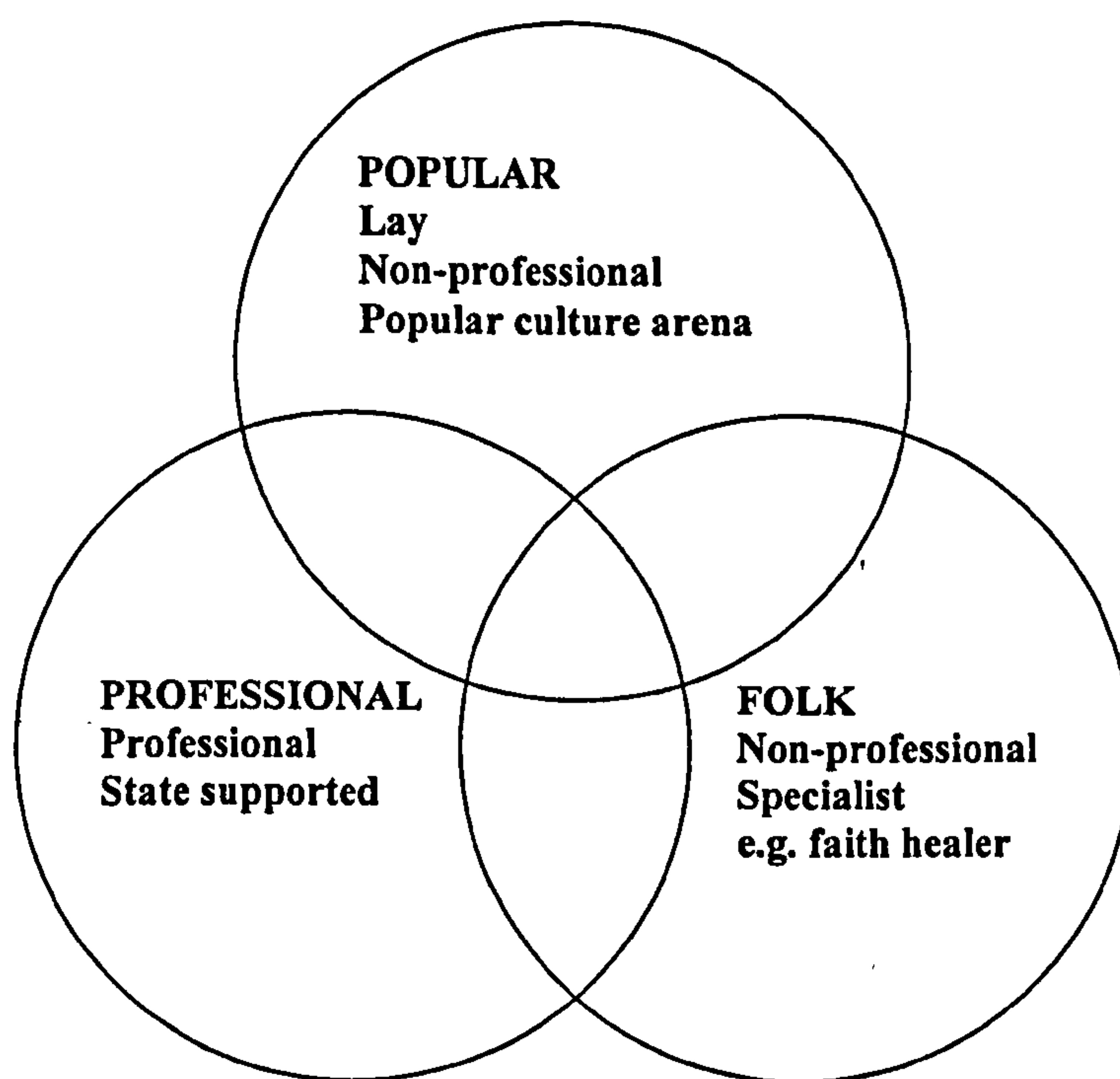
Whilst the above theories provide the foundation to self-management programmes such as the EPP, they are open to criticism for being constructed with an implicit assumption of the superiority of professional knowledge. The Health Belief Model is about beliefs rather than knowledge, thus although a person may have beliefs about an illness this is inferior to knowledge about the illness (Prior, 2003). All the above models have the principle of non-compliance leading to a deleterious effect (Buchmann, 1997). However, non-compliance is professionally defined and actions that may be viewed as non-compliant by a professional do not necessarily lead to poor health outcomes (Roberson, 1992; World Health Organization, 2003). Despite many clinicians' misgivings, self-management does not mean blindly following instructions in order to adhere to a treatment regimen (Michie *et al.*, 2003). Indeed a study by Koch *et al.* (2004) suggested that people who have lived with a condition over a number of years are likely to develop a self agency model of self-management which includes the learning of tricks, deciding what and what not to share with clinicians particularly about making changes to their medications, and taking control and being self-determined.

It is therefore appropriate to explore frameworks that acknowledge the construction of self-management by the lay person. One that has received significant attention is the Kleinman framework.

3.3.5 Kleinman's Health Care Sectors

The psychiatrist and anthropologist Kleinman (1980, 1988) critiqued health professionals as viewing in the same reductionist manner both disease and illness. In contrast to the pathological definition of the former, he defines the latter as the perception and response to symptoms and disability by the individual, their family and wider social network. This critique is extended by arguing that professionals often fail to take into account the sociocultural origin, structure, function and significance of health care (Kleinman, 1980).

Kleinman (1980) described all health care systems as having three overlapping sectors (figure 5). The popular sector is the lay cultural arena where illness is first defined and care activities initiated, providing the potential gateway to the other two sectors, and whilst it is the largest part of any health care system it is also the least researched and understood (Kleinman, 1980). This is the sector where health beliefs are formed from popular culture, where self-care activities are defined, and where the contribution of the other two sectors is evaluated and responded to. Kleinman (1980) suggests that each sector, rather than individual people, has its own specific body of knowledge, values and



Health Care sectors (Kleinman 1980)

Figure 5

beliefs, and that these are governed by explanatory models (Kleinman, 1980; Kleinman, 1988). Explanatory models seek to explain a number of questions

about illness episodes such as aetiology, time and mode of onset, pathophysiology, course of the sickness including type of sick role, and treatment. Whilst professionals attempt to answer all of these questions, lay people focus on the questions most salient to them, with particular problems arising when there is significant distance between the individual's and professional's explanatory model. In professional-set self-management, problems may arise if the professional uses verbal persuasion to encourage practices that are aimed at preventing the long-term consequences of a poorly controlled disease process, whereas the recipient may only be focused on reducing the effects of the disease on current daily activities. Professionals may also perceive the use of other sectors such as complimentary therapies (Thorne *et al.*, 2002) as illegitimate and hence individuals do not share information about their use of these alternative treatments (Stevenson *et al.*, 2003).

The reliance on the professional sectors' explanatory model and frequent rejection of the popular and folk sector's model contributes to self-management being a schismatic concept.

This section has presented examples of theoretical models that underpin self-management. The theories are drawn from two ends of a continuum between professional and lay perspectives which represent the major bulk of work in this area. However, as I draw on a critical theorist framework throughout the thesis (explored in depth in the next chapter), the remainder of this chapter will deal with the aspects of self-management which would further contribute towards a critical theorist model of self-management. As Bhaskar would argue that the last layer of a phenomenon should be understood first before underlying structures can be explored (Collier, 1994), strategies to promote self-management and outcomes of self-management will now be discussed.

3.4 Strategies to promote self-management

This section will provide an overview of the strategies that are used to promote self-management ranging from simple information giving to empowerment strategies.

3.4.1 Information giving

It is acknowledged that there is a huge amount of literature pertaining to information giving, however the purpose of this section is to briefly sketch the themes. The themes linked to the findings of this study (for example use of the Internet) are explored more fully in the Discussion chapter.

There is a general assumption that increased knowledge will lead to increased self-management skills, and for knowledge development information should be presented in a clear manner, appropriately paced (Heisler *et al.*, 2002). The timing and form are also deemed important with well validated references and web sites being given for further reference, translations as necessary, and patient held records (Department of Health, 2002a). Individuals appear most receptive to information at a first hospital admission (Osman, 1997) or when newly diagnosed (Sylvain & Talbot, 2002), and a number of written materials have been designed to reinforce oral information (Kennedy, 1999). However, the link between knowledge and self-management is disputed by others who argue that the former does not necessarily lead to the latter (Coates & Boore, 1998; Newman *et al.*, 2004).

More recently attention has increasingly been given to the concept of health literacy which is defined as the degree to which people are able to obtain and understand basic health information in order to make appropriate decisions about their health (Vass, 2003). A study by Gazmararian *et al.* (2003) of 653 older people with a range of chronic conditions concluded that health literacy level was an independent predictor of patient's knowledge of their chronic disease even after controlling for other variables such as age and attendance at a condition-specific education programme.

3.4.2 Self-management intervention programmes

Programmes can be delivered to individuals or groups and little difference of outcomes has been found between the two (Barlow *et al.*, 2002), although the latter is more cost-effective (Liljas & Lahdensuo, 1997). It is suggested that a mixed approach may be most effective where group sessions are supplemented

by individual counselling (Lahdensuo, 1999). There is also some debate as to whether generic education for chronic illness is more effective than condition specific, with Lorig *et al.* (1996) arguing there are general skills to manage all long-term conditions, whereas others suggest that there are specific issues for each disease (Rapley & Fruin, 1999). The process evaluation of the EPP also suggested that participants particularly with diabetes would prefer a condition-specific course (Rogers *et al.*, 2005a). Content of a programme may range from general guidance and support (Sylvain & Talbot, 2002), to a prescriptive content generally covering information, drugs, symptoms, psychological consequences, life style, social support, and communication. In the CDSMP (Lorig *et al.*, 1996) these are presented as interactive sessions, led by a role model and using learning contracts. Again, little difference in outcomes has been found between using a lay person versus professional to facilitate the group (Barlow *et al.*, 2002; Bury *et al.*, 2005).

Many programmes such as the CDSMP utilise a cognitive behavioural approach, exemplified by encouraging behaviour change in small steps (Von Korff *et al.*, 2002). Buchmann (1997) suggests that the use of referent power (being a frame of reference) is a useful strategy in this approach (table 7), exemplified by the lay tutor role in the EPP.

- | |
|--|
| <ol style="list-style-type: none"> 1. Give acceptance statements 2. Talk and act in a benevolent fashion 3. Encourage self-disclosure to gain insight 4. Use selective positive feedback 5. Build a sense of personal responsibility 6. Attribute endorsed norms to a respected secondary group 7. Elicit commitment to taking the actions necessary to complete specific recommendations 8. Maintain an attitude of positive regard 9. Plan for termination of care from the onset |
|--|

Ways of increasing referent power (Buchmann, 1997)

Table 7

However, although a route to increasing self-efficacy this strategy needs to be sensitively implemented if it is to prevent paternalistic overtones (Coulter, 2002).

3.4.3 Written guidelines

This is a growing area of tools used in the promotion of self-management and has been led by asthma care. Two examples of such guidelines are the Asthma British Plan, and International Asthma Management Plan (Fishwick *et al.*, 1997). Although patient preferences have been little explored, Fishwick *et al.* (1997) found that smaller, less detailed plans are preferred, with less reliance on peak flow readings as the sole self-assessment measure. A qualitative survey of the Asthma British Plan also suggested that shared goals on such plans are better achieved when there is a focus on everyday life rather than just disease management (Steven *et al.*, 2004). Indeed, as raised earlier the importance of focusing on patient-defined personal goals cannot be overstated (Health & Social Care Campaigners International, 2005).

3.4.4 Empowerment strategies

Empowerment is a contentious concept and has a number of definitions. Within this thesis I interpret empowerment as engendering autonomy and self-direction (see Discussion chapter). However, it should be acknowledged that the reality of autonomy within self-management is generally confined to a set pattern and rules that are professional-defined (Willems, 2000), such as asthma self-management plans.

Problem orientated participatory education has been used in Sweden for diabetes self-management, but was found to have little effect on HbA1c (NHS Centre for Reviews and Dissemination, 2000). The ASMP has been extended to include a Personal Independence Course. However, although participants felt more knowledgeable about health care services, they continued to perceive themselves as powerless in addressing barriers they met in health care provision (Barlow & Williams, 1999). A strategy currently being developed is the WISE Approach (Kennedy & Rogers, 2001). It deals with many of the perspectives that may impinge on an individuals' ability and willingness to self-manage, and has involved patients as co-developers of the tools and strategies within the approach (table 8). This acknowledgement of the "lay

sector” resonates with Kleinman’s framework (3.3.5). Evaluations of this approach indicate a rise in patients’ self-efficacy and decrease in visits to out-patients and GP consultations, and symptoms (Kennedy *et al.*, 2004b).

The chapter will now explore outcomes of self-management in further depth.

STRATEGY	METHOD
Improve information	Develop the use of patient information that is relevant, accessible and uses a combination of lay and traditional evidence-based knowledge
Improve access to services	Change access arrangements to health services and use patient/professional contacts as a means of impacting on future utilization.
Change professional response	Promote flexibility in professional response through a patient-centred approach.

WISE Approach (Kennedy & Rogers, 2001)

table 8

3.5 Outcomes of self-management

Whilst not providing a systematic review of self-management programmes, this section will provide an analysis of the literature that described outcomes of self-management programmes. Literature was searched from the past ten years to capture content and effectiveness of interventions from the last fifteen years. An electronic search within PubMed, Cinahl, Assia and PsychLit databases was carried out using the search terms “chronic illness”, then “self-management” or “self-care”, and then “education*” or “program*”. To refine the search further specific diseases were then screened (asthma, arthritis and diabetes). These were selected because of their high incidence and the associated costs to health services. In addition, recent disease non-specific self-management initiatives were also screened (anticoagulation and generic programmes) to provide contrast to condition-specific programmes. Out of a total 133 papers, 48 were used for this review. Papers were rejected either because of a lack of detail regarding the intervention or outcomes, or because

the intervention was reported in-depth in an included paper. The bulk of the studies reviewed attempted to provide evidence of effectiveness via a randomised controlled trial (RCT), however it should be noted that the majority of these have been criticised as methodologically weak (Bury *et al.*, 2005; Gibson *et al.*, 2002; Riemsa *et al.*, 2002). It is also apparent when applying the definitions developed in 3.3 that some of the self-management programmes are actually developing self-care skills. In addition, patient-defined outcomes were rarely identified, with the majority focusing on professionally-defined outcomes.

3.5.1 Asthma

The largest volume of work was found on asthma (Bodenheimer *et al.*, 2002a) with a range of outcomes described. Whilst a few reports attribute programmes to improved symptom control (Kauppinen *et al.*, 1998; Liljas & Lahdensuo, 1997) and self-efficacy (Lucas *et al.*, 2001), the vast majority of studies are inconclusive with very few showing any improvement in lung function (Bodenheimer *et al.*, 2002a; Clark & Nothwehr, 1997). However, concerns are raised in the literature regarding the reliance on peak flow readings as the sole measurement of lung function (Partridge, 1997), but despite this, peak flow readings are seen as the main outcome measure in the majority of studies. Several authors link positive outcomes of a programme with the severity of the disease with higher success rates seen in chronic severe asthma rather than mild (Fishwick *et al.*, 1997; Lahdensuo *et al.*, 1996). However, although poor attendance is noted in one study as a problem (Jones *et al.*, 2000) even those who do complete the programme were found to be ignoring advice regarding smoking and keeping pets (Makinen *et al.*, 2000). Lahdensuo *et al.*'s (1996) RCT exemplifies the unclear nature of the outcomes for whilst oral antibiotic and steroid use, and unscheduled out-patients visits were reduced in the intervention group, there was no change in rates of hospitalisation between the control and intervention group. Kauppinen *et al.*'s (1998) RCT also suggests these programmes may not be cost-effective. Systematic reviews of asthma self-management programmes indicates that self-management has no effect on lung function except when the patient is

enabled to take over self-treatment (Gibson *et al.*, 2002; Lahdensuo, 1999; Newman *et al.*, 2004).

3.5.2 Arthritis

A considerable amount of work has been carried out in the UK evaluating the outcomes of the ASMP (Barlow & Barefoot, 1996; Barlow *et al.*, 1998a; Barlow *et al.*, 1998b; Barlow & Williams, 1999; Barlow *et al.*, 1999).

Outcomes in terms of psychological state are found to be very positive with increased self-efficacy as measured by the Stanford self-efficacy tool (Barlow & Barefoot, 1996; Barlow *et al.*, 1998b). However, fatigue and depression have not been affected by the programme (Barlow & Williams, 1999). It is also claimed that the ASMP has a significant effect on pain control equal to 20-30% of the strength of a non-steroidal anti-inflammatory drug (Barlow *et al.*, 1998a). However, systematic reviews of self-management programmes for rheumatoid arthritis summarise outcomes as being limited and short-term, with no demonstrable long-term benefits (Riemsma *et al.*, 2002; Taal *et al.*, 1997). This is exemplified in Barlow *et al.*'s (1998a) long-term study that found after one year, although pain control remained stable, visits to the GP had increased significantly. Buszewicz *et al.*'s (2006) more recent RCT showed no significant effect on pain, physical function or contact with primary care.

3.5.3 Diabetes

Although a systematic review of diabetes self-management programmes indicated an improvement in HbA1c (Newman *et al.*, 2004), very few studies have long-term follow-up (Goudswaard *et al.*, 2004). A review of the range of approaches used in diabetes care could find no evidence to prove their efficacy (NHS Centre for Reviews and Dissemination, 2000). Other authors highlight the lack of a link between self-management programmes and increased HbA1c control (Bodenheimer *et al.*, 2002a). Paradoxically, whilst it is acknowledged that HbA1c is affected by a number of factors apart from self-management activities (Toljamo & Hentinen, 2001), professionals continue to use it as the evidence for effective self-management (Pill *et al.*, 1999).

3.5.4 Anticoagulation

This is a new and growing area of self-management, and of particular interest as the development of International Normalised Ratio (INR) home testing equipment has enabled self-management and self-dosing (Fitzmaurice & Machin, 2001). Three controlled trials (Heidinger *et al.*, 2000; Sawicki, 1999; Watzke *et al.*, 2000), three RCTs (Fitzmaurice *et al.*, 2005; Menendez-Jandula *et al.*, 2005; Murray *et al.*, 2004) and a randomised cross-over comparison (Cromheecke *et al.*, 2000) demonstrate that self-management and self-dosing results in a significantly improved INR therapeutic range when compared to clinic based testing and dosing. Despite this evidence and the examples of the US and Germany where self testing and dosing are the norm, there continues to be clinician resistance to this form of self-management in the UK (Wilson, 2002).

3.5.5 Generic self-management programmes

The CDSMP has been extensively studied with a number of positive evaluations in terms of improving self-efficacy (Dongbo *et al.*, 2003; Farrell *et al.*, 2004; Schreurs *et al.*, 2003), and reduction of health resource usage (Lorig *et al.*, 1999). Previous work by Lorig *et al.* (1986) suggested no difference in outcomes between a lay or professional-led programme, but an obvious cost-saving in the former. Therefore, the CDSMP is designed to be taught by two trained voluntary lay tutors. A six-month RCT (Lorig *et al.*, 1999) suggested that the 664 participants in the intervention group (receiving the CDSMP) had significant outcome variables improvement such as self-rated health, pain and psychological well-being when compared to the 476 in the control group (on 6 month waiting list for CDSMP). Health service utilization was also significantly less in the intervention group. However, a follow-up study (Lorig *et al.*, 2001) following the same participants also demonstrated improvements in many outcomes but the improvement trend had dropped off significantly. There are a number of positive evaluations globally including China (Dongbo *et al.*, 2003) and Australia (Swerissen *et al.*, 2006), but again evaluations tend to be short-term.

The Expert Patients Programme has undergone an internal evaluation of nearly 1000 participants from 245 EPPs. Whilst the results of this evaluation are very

positive (table 9), the early results from an external RCT of the EPP are slightly less glowing. This trial recruited 315 patients to the intervention arm (immediate participation in an EPP) and 316 to the control arm (waiting list for EPP) (Bower *et al.*, In press). At the time of submitting this thesis the results from the RCT were not published, however the findings have been presented as an unpublished paper (Bower, 2006) (table 10).

- 45% more confident that common symptoms would not interfere with their lives
- 38% symptoms less severe
- 33% better prepared for consultations
- 7% reduction in GP appointments
- 10% reduction in out-patient appointments
- 16% reduction in A&E visits
- 9% reduction in physiotherapy use

Internal evaluation of the EPP (Expert Patients Programme, 2004) Table 9

Whilst the external evaluation confirms that at the very least the EPP “does no harm” and is cost neutral, it underlines the criticism made that other evaluations have tended to overstate the effectiveness of such interventions (Bury *et al.*, 2005), ignore those participants who have dropped out of the programme (Bury & Pink, 2005) and that the courses have failed to recruit (Anderson, 1996) or engage those most in need (Foster *et al.*, 2003; Griffiths *et al.*, 2005).

- medium effect on self-efficacy
- small effect on energy levels
- no effect on health utilization
- £27 saving for PCT per patient who attends an EPP in a six month period – cost neutral for NHS

External evaluation of the EPP (Bower, 2006)

Table 10

3.5.6 Self-management outcomes: an overview

Although many claims have been made regarding self-management programmes including reducing visits to the GP by up to 17% (Corner, 2001;

Edwardson & Dean, 1999), improved symptom control (Lorig *et al.*, 1996) and self-efficacy (Barlow *et al.*, 2002), the studies reviewed for this chapter did not provide clear evidence for this. Proponents of self-management attribute this to weaknesses in appropriate methodology (Barlow *et al.*, 2002; Newman *et al.*, 2004) and a lack of research in this area (NHS Centre for Reviews and Dissemination, 2000; Riemsa *et al.*, 2002). This review also suggests that it is professionals who are defining successful outcomes, often focusing on physiological measurements (Clark, 2003b). These type of outcome appear most successful when individuals are enabled to take over treatment and dosing management, such as in asthma (Gibson *et al.*, 2002) and anticoagulation (Fitzmaurice & Machin, 2001). This may be due to the huge diversity in efficacy between pharmacological interventions when compared to other self-management interventions and it is the case for the latter that still needs to be proved (Bury *et al.*, 2005). Additionally there is a need to explore the nature of successful outcomes as defined by the patient, as the literature suggests an enduring focus on improving professional defined compliance (Vaughan & Pearson, 1998).

The last two sections have explored the visible structures and outcomes of self-management. The chapter will now go on to its conclusion by analysing the often hidden aspects of self-management: personal drivers and inhibitors, and the professional response to self-management.

3.6 Drivers and inhibitors of self-management

Personal drivers in self-management can be divided into those external and internal to the individual. It is suggested by a number of authors that self-management ability is learnt early in life within the social context (Backman & Hentinen, 1999; Rapley & Fruin, 1999), with a strong link to formal education (Bury *et al.*, 2005; Muntner *et al.*, 2001). However, a study by Toljamo and Hentinen (2001) found no link between education or age and self-management abilities in diabetic patients. Friends, family and colleagues are also seen as providing a significant external driver for self-management, although they can have the opposite effect if they are seen as nagging or viewing the condition as a stigma (Clark & Nothwehr, 1997; Dilorio *et al.*, 2003).

Much of the literature reviewed highlighted the effect of internal personal drivers, such as an internal locus of control where the individual does not ascribe responsibility for the condition to outside elements (Coates & Boore, 1995) such as “fate” or the medical profession, but rather the person has an internal sense of their own ability to control and manage the disease and or behaviours. The perceived severity of the disease will have a direct influence on willingness to self-manage, with the opposite effect provided by silent diseases such as hypertension (Lahdensuo *et al.*, 1996; Lau-Walker, 2004; Muntner *et al.*, 2001; Roberson, 1992).

The process of becoming ready to take on self-management is described as re-identifying the condition to being a part of oneself, with self-management as a tool to reach normalisation (Adams *et al.*, 1997; Baker & Noerager Stern, 1993). This outcome of the process of normalisation can only be reached at a certain stage of the illness trajectory (Chapple & Rogers, 1999), and thus problems may be encountered if self-management is imposed on an individual at an inappropriate phase of their disease, such as immediately following diagnosis.

Personal drivers for self-management can be described in a hierarchy (Edwardson & Dean, 1999) but the ultimate driver appears to be seeking self-management strategies that make the disease manageable, “liveable with” and effective from the individual’s perspective.

Depression and psychological state can be a major inhibitor to self-management (Boonpongmanee *et al.*, 2003; Jerant *et al.*, 2005), as can characteristics such as being unable to take a long-term view (Hjelm *et al.*, 1999), viewing oneself as sick and therefore dependent (Baker & Noerager Stern, 1993), and lacking motivation and time management skills to maintain many self-management activities (Barlow & Barefoot, 1996). The existence of co-morbidities is also likely to inhibit self-management (Bayliss *et al.*, 2003). Both Backman and Hentinen (1999) and Toljamo and Hentinen (2001) suggest that poor self-managers tend to be lonely, isolated and not caring about what happens to them. It is also worth noting that even those who do develop proficiency in self-management may not retain expertise as a constant, with self-management skills varying over time (Paterson & Thorne, 2000).

Beliefs may also act as a potentially significant inhibitor, with concerns over long-term use of medicines (Adams *et al.*, 1997; Osman, 1997; Stevenson *et al.*, 1999) combined with a mistrust of medical judgement (Coulter, 2002) acting as a major deterrent to professionally set self-management. The perceived stigma of disease may also act as an inhibitor (Riley *et al.*, 2001), for example the fear of being seen as a “weakling” when using an inhaler in public. Misinterpreting the disease as an acute short-term illness rather than a chronic condition may also lead to poor self-management, and often the transition from acute to recovery onset phases will lead to a decrease in self-management (Barlow & Barefoot, 1996).

However, it is argued in papers from a critical social science perspective that it is often practicalities that most inhibit self-management, such as a lack of resources to self-manage (Chapple & Rogers, 1999; Wilson, 2001). For example, a patient who is not provided with a home INR testing kit will be unable to self-test and self-dose (Wilson, 2002). In addition, what the professional instructs the patient to do for self-management may be unacceptable to the individual in the way they perceive their life (Tang & Anderson, 1999).

3.7 The professional response to self-management

The professional response to active patients is explored in-depth in the discussion chapter but it is appropriate at this point to highlight that the professional may be the greatest inhibitor to self-management. Whilst some professionals understand that the disease is owned by the patient and therefore self-care is a requisite (Sigurdardottir, 1999), it is argued elsewhere that professionals see it as legitimate and benevolent to take over the management of the condition but find it hard to relinquish this control (Corner, 2001). It is recognized that professionals may find self-management culturally challenging (Lahdensuo, 1999), whilst dominating and directing self-management may fail to acknowledge the patient’s self in the process (Corner, 2001). The use of strict criteria such as HbA1c as measures of self-management success (Coates & Boore, 1995) may result in the patient being seen as the agent of their own misfortune (Pill *et al.*, 1999). In a study by Thorne *et al.* (2000) it was found that professionals would respond to patient

expertise in self-management by controlling information, assuming the patient was non-compliant and developing punitive gate-keeping to other services. Patients' knowledge is frequently seen as non-legitimate (Paterson, 2001), and are viewed as poor judges of their own health (Jones *et al.*, 2000). Coulter (2002) summarises the tensions in the relationship created by self-management as shown in table 11.

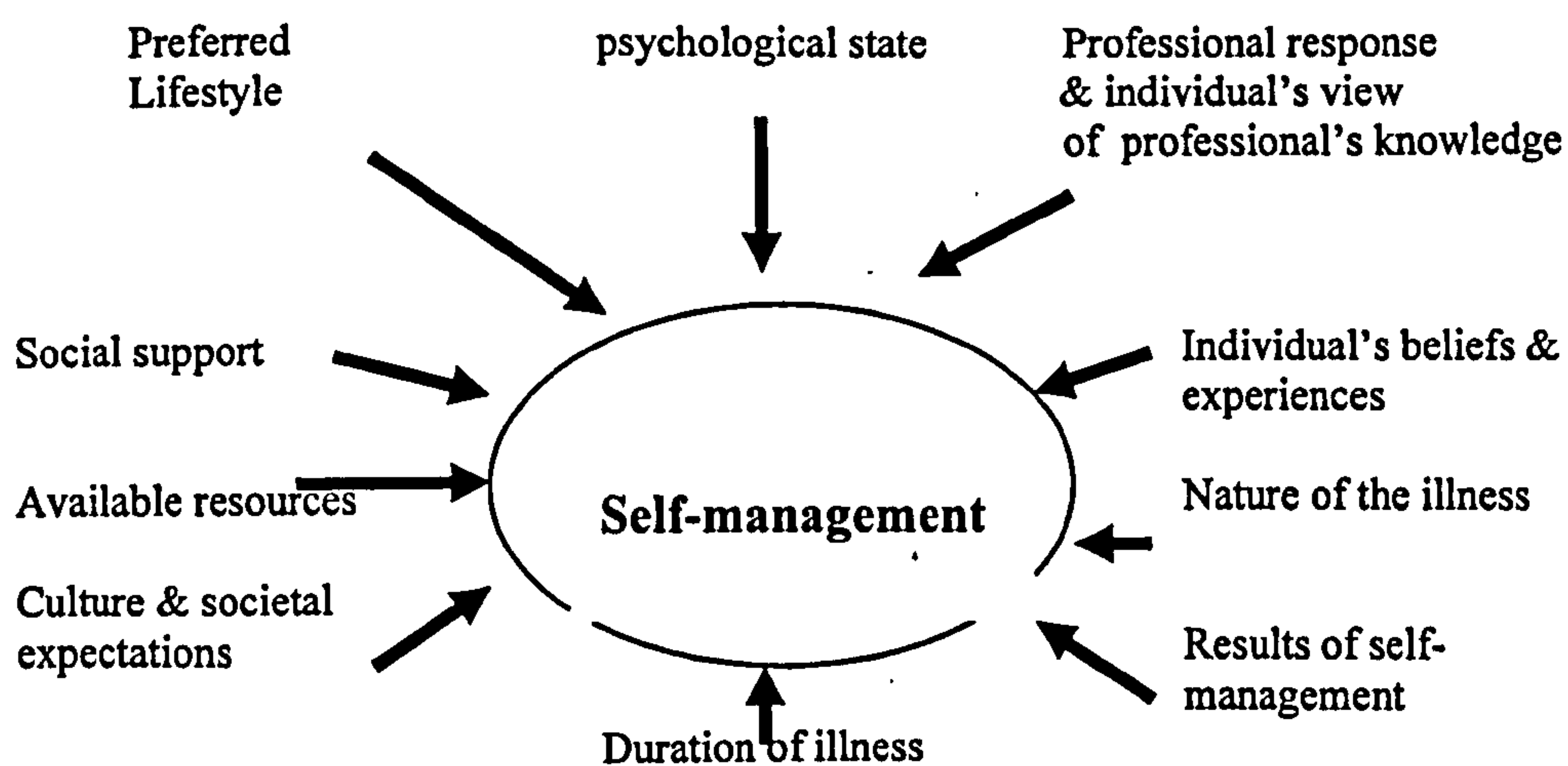
- | |
|---|
| <ul style="list-style-type: none"> • professionals feel threatened by well-informed patients • either one or both may be misinformed • both may make different interpretations of information • either or both are unwilling to share the decision-making process • patients may be unsuccessful at communicating their preferences or the professionals do not listen |
|---|

Tensions in the self-management relationship (adapted from (Coulter, 2002)

Table 11

3.8 Summary: towards a critical realist perspective

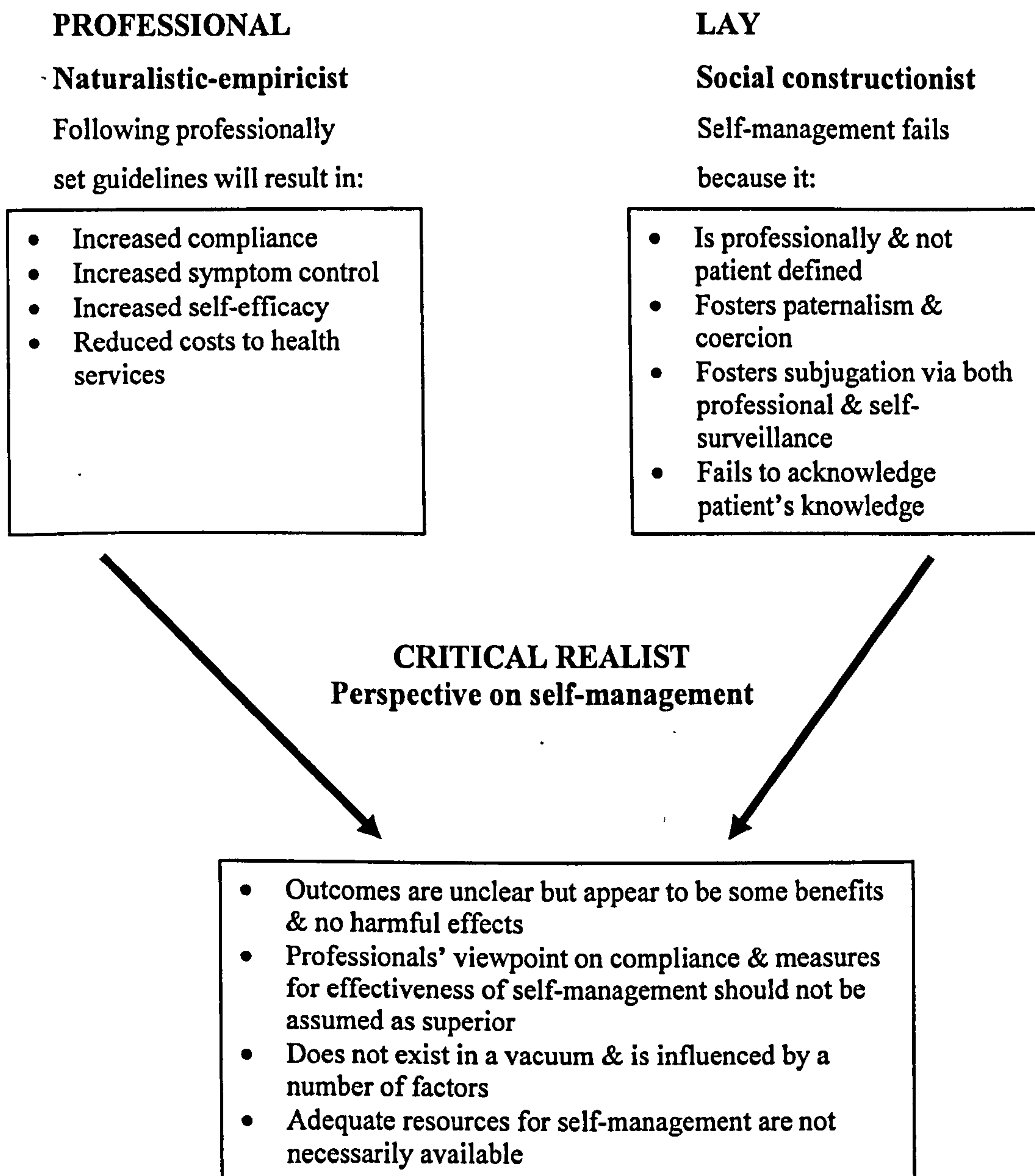
The policy makers and much of the literature attempt to make a strong case for the value of self-management, and whilst it appears that self-management has benefits and at the very least is unlikely to do harm, it is also apparent that self-management is defined differently by both professionals and lay people, and that it does not exist in a vacuum being influenced by a number of factors (figure 6). Much of the literature presents arguments surrounding self-management through the professional empirical stance or the socially constructed perspective. No literature was found that explored self-management through an explicit critical realist framework.



Factors influencing self-management

Figure 6

Therefore, this chapter concludes with a proposed diagrammatic framework for self-management underpinned by critical realism (figure 7).



A critical realist framework of self-management

Figure 7

3.9 Conclusion

This chapter has attempted to map both the policy response to long-term conditions and the very unclear picture of self-care and self-management. A definition has been proposed for self-management as the activities an individual undertakes in their health care that have previously been the remit

of professionals. Factors impinging on self-management have been discussed and the chapter has concluded with a proposed framework underpinned by critical realism. Many of the issues discussed in this chapter will be returned to later in this thesis and explored in-depth within the discussion chapter. The thesis will now develop a case for the methodology and methods drawn on in the study.

CHAPTER FOUR

RESEARCH METHODOLOGY AND METHODS

4.0 Introduction

This chapter is divided into two major sections, the first focusing on the underpinning methodology guiding the study, with the second half exploring the methods used in the data collection. This latter section will also present the process of data analysis, concluding with a discussion on issues surrounding ethics, reliability and validity. However, in order to set the context of the whole chapter there will first be an explanation of the identification of the research focus.

4.1 Identification of the research focus

As discussed in the preceding chapters there have been a number of global and UK policy initiatives in response to the increasing incidence of chronic illness and consequent health care resources. In addition to new systems of care management (Department of Health, 2004c) and patient participation in decision making regarding health care delivery (Department of Health, 1997), there has also been a growing emphasis on self-care and self-management in chronic illness (see chapter 3). Whilst the whole notion of self-care in long-term conditions is now well established (see for example the work of Lorig *et al* 1996), the expertise an individual often develops over the years living with and managing a long-term condition has only comparatively recently been acknowledged. The previous chapter explored the development of active and informed patients, culminating in the UK with the idea of expert patients (Department of Health, 1999a), and within the introductory chapter a working definition of an expert patient was presented (1.2). However, the response by health professionals to the title of expert patient appears less than enthusiastic with calls for a change in the term (Shaw & Baker, 2004). Nonetheless, issues regarding the response of health professionals to active and informed patients had emerged prior to this new term of expert patient and whilst much of the research surrounding this had been conducted in North America (Paterson, 2001; Thorne *et al.*, 2000), work in the UK is suggesting a lack of engagement

with the notion of expert patients (Kennedy *et al.*, 2004a). Kennedy *et al.*'s (2004) evaluation of the EPP serves as confirmation for the original impetuses of this PhD study. The primary trigger for the research was one of the findings of a Masters study that explored the relationship between district nurses and their patients with long-term conditions (Wilson, 2000), which suggested that nurses regarded self-care as a resource saving tool rather than an empowering activity for patients, and a preference for passive patients in direct contrast to active expert patients. The second trigger was a personal response to having a long-term condition and whilst the significance as an influence on the researcher's perceptions and interpretations is dealt with more fully in 4.8, this section will go on to briefly reflect on the personal experience as a precursor to the research focus.

4.1.1 Research focus: a personal reflection

In 1991 I was diagnosed with Antiphospholipid (Hughes) Syndrome and following a trans ischaemic attack was commenced on long-term anticoagulation therapy. My experiences of having chronic illness were mirrored in the literature reviewed, feelings of denial and then anger when diagnosed and then the process of developing strategies to minimise the effects of the condition, and more pertinently in my case the treatment. After a number of years I was able to predict the effects of for example, diet and ambient temperature on my INR, and by observing patterns felt competent in my potential ability to self-dose on receipt of an INR reading. On one visit to the phlebotomy clinic, the nurse specialist approached me to tell me about the new home monitoring machines for INR testing which required a finger prick test rather like a glucometer. Having agreed that with my professional experience I would not find it problematic to self-manage, she proposed to discuss it with the consultant. When we next met there was an obvious change in her response. The consultant had become angry at the suggestion of self-management, arguing that I was likely to wrongly self-dose leading to a massive haemorrhage for which he would be accountable. If I wanted to self-manage the only suggestion she could offer was to discharge myself from the haematologists, purchase an INR meter and hope that my GP would support me. Whilst feeling not able to take such a drastic step I was also puzzled about

the reasons for such resistance when the literature suggests safety and efficacy of patient self-management in anticoagulation (see 3.4.4). It was the reflection upon my own story and the realisation that if I as a health professional faced such resistance and felt so unsupported in self-management, what was it like for other patients with long-term conditions?

4.2 Research Methodology

This section will discuss the methodology adopted for the study. It will commence with a personal reflection on the methodological choice and provide an introduction to Grounded Theory. Finally, critical realism as an underpinning philosophy will be discussed and analysed.

4.2.1 Methodological choice: a personal viewpoint

As discussed in 4.1.1 the choice of research topic was significantly shaped by personal history and biography (Armstrong, 1993; Bell, 1993). Similarly, it is also important to acknowledge the influence of personal philosophy on methodological choice (Procter, 1998)(see 4.2.3 for further discussion on this), however it is the fundamental need to choose a methodology that will enable answers to the research questions that first needs to be addressed.

The research aims presented in 1.3 clearly indicate that in contrast to an outcome study of a particular intervention, this was a study in which it was important to understand meaning from the participants' perspectives and within the current context of the Expert Patient to understand the processes by which events and actions took place, consequently an overriding qualitative approach was adopted (Maxwell, 1998). This was reinforced by the belief that the experience and response to chronic illness is uniquely personal (Paterson, 2003) whereas paradoxically the majority of empirical work around long-term conditions has been framed by the professional perspective (McEvoy & Richards, 2003; McPherson *et al.*, 2004). Whilst a qualitative approach was implicit within the research aims, unpicking an appropriate epistemological basis from the various qualitative methodologies required further exploration. It could be argued that the focus of the study was the cultural landscape of the Expert Patient initiative and the encapsulation of cultural meaning for the differing stakeholders, indicating an ethnographic methodology (Hammersley

& Atkinson, 1995). Equally it could be argued that the lived experiences of the participants were the prime focus with phenomenology as an appropriate methodology (Ekman *et al.*, 1999; Koch *et al.*, 1995). However, the broad scope of the research aims suggested that a methodology was required that was able to capture the myriad of personal meanings from both the lay and professional perspective, and also able to paint a vivid picture of the context. Whilst an ethnographic approach may well have fulfilled this criteria (Morse, 1992) it was the added factor of the research topic being relatively under-researched that proved to be the major guide in the adoption of a grounded theory methodology.

4.2.2 Grounded Theory – roots and history

Grounded theory is a qualitative methodology that inductively derives theory from the study of a phenomenon through a process of discovery and development via a systematic process of data collection and analysis (Strauss & Corbin, 1990). The roots of grounded theory are to be found in symbolic interactionism, an approach to the study of human conduct and group life (Eaves, 2001). Traced back to the work of George Herbert Mead (Mead, 1934) symbolic interactionism assumes that people construct their realities through interaction with others, and that these interactions as processes use symbols, interpretations, words and languages (Cutcliffe, 2000; McCann & Clark, 2003a). Thus, social interactions create meaning and as a shared meaning between people shapes society (Heath & Cowley, 2004).

Symbolic interactionism developed as a key sociological theory through the Chicago School of Sociology, with Herbert Blumer seen as the founding figure of the perspective (Kivisto, 1998). Blumer developed three basic premises of symbolic interactionism (Eaves, 2001), firstly that humans act towards things depending on the meaning that thing has for them. For example, observations from the empirical element of this study suggested that diabetic patients dreaded their annual review with the nurse, seeing it as a judgement on their diabetic management skills, whereas the nurses saw it as a routine part of their work. Secondly, this meaning derives out of interaction one has with others so taking this example further it is likely that these patients attached this meaning of judgement via previous interaction. Finally, Blumer

(1969) posits that these meanings are handled and modified by an interpretive process that the individual uses when dealing with encounters. Thus it would be expected that “judgement” is not the sole meaning patients place on the annual review.

Anselm Strauss, a Chicago School sociologist was greatly influenced by the work of Blumer, an influence that was central to his later work with Barney Glaser. Glaser’s background was in quantitative research methods but had a developing interest in qualitative approaches. The coming together of these two men was key in the development of grounded theory, Glaser wishing to develop a more systematic method for qualitative data analysis, and Strauss shaping the philosophical underpinning of grounded theory (Glaser & Strauss, 1967). The mid 1960’s saw the arrival of grounded theory nursing studies amongst which was the work of Juliet Corbin (Corbin & Strauss, 1992). Her collaboration with Strauss led to a second seminal publication on the methodology (Strauss & Corbin, 1990) which was seen by some as a major development of the approach but critiqued by Glaser as an unhelpful dilution of the original work (McCann & Clark, 2003a). Despite Glaser’s purist perspective it does appear that grounded theory as a relatively new methodology is bound to evolve and change (Woods, 2003), and some examples of modification will be discussed later. However, having presented the history of the methodology it is appropriate now to develop the discussion into an exploration of what a grounded theory approach is.

4.2.3 An overview of Grounded Theory

As suggested by its name, the central tenant of grounded theory is that it generates theory inductively from the data as opposed to theories hypothesised prior to data collection (Dey, 2004; Glaser & Strauss, 1967). Glaser and Strauss (1967) argue that if the theory is grounded in the data it has far greater claims to validity and fitness for purpose. Two types of theory may be generated by a grounded theory study. Substantive theory is developed for a specific area of inquiry (Glaser & Strauss, 1967), for example in this study self-management of long-term conditions whereas formal theory is more global and can be applied to a number of contexts (Charmaz, 1990).

The need to derive theory from the data gives rise to the major characteristic of grounded theory, the emphasis on data analysis. The systematic approach to data analysis is discussed in depth in 4.7 but it is worth highlighting that in order to derive the theory from the data an iterative process between data collection and analysis is fundamental (Glaser & Strauss, 1967). Known as constant comparative analysis (Eaves, 2001) it is a unique feature of grounded theory. Whilst the strong focus on data analysis is seen as a strength by providing rigour (Eaves, 2001), it is also a source of criticism in being too rigid (Heath & Cowley, 2004) and is often in danger of being seen purely as a process of data analysis rather than a methodology with a distinct epistemological stance (McCann & Clark, 2003b). Whilst this critique will be further developed the discussion will now analyse the evolving approaches to grounded theory.

4.2.4 Evolving approaches in Grounded Theory

As discussed earlier, two major branches of grounded theory have developed; the classical interpretive approach (Glaser & Strauss, 1967) (Glaserian) and the post-modern approach (McCann & Clark, 2003b; Strauss & Corbin, 1990). Whilst both approaches are to some extent informed by a positivist influence they draw on differing ontologies (McCann & Clark, 2003b). Deriving from a critical realist ontology, the classical interpretive approach views reality as existing but not always visible or measurable (see 4.2.7 for discussion of critical realism). In contrast, Strauss and Corbin's (1990) (post-modern/Straussian) approach is derived from social constructionism where reality can never be defined but can be interpreted (Burr, 1995). The epistemological underpinning influences the role a grounded theory researcher takes, with the classical grounded theorist seeking independence whilst the post-modernist would seek a dialectic and active role (McCann & Clark, 2003b). The former approach also indicates a focus on micro context or the socially constructed world of the participants, whereas the latter focuses not only on the micro but the cultural scene or macro context (McCann & Clark, 2003b). There are also key differences in the research process within the two approaches. The literature review is one of the more contentious illustrations of this (Heath, 2004; Heath & Cowley, 2004) with Glaser arguing

against any form of preliminary review in order to prevent preconceived ideas or fitting the data to pre-known theories (Maijala *et al.*, 2003). However, Strauss and Corbin (1990) argue that the researcher will undoubtedly come to the field with pre-existing knowledge and some familiarity with theories and it is unrealistic to assume that the researcher can start with no ideas (Strauss & Corbin, 1990). They suggest that a limited preliminary review of literature is useful for stimulating theoretical sensitivity (Strauss & Corbin, 1990), with others also arguing that a limited review is necessary in order to negotiate current research management and governance systems and to enrich the themes underlying interviews (Maijala *et al.*, 2003). In this study a preliminary literature review was undertaken on the nature of chronic illness and self-management (chapters 2 and 3), but the remaining literature drawn upon to articulate the substantive and formal theories was read after data collection and analysis. Another important difference is that Glaser argues that the research questions should emerge totally from the study, whereas Strauss and Corbin take a more pragmatic view and acknowledge that personal experience or suggestions by others may play a key part in the researcher's choice of research focus (Strauss & Corbin, 1990), which, as discussed in 4.1.1, was the case in this study. McCann and Clark (2003b) suggest two other key differences, firstly that Strauss and Corbin developed a more rigid set of rules and procedures for data analysis – critiqued by some as potentially too cumbersome and containing jargon (Charmaz, 1990), but on the other hand providing a rigorous approach especially suited to the novice researcher (Duffy *et al.*, 2004; Eaves, 2001). The final key difference is the criteria for evaluation with the Glaserian approach searching for fit, work, relevance and modifiability, whereas Strauss and Corbin (1990) draw on the criteria for the evaluation of qualitative research drawn up by others (Patton, 1990). These two branches of grounded theory have given rise to examples of further modification. One significant example is the work of Kate Charmaz (1990) whose grounded theory study uncovered an identity hierarchy in chronic illness (see section 2.6.3). Whilst Eaves (2001) identifies that Charmaz adopted a Glaserian approach to data analysis, Charmaz clearly articulates her approach to grounded theory as being drawn from social constructionism and acknowledges the influence of her pre-existing knowledge regarding

sociological theory (Charmaz, 1990). Her most recent work indicates a deep commitment to intimate familiarity with the phenomenon and argues against Glaser's (Glaser, 2002) suggestion that people will tell you what most concerns them, noting that observation may often refute what is articulated (Charmaz, 2004). Eaves (2001) attempts to synthesize the approach of Charmaz (which Eaves links with the Glaserian approach), Chesler's simplified data analysis (Chesler, 1987) and the Strauss and Corbin (1990) system, developing her own synthesis model (Eaves, 2001). Another development in grounded theory is the notion of cumulative grounded theory studies with the results of one study leading on to the next until a whole series have been completed on a topic area (Olshansky, 1996). Again, this a move away from the classical model of developing the research questions once in the field (Glaser & Strauss, 1967).

As the above discussion indicates, there is no one clear cut way to proceed with a grounded theory study, each researcher brings their own personal stance, disciplinary perspective and own way of conducting it (Heath, 2004; McCann & Clark, 2003b). Indeed when I attempt to place this study within either the Glaserian or Strauss and Corbin branches it does not fall entirely into either (figure 8).

However, McCann and Clark's framework (2003b) (figure 8) can be criticised as linking critical realism totally to the Glaserian approach, whereas it is argued in this thesis that there is congruence between critical realism and the Straussian approach as both have an emphasis on the micro and macro context, and both have scope for multiple truths. This chapter will go on to explore critical realism as the underpinning philosophy, but first there will be a drawing together of the various critiques of grounded theory that, as will be seen, provide the link to critical realism.

Glaser		Strauss & Corbin
Epistemology		
Critical realist		Social constructionist
Postpositivist	X	Poststructuralist
Researchers role		
Independent	X	Dialectic & active
Theory		
Emphasis on theory	X	Emphasis on verification & validation
Generation		
Focus in the field		
Micro	X	Contextual, micro & Macro
Literature review		
Main review to support emerging theory	X	Preliminary review Main review to support emerging theory
Research problem		
Emerges in study	X	Personal experience Suggested by others & literature
Data collection & analysis		
Principles & practice of qualitative Research. Guided by participants & socially constructed reality	X	Rules & procedures Paradigm model to provide structure
Evaluation		
Fit, work related & modifiability	X	Criteria drawn from other qualitative research approaches
X = researchers position within the Glaser and Strauss & Corbin approaches		

Position of study in relation to Glaser and Strauss & Corbin approaches

Figure 8

4.2.5 A critique of Grounded Theory

Critiques of grounded theory focus on two issues, firstly validity and secondly epistemological underpinning. Dey (2004) states that grounded theory is weak

in validation and goes on to argue that rather than a process of induction or even deduction, grounded theory is a method of abduction, which relies purely on the researcher's own interpretation of the observation. Whilst questions persist as to whether the data would be interpreted by others in the same way (Clarke, 1992), this argument is fundamentally linked to the philosophy of science. Clarke (1992) and Dey's (2004) critique have an implicit assumption that knowledge and meaning is possible without interpretation, an assumption strongly bedded within the positivist paradigm where knowledge is understood as objective (Popper, 1972). However, positivism itself has been critiqued as socially constructed by the scientific community (Kuhn, 1970), with the ongoing criticisms of empirical assumptions giving rise to a paradigmatic shift towards interpretism and social constructionism (Appleyard, 1992). Clarke (1992) and Dey (2004) rather miss the point with interpretation in grounded theory as the roots of symbolic interactionism identify that meanings will be attached to actions (Heath & Cowley, 2004), but one of the imperatives of validity in grounded theory is that the interpretation is acknowledged and made clear (Charmaz, 2004). Mechanisms for the articulation of meaning in this study are discussed in 4.7 but perhaps Clarke's (1992) other two criticisms of grounded theory provide an insight on how interpretation may be lost. First, he goes on to question whether categories emerge from the process of grounded theory rather than the data itself, with McCann and Clark (2003b) suggesting that the process of grounded theory is often unclear and jargon between the branches frequently conflicting. In particular, the Strauss and Corbin (1990) approach is critiqued as being procedurally unmanageable (Eaves, 2001), Secondly, Clarke (1992) asks whether the researcher is prone to selective sampling in order to avoid conflicting data. In contrast the key texts on grounded theory (Glaser & Strauss, 1967; Strauss & Corbin, 1990) illustrate the use of conflicting data in order to facilitate the process, but it is acknowledged by others that problems do arise when the process of grounded theory is not adhered to thoroughly (Charmaz, 1990), in particular when the researcher selectively rather than theoretically samples, lacks constant comparative analysis, relies on computer programmes to identify variables by frequency and prematurely completes the study (Eaves, 2001).

The second area of critique in grounded theory surrounds the epistemological underpinning. Charmaz (1990) suggests that symbolic interactionism as the sole epistemological stance makes grounded theory a very narrow methodology, a view echoed by McCann and Clark (2003b) who argue that the epistemological assumptions of grounded theory are unclear. Neither Glaser and Strauss (1967) or Strauss and Corbin (1990) explore the epistemological roots of grounded theory, spending more time describing how to do it. As discussed earlier, it appears imperative to articulate the philosophical underpinning of a research study as there will clearly be an influence on how the study is guided and meaning attached. It also facilitates consistency when using a number of methods and grounds them in an accepted epistemological paradigm (Procter, 1998). Whilst Charmaz (1990) drew on phenomenology and social constructionism to inform her grounded theory study, it will be argued in the next section that critical realism is an appropriate philosophical underpinning for this study.

4.2.6 Critical Realism - background

Critical realism is a philosophy of science that moves beyond examining specific social instances to also exploring the structural context of the actions (Porter, 2002). Whilst there are a number of key philosophers (Bunge, 1997; Harre, 1972), critical realism is mainly attributed to the work of the British philosopher Roy Bhaskar (Archer *et al.*, 1998; Bhaskar, 1978; Bhaskar, 1986; Bhaskar, 1989), and has emerged as a major intellectual tendency in English speaking academia (Callinicos, 1994). The rise of this paradigm is partly in response to the growing critique of social constructionism and the demise of post-modernism (Williams, 1999). Social constructionists see the world as socially manufactured through human agency and language, with understanding historically and culturally specific (Houston, 2001a). A main protagonist of this viewpoint is Foucault (Foucault, 1976) who argued that the experience of, for example, illness is shaped by social discourse and the tacit acceptance of medical dominance. This socially constructed power is omnipresent within every interaction between people, displaying relations of inequality (Porter, 1998). The notion of “panoptic” or all-seeing power is a key element in Foucault’s thinking and exemplifies the social constructionist

viewpoint that there are no essential structures in society (Houston, 2001a), only those created in our minds. Although Foucault has challenged the following (Gordon, 1980), his idea of immovable panoptic power is critiqued as having no scope for social reconstructionism or acknowledgement of the possibility of human agency (Porter, 1998). Bhaskar would argue that a constructionist view such as there is no such thing as chronic illness or disability as it is socially constructed, is articulated by those who have no practical experience of chronic illness (Collier, 1994), essentially refuting (and this will be discussed further below) the idea that there is no such thing as reality. However, whilst this notion of certainty of reality is a shared viewpoint with positivism, followers of critical realism rejection of some of social constructionism's claims does not result in a paradigmatic shift back to positivism. Protagonists of critical realism reject two key tenets of positivism, firstly that only what can be perceived can be known, and secondly that all that is known can be looked at as isolated beings (Han, 2002). In an environment as complex as health care it is argued that neither extreme approaches of positivism or constructionism are entirely helpful (Procter, 1998). An overview of critical realism will now be presented, illustrating how this paradigm provides a bridge between the dichomatic worlds of positivism and constructionism (Wainwright, 1997).

4.2.7 An overview of critical realism

Whilst Bhaskar refutes the constructionist view that there is no such thing as illness, he does accept that there is construction via a cultural understanding (Bhaskar, 1989). For example, whilst someone with Multiple Sclerosis would probably reject the idea that their condition is not real, they may also have a cultural understanding that they may be seen as a burden, particularly when drawing out their Incapacity Benefit with all the associated meanings surrounding "Incapable". With one root of critical realism derived from transcendental realism and its fundamental "a priori" question, what must be in place to make something possible (Littlejohn, 2003), it shares the same characteristics as other realist theories such as theory realism, entity realism and constraint realism (Hussey, 2000)(table 12).

- ◆ Objectivity – it is real whether known or unknown
- ◆ Fallibility – open to refutation by further information
- ◆ Transphenomenality – knowledge is not just about what appears but of underlying structures that may last longer than the appearance
- ◆ Counter-phenomenality – knowledge of the deep structure of something may not just go beyond and not just explain, but also contradict appearances

Characteristics of realist theories (Collier, 1994)

Table 12

As shown in the above figure, there is allowance for knowledge to be counter-phenomenal thus providing scope for liberation and the promotion of transformational theories, and whilst recognising that marginalisation of people is brought about by relatively enduring structures, the “critical” element of critical realism directs attention towards the altruistic task of transforming these structures (Bhaskar, 1986; Connelly, 2001; Houston, 2001b). As well as neutrality (Connelly, 2001), Bhaskar also rejects the positivist horizontal mode of explanation where an outcome is produced by the mix of an antecedent and mechanism (Collier, 1994). Whilst this form of explanation may be suitable for a closed system such as a test tube experiment, he argues that a vertical mode of explanation is needed for open systems such as the social world where reality exists at different levels (Procter, 1998) (table 13).

EMPIRICAL Experiences and observable events

ACTUAL Events which may or may not be observed

REAL Structures and processes which make reality and produce events

Three levels of reality (Procter, 1998)

Table 13

For example, in chapters 5 and 6 a descriptor of an expert patient is developed, but whereas a horizontal explanation may have only uncovered the reading and research these patients undertake, a vertical explanation uncovers other

mechanisms such as occupational skills, gender, culture and so on. Bhaskar contrasts this vertical model of explanation to the traditional stratification of science in positivism (Collier, 1994). The latter model indicates that all phenomena in the natural world can be studied under the laws of physics, then every material under the laws of chemistry but only some of these under the subject of biology. This argument demonstrates a one way hierarchy such as there can be no biological mechanisms without chemical ones but not the reverse. In contrast Bhaskar argues that in open systems one is never able to predict higher level mechanisms from our knowledge of a more basic one with a need to discover higher level mechanisms first and then to work backwards (Collier, 1994). In this study the higher level mechanism can be regarded as the expert patient with the research process working to uncover the underlying mechanisms.

Bhaskar posits that there are a multiplicity of causal mechanisms and not all are easily perceived, however perception is just one criterion of reality with the other being the causal criterion (Porter, 2002). This is defined as the capacity of an entity to bring about changes in material things such as the popular belief that constant worrying brings about prematurely grey hair. Critical realism has a number of key concepts as part of the process of explanation in open systems. Firstly, Bhaskar argues that power is present even when not being exercised (Collier, 1994). For instance, two customers enter a shop and although off duty their respective occupations are known to the shop owner. Whilst the lawyer out of the two is not consciously exercising power it is easy to imagine that he may be treated differently to the other customer who is a labourer. Bhaskar explains this by the second concept of tendencies (Han, 2002) where phenomena tend to happen in certain ways, such as the scenario described above. Bhaskar's focus for investigation is the third concept of structures that he argues can be investigated independently of any power they generate as they exist whether the power they can generate is being exercised or not (Collier, 1994). Another key concept is that of generative mechanisms (Connelly, 2001; McEvoy & Richards, 2003) which is the aspect of the structure by virtue of which it has certain power, but only will work when suitably triggered. Bhaskar suggests that in open systems generative mechanisms are not isolated but when triggered will operate in

conjunction with other generative mechanisms producing a very complex outcome (Collier, 1994). Taking the scenario described above a little further one can imagine that the labourer would feel very discontent if he saw the lawyer receiving preferential treatment. A range of other generative mechanisms may come into play such as his personality – he may decide aggression is a power he could exercise, or family influence – he suddenly realises that his mother’s lectures on the need for a good education to get on in life were correct and decides to do something about it. These two examples could also be applied to tendencies, so if the labourer perceives inequality he will always react with aggression. The final important concept is necessity that Bhaskar describes as the tendency having to work once the conditions for its working are there (Collier, 1994).

Bhaskar develops a pattern of explanation in open systems (RRRE) (table 14), and describes the skills needed for RRRE as that of a detective (Bhaskar, 1989; Collier, 1994). The relationship of this model with grounded theory is further discussed in section 4.3.

1. *Resolution - the process is analysed into its various causal components*
2. *Redescription - redescrbing the causal components in terms of pre-known theory*
3. *Retrodict – the causes of these components, but as we are in an open system there will be any number of possible causes so we need to:*
4. *Eliminate – as many as possible by means of independent evidence about antecedent events.*

Pattern of explanation in open systems – RRRE (Bhaskar, 1989; Collier, 1994)

Table 14

The final part of Bhaskar’s work to be discussed in this section is his argument surrounding social explanation. He describes a continuum of social explanation ranging from the humanistic end where human agency is paramount to structuralism where social structure is seen as key. Bhaskar argues that both are real, purposive agency has effects but so too does structural causality – people make societies and societies make people (Bhaskar, 1989; McEvoy & Richards, 2003). He goes on to posit that it is not so much the study of relationships between individuals that is important but the relationship between positioned practices which endure longer than

individual bearers (Collier, 1994). This transformational model of social activity is used to illuminate the findings of the study presented in chapter 5. This section has provided a brief overview of critical realism, but before developing the discussion further by exploring potential use both with grounded theory and health and social care research, the next section will present a critique of critical realism.

4.2.8 Critical Realism: a critique

It is argued by some (Callinicos, 1994; Han, 2002; Klein, 2004; Wainwright, 1997) that Bhaskar's work lacks originality and in particular borrows much from Marx (Marx, 1968) and Giddens (Giddens, 1984). Whilst Bhaskar acknowledges the influence of Althusser (Althusser, 1969) in producing much Marxist underpinning to his work (Bhaskar, 1989), he argues the duality of structure and action more forcefully than Giddens (Callinicos, 1994), and emphasises a stronger ontological grounding for structure, whereas Giddens has more emphasis on the autonomy of social actors (Han, 2002). Bhaskar has also been criticised for placing too much emphasis on his anti-positivism views and over stating the differences between the natural and social world (Collier, 1994), however Bhaskar appears to balance this with a critique of the hermeneutical tradition (Bhaskar, 1989) although this is seen as having room for greater development (Klein, 2004). In contrast, critical realism is also vulnerable to the postmodernist critique that structures are created by the critical realists themselves (Porter, 2002), but Bhaskar uses the argument that as a realist theory these structures are at least open to refutation (Bhaskar, 1989). The actual methods encouraged for use in explanation by Bhaskar are also critiqued as being over-reliant on interviews and actors accounts (Connelly, 2001; Houston, 2001a) which fits well with Charmaz's (2004) argument that observation may often contrast with accounts. As will be discussed in the latter section of this chapter, in addition to interviews both observation (Porter, 2002; Porter & Ryan, 1996) and focus groups were used in this study.

Another criticism raised against the work of Bhaskar is that his use of language may pose difficulties for the reader (Callinicos, 1994). Whilst it seems no more jargonised or complex when compared to other contemporary

paradigmatic descriptions, its conceptualisation into practice may be one of the reasons why it is just emerging as a significant philosophical underpinning in health and social care research.

Finally, and in contrast to the last point, critical realism has been accused of being an outdated philosophy, but with scope for overhauling and development (Klein, 2004).

4.2.9 Critical realism as a developing paradigm in health research

Although relatively unadopted so far in the medical sociology (Procter, 1998; Williams, 1999) and nursing arenas (Hussey, 2000; Porter, 2001), a growing number of analyses informed by critical realism are beginning to emerge in health and social care academia (McEvoy & Richards, 2003). Han (2002) uses a critical realist framework to explore the current pluralist approach to conventional and complementary medicine in the western world. He argues that critical realism illuminates both structure and agency, concluding that whilst a patient seeking complementary therapy is enabled or constrained by the conventional medical system, the patient's action of seeking in turn will reproduce or transform conventional medicine systems. Houston (2001b) uses critical realism to develop a bridge between two different approaches towards child protection. He argues that the objective approach is misguided in its assumption that risk can be predicted and managed in a rational way, but also critiques the subjective approach towards child protection as neglecting the role of real material and constitutional factors in shaping children's lives. Houston describes critical realism as a vehicle to redirect attention to the deep-seated causes of harm and the underlying mechanisms that when activated give rise to at risk situations.

These two examples illustrate how critical realism can be applied to critical commentary, however as discussed in 4.3, critical realism has been further used in this thesis as an underpinning philosophy for grounded theory. At the time of writing no published work could be found describing the use of critical realist grounded theory, but critical realism is beginning to emerge as an underpinning for ethnography, participatory action research, and other qualitative methods (McEvoy & Richards, 2003; Wainwright, 1997). Hammersley used the term subtle realism where the influence of human

agency is acknowledged whilst at the same time being aware of the effect of structure on action (Hammersley, 1992). A critical realist ethnography of the theory-practice gap in nursing (Porter & Ryan, 1996) illustrated that whilst nurses both understood and agreed with the use of nursing models, time constraint was a major barrier in the use of a model. Porter and Ryan (1996) utilised a critical realist framework to illustrate the links between time and financial restraint, employing the sociological concept of capitalism for illumination. Another example of critical realist ethnography is Porter's study of ethnic minority doctors and white nurses working in an Intensive Care Unit (Porter, 2002). Whilst the ethnography illuminated latent racist tendencies of the nurses, it also revealed that this did not significantly affect the power relations between the two groups. Porter argues that a critical realist framework revealed the racist generative structure, but as it operated in an open system along with a number of other structures, its effects were revealed as tendencies rather than a constant.

Moving away from ethnography, Procter (1998) utilised realism in a multi-method study exploring perceptions of quality in a Maternity Unit. Using both retrodution and abduction she demonstrated that a realist framework strengthens triangulation and consequently the depth of understanding. Clark employed critical realist underpinning in a qualitative study exploring lay perspectives of stress and myocardial infarction (Clark, 2003a). Data generated from semi-structured interviews with patients revealed differences in perception when compared to the professional viewpoint. Clark (2003) posits that critical realism recognises the legitimacy of both lay and professional perspectives and is therefore a valuable philosophical stance to take in nursing research.

The next section will develop a case for using critical realism as an underpinning framework for a grounded theory study.

4.3 Critical Realist Grounded Theory

It is proposed in this thesis that critical realism is compatible with grounded theory and provides a bridge between the Glaserian and Straussian branches. Fundamental to critical realism is the notion of transformational social activity, the two way process between human agency and structure and

similarly symbolic interactionism acknowledges a relationship between the shaping of society and human interaction as a series of actions (Heath & Cowley, 2004). Whilst the classical branch (Glaserian) is clearly underpinned by a critical realist ontology (McCann & Clark, 2003b), it is argued in this thesis that it is also congruent with Strauss and Corbin's (1990) approach. Firstly, whilst the classical approach focuses on the micro context of participants, Strauss and Corbin extend this focus to the macro context allowing more scope for the exploration of structures vital in a critical realist approach. Porter and Ryan argue that a critical realist approach needs to be combined with a methodology which is able to uncover the understandings of the participants and seeks to understand what social structures must be in place to influence these understandings (Porter & Ryan, 1996), an emic and etic view that grounded theory has the potential to offer. Secondly, Procter (1998) posits that a realist approach enables a researcher to have greater awareness of their impact on the research environment and hence develop a greater degree of theoretical sensitivity as described by Strauss and Corbin (Procter, 1998). Thirdly, a research process informed by critical realism has congruent phases with that described by Strauss and Corbin as illustrated in table 15. As the table demonstrates, whilst there is similarity in each general phase, grounded theory adds detail to the basic structure suggested as a critical realist methodology.

Finally, it is argued that not only does grounded theory provide more detail on process, but reciprocally critical realism has the potential to help bridge the gap between grounded and grand theory (Wainwright, 1997), a task that is recognised as challenging (Charmaz, 1990). Strauss and Corbin also take a more pragmatic view about the use of pre-known theory within a grounded theory study, again more congruent with Bhaskar's use of pre-known theory in the re-description phase of the RRRE model (Houston, 2001a)(see table 13). Houston (2001b) goes on to describe the retroduction phase of Bhaskar's RRRE model as identifying patterns of behaviour, developing some hypotheses and then searching for supportive and disconfirming evidence,

Critical Realist Methodology (McEvoy & Richards, 2003; Procter, 1998)	Grounded Theory Methodology (Strauss & Corbin, 1990)
Inductive (formation of general inferences) + Deductive (testing specific hypotheses) = Abductive strategy & triangulation + Retrodution (making observations and devising theory to explain them)	Data collection (initial coding and discovery of potential categories) + Constant comparative analysis (using next phase of data collection to test out analysis from previous phase) + Axial coding, conditional matrix & paradigm formation (developing links to explain the relationship between action, context, causal conditions and a phenomenon). Development of substantive and formal theory.

A comparison of critical realist and grounded theory methodologies

Table 15

as illustrated in the above figure, a process congruent with the development of a paradigm model and conditional matrix and grounding of the theory by validating it against the data in the Strauss and Corbin approach. Connelly (2001) suggests a series of research questions a critical realist needs to ask (table 16).

- | |
|--|
| <ul style="list-style-type: none"> • How are effects caused? • What triggers them? • What inhibits them? • How are they reproduced and maintained? • Are they politically and ethically legitimate? • If not, how can they be changed? |
|--|

Critical realist research questions (Connelly, 2001)

Table 16

Whilst the first four are totally congruent with the type of exploration occurring in a grounded theory approach, the last two highlight the critical element. Whilst Glaser sees the researcher as having an independent role, Strauss and Corbin describe a researcher's role as dialectic and active (Strauss & Corbin, 1990), and as presented by other grounded theorists such as Kathy Charmaz (Charmaz, 1991; Charmaz, 1999) it is possible to interpret this active role as illuminating any oppressive structures in order to raise the potential for change.

4.4 Summary

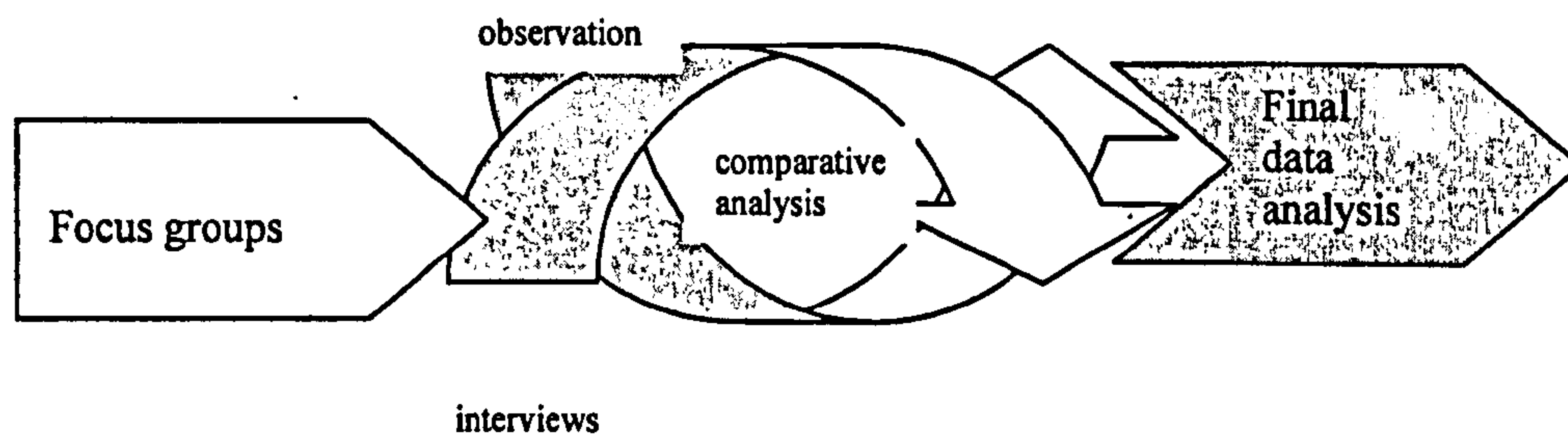
The first half of this chapter has provided an overview of the underpinning methodology of this study. The influence of both the current context of health care in long-term conditions and the research student's personal biography on the choice of research focus has been discussed. In addition, methodological choice is identified as being shaped by both the research questions and personal philosophy. The discussion was then developed into a critical commentary on the roots, methodology and differing branches of grounded theory. The critique of grounded theory as being epistemologically weak contributed to the final argument of this section, with critical realism presented as an appropriate underpinning for both the research focus and grounded theory methodology. The chapter will now go on to present the data collection and analysis methods used in the study, and will conclude by discussing issues surrounding ethics, reliability and validity.

4.5 Methods

Following a presentation on the research design and a discussion on the approach to sampling, this section will present the methods used within the research process: focus groups, interviews and observation.

4.5.1 Design

In order to facilitate comparative analysis, data collection occurred in two parallel strands (figure 9). Whilst focus groups were held initially to identify early themes, the remaining methods were used concurrently so that emerging categories could be checked, verified or rejected (Strauss & Corbin, 1990).



Study design

Figure 9

4.5.2 Sampling

Whilst there are little precisely defined rules regarding sampling within qualitative research (Tuckett, 2004) and an ongoing debate as to whether the positivist notion of sampling is even necessary within the interpretive paradigm (Gobo, 2004), it is generally recognised that for interpretable results, the issues regarding sampling need to be addressed within a study (Moseley & Mead, 2004). Qualitative studies have been critiqued as often underreporting the sampling process whereas the sampling method should be guided by the underpinning methodology (Higginbottom, 2004). In contrast to the positivist paradigm, sampling within qualitative research is not a static process and sampling criteria may change as the study proceeds (Higginbottom, 2004; Tuckett, 2004). Although Patton (1990) argues that all sampling within qualitative research is purposeful where the researcher seeks out cases that are most likely to contain the largest range of fruitful data, the literature suggests that this is just one of a number of possible sampling strategies. Gobo (2004) identifies three further procedures; quota sampling which is employed when a range of respondents is required, emblematic case sampling where a single case may have the features of being average, excellent or emerging, and snowball sampling where respondents who feature the necessary characteristics make recommendations on finding other similar participants. Grounded Theory methodology is most closely identified with the process of theoretical sampling (Glaser & Strauss, 1967; Strauss & Corbin, 1990).

However, the term is often mistakenly used interchangeably with purposeful sampling (Cutcliffe, 2000; Higginbottom, 2004). Seen at its conception as methodologically bold by enabling rigorous qualitative research to move on from the impossible search for a representative sample (Dey, 2004), theoretical sampling is employed as the evolving theory emerges, with the researcher actively seeking cases that are likely to contain concepts of theoretical relevance to the emerging theory (Strauss & Corbin, 1990). This process of sampling is complete when no new concepts or emergent themes are generated, a stage termed as data saturation (Glaser & Strauss, 1967). Although theoretical sampling continues to be critiqued from the positivist perspective that it is incongruent with generalisability (Dey, 2004), Glaser and Strauss (1967) argue that rather than a lack of generalisability the emerging theory is validated by being grounded in the data via the process of theoretical sampling, data saturation and confirmation of theoretical relevance. However, as theoretical sampling can only be used once themes start to emerge and a study has to start somewhere, the process of purposeful sampling is generally utilised as an initial strategy within a grounded theory study (Cutcliffe, 2000; McCann & Clark, 2003a). The remainder of this section will now describe the sampling process employed within this study; purposeful, snowballing and theoretical sampling (tables 17 & 18).

	<i>Proposed recruitment</i>	<i>Original recruitment</i>
Purposeful sampling	3 groups of 15-20 nurses 3 groups of 6-8 patients 2 GPs for interview 2 Practice Nurses (PNs) 2 Nurse specialists 2 Consultants 14-20 patients 2 EPP tutors	3 groups of 6-20 nurses 2 groups of patients affected by diabetes and cardiac disease. Latter group had connections with Parkinson's Disease Society. 2 GPs for interview 2 PNs 2 Nurse specialists 1 Consultant 11 via PCTs 1 EPP tutor

Original sampling & recruitment

Table 17

Snowball sampling	<p>Parkinson's disease group snowballed from cardiac group</p> <p>3 patients for interview via the Parkinson's disease group</p>
Theoretical sampling	<p>Parkinson's disease group snowballed and theoretically sampled as themes to do with spouses/carers in LTC were emerging & this group included carers.</p> <p>2 groups of 15-20 nurses to confirm theoretical relevance of litigation & trust.</p> <p>1 GP who was female as the other 2 were male with gender emerging as a theme.</p> <p>1 PN to confirm theoretical relevance of litigation & trust</p> <p>1 Consultant who was female as other one was male with gender emerging as a theme.</p> <p>2 groups of physiotherapists and 2 for interviews as Parkinson's disease group revealed therapists as significant in self-management</p> <p>8 female patients via MS Society and Osteoporosis Society with gender as an emerging theme</p> <p>1 female EPP tutor to confirm theoretical relevance of gender</p>

Further sampling & recruitment

Table 18

Purposeful sampling

In order to start investigating the areas identified in the research aims (1.3) an initial purposeful sample was identified as containing adults affected by physical long-term conditions and professionals most likely to be involved with them, which at the beginning of the study was expected to be nurses and doctors. The quota sample process (Gobo, 2004) was used with the professionals to ensure that there was a range of nurse grades (relatively newly qualified to nurse specialists) and medical specialisms in primary and secondary care. EPP tutors were identified as emblematic cases (Gobo, 2004) as by the very nature of being an EPP tutor they would be identified as expert patients. As illustrated, purposeful sampling was superseded by snowballing and theoretical sampling.

Snowball sampling

Originally the sample of individuals affected by a long-term condition was drawn from PCTs attended or waiting for EPP lists or via PCT connections with patient support groups. The cardiac support group recommended contact with a local Parkinson's disease society branch to form the third focus group, who in turn recommended three expert patients for interviews.

Theoretical sampling

As themes surrounding spouses as carers were beginning to emerge from the patient focus groups and interviews, a third focus group was sought that included spouses as carers with the Parkinson's disease group fulfilling this criteria. In turn it emerged from this group of patients and carers that self-management was seen as being facilitated most by therapists, therefore physiotherapists and other rehabilitation therapists were theoretically sampled. Two major themes also started to emerge as the data collection and analysis proceeded. Firstly, gender was a frequently recurring code found in both the professional and patient data and so female doctors, patients and EPP tutors were theoretically sampled to confirm the theoretical relevance. Whilst the doctors were approached via snowballing, the patients and EPP tutor were recruited via support groups that were likely to have a predominance of female members because of disease gender specificity or prevalence rates (National Osteoporosis, Endometriosis and Multiple Sclerosis Societies). Secondly, litigation and trust was emerging as a major category in the analysis of the

nurses' data, therefore an additional interview with a practice nurse and two nurse focus groups were theoretically sampled to confirm the theoretical relevance.

The chapter will now go on to explore the data collection methods in more depth.

4.5.3 Focus Groups

Originally attributed to Bogardus in the 1920's (McLafferty, 2004), his work in using a group interview as a way of checking peoples' attitudes towards such issues as race relations was adopted as a key method in market research (McLafferty, 2004). Whilst firmly embedded as a key market research tool the use of focus groups has migrated into social research (Macnaghten & Myers, 2004), and latterly has become increasingly popular in nursing research (Macleod Clark *et al.*, 1996). Their use in market research continues in popularity mainly because they are seen as a cost effective and quick way to gain consumers views (Reed & Roskell Payton, 1997). However, the emphasis in focus group research is on the group interaction to produce data and insights (Reed & Roskell Payton, 1997), a process found neither to be quick or particularly cost effective when compared to other methods (Macleod Clark *et al.*, 1996).

Despite their increasing use in nursing research there is both a dearth of literature on the method (Webb & Kevern, 2001) and lack of a clear definition (McLafferty, 2004; Reed & Roskell Payton, 1997). Definitions range from a facilitated small group discussion on selected topics (Mansell *et al.*, 2004) through to a purposeful use of group interaction to understand and describe a particular issue from the perspective of a group (Rice & Ezzy, 1999), and generate data that is only accessible via group interaction (Macleod Clark *et al.*, 1996; Morgan, 1997) in order to reflect the social realities of a cultural group (McLafferty, 2004). It is the latter two points that contribute to the rationale for commencing this study with a series of focus groups; what were the perceived realities for both health professionals and patients in the current context of active patients and long-term conditions. Whilst focus groups can be found within a quantitative study in order to identify constructs prior to the main data collection (McLafferty, 2004), Morgan (1997) argues that focus

groups are particularly useful when used prior to individual interviews, helping to devise the interview guide by directing the researcher to explore either themes arising out of the focus groups or by alerting them to potential issues that were underrepresented by the groups. Similarly, focus groups are useful prior to participant observation in acclimatising the researcher to the context and issues (Morgan, 1997). Distinct themes did arise from the focus groups which were used specifically as part of the constant comparative analysis (Strauss & Corbin, 1990) both between the groups and with the observation and interviews (see figure 9), and when used in this way focus groups are an appropriate method within a grounded theory study (Webb & Kevern, 2001).

Data collection commenced with a series of focus group interviews with nurses, physiotherapists/rehabilitation specialists and patients with long-term conditions, details of which are presented later in this section (see table 19).

Focus group	Participants	Number in group	Group characteristics
1	Post registration nurses attending a Diabetes Care course	14	Mode age range 30-49. Mean years post RN qualification 18 years. Ratio current hospital to community staff 5:9. All female
2	Post registration nurses attending a Respiratory Care course	6	Mode age range 30-39. Mean years post RN qualification 19 years. Ratio current hospital to community staff 4:2. All female
3	Post registration nurses attending an Anticoagulation Nursing course	20	Mode age range 30-49. Mean years post RN qualification 21 years Ratio current hospital to community staff 20:0 All female.
4	Individuals with long-term cardiac conditions	7	Age range 45-72 Years since diagnosis range 1-

			9 5 males, 2 females
5	Individuals with Parkinson's Disease and informal carers	9	Age range 55-78 Years since diagnosis range 5-25. With condition 4 males, 3 females. 2 female carers
6	Rehabilitation practitioners from one community based Neurological Rehabilitation Centre (4 physiotherapists, 2 occupational therapists, 2 rehabilitation care assistants, 1 psychologist, 1 nurse)	10	Mode age range 30-39 Mean years in practice 15. All female.
7	Physiotherapists	20	Mode age range 30-39 Mean years in practice 19. 5 males, 15 females Ratio current hospital to community staff 18:2
8	Post registration nurses attending a Diabetes Care course	15	Mode age range 30-49. Mean years post RN qualification 19 years. Ratio current hospital to community staff 8:7. All female
9	Post registration nurses attending an Anticoagulation Nursing course	20	Mode age range 30-49. Mean years post RN qualification 20 years Ratio current hospital to community staff 20:0 19 female, 1 male.
10	Individuals with diabetes	7	Age range 53-76. Years since diagnosis range 2.5-23. 4 males, 3 females.

Focus groups profile

Table 19

Whilst Macnaghten and Myers (2004) recommend theoretical sampling for groups, as discussed in 4.5.2 the earlier focus groups were purposively sampled (Mansell *et al.*, 2004). The nurse focus groups consisted of post-registration nurses who were attending a course on specialised care of particular conditions or treatments; diabetes, respiratory and anticoagulation. Part of the course content was a ninety-minute session on the Expert Patient that I had presented prior to the commencement of the PhD study that invariably produced a large amount of discussion providing a potentially rich source of data. With the permission of the course leaders, ethics approval (see 4.6) and the informed consent of the students (appendix 3), the end discussion of the lecture based on scenarios (appendices 4a-c) was used as a focus group, with the teaching room as the venue remaining unchanged. As can be seen from table 18, the number of participants often exceeded the recommended maximum focus group size of ten to twelve (Macleod Clark *et al.*, 1996; Mansell *et al.*, 2004), but both Morgan (1997) and McLafferty (2004) suggest that larger numbers may be appropriate. In order to manage the larger groups the participants were asked to break up into smaller groups of four to five, discuss the scenario and then to return to the larger group in order to feedback their discussion, with the plenary audio-taped. Whilst not the usual format of a focus group, this did enable the majority of views to be heard as the less vocal participants appeared to feel more at ease to voice their views. The bringing together of small group perspectives also appeared to allow a more iterative process with a continuum of views presented. Despite the use of a presentation prior to the focus group and a scenario to trigger discussion not being the normal format of a group interview, Van Eyk and Baum (2003) suggest that it is a useful approach not least because it imbues the participants with a sense of researcher preparation for the group. The same format was used with both the rehabilitation therapist and physiotherapist focus groups (appendices 4b & d) but there were differences in sampling and recruitment. The focus groups with both the cardiac and Parkinson's Disease groups suggested that rehabilitation and physiotherapists played a significantly different role in enabling self-management abilities, thus these two professional groups were sampled theoretically. The host PCT for both professional groups facilitated recruitment by enabling contact with key personnel involved with in-service

training for both groups. It appeared that access was greatly enhanced by offering an in-service session on the Expert Patient initiative, followed by the focus group. The training officer circulated the Information Sheet (appendix 5) and session format six weeks before the event. Attendance was very high (as indicated by table 18) with one hundred percent of rehabilitation staff attending and approximately ninety percent of the physiotherapist total staffing. When I asked the groups whether staff development usually evoked such a good attendance, both groups indicated that this was not usually the case but the topic was of great interest to them. The venues for both groups were gymnasiums which, whilst causing some difficulty in audio taping (overcome by using two recorders in different positions), did allow enough room for the small group discussions. The sessions were held over a ninety-minute lunch period with staff eating their packed lunches during the presentation in the first part. Unfortunately early enquiries at the proposal stage of the study indicated that there would not be such a similar response from GPs, a view reiterated during the study by various PCTs.

The focus groups with patients were recruited via a PCT's links with two support groups for people with cardiac problems and diabetes respectively. The Parkinson's Disease group was recruited via a contact made in the cardiac group. The Support Groups for the latter two conditions made the arrangements for these two focus groups by circulating the Information Sheet/invitation (appendix 6) to their members, and arranging the venue, date and time with willing participants. Both groups were held in a member's house, the cardiac group in an evening and the Parkinson's Disease group in the afternoon. The diabetes group was recruited differently for whilst the support group circulated the Information Sheet/invitation (appendix 7) and provided a list of names and addresses of willing participants, the agreement form (appendix 8) was posted to the potential participants by myself, and following their responses I telephoned with the most popular date and time and suggested venue. A room in a centrally located Community Hall was hired for the session, with a letter of confirmation and map sent to the volunteers. Eight people had agreed to this focus group but one did not arrive, in contrast all volunteers in the cardiac and Parkinson's Disease group attended. I provided appropriate refreshments at each of these groups, participants were

asked to allow two hours for the event with the group interview being kept to ninety-minutes. The rest of the time was used to allow for late arrivals, explanation of the study and opportunities for questions. The format followed a more usual approach with a number of trigger questions to facilitate group discussion (Morgan, 1997) (appendix 9). As with the professional groups, the group discussion was audio-taped. In order to facilitate initial engagement with the emerging issues, I transcribed the tapes myself, a time consuming but worthwhile task.

4.5.4 Interviews

Charmaz's (2004) first premise of qualitative research states that a deep understanding of studied life entails entering it. Within this study, the research interview is seen as one way of understanding the world from the respondents' point of view, to explore the meaning of their experiences of the lived world (Kvale, 1996) and to elicit rich, detailed data (Fielding, 1993). Interviews are seen as well suited to the exploration of values and beliefs (Barriball & While, 1994), and particularly appropriate in studies focusing on long term conditions where detailed individual chronicles are of use (Charmaz, 1990).

Philosophically, interviews can be described through the use of two metaphors. Firstly, interviews can be seen as an excavation (Mason, 2002) or mining (Kvale, 1996) for knowledge. Alternatively, interviews are described in terms of construction (Mason, 2002) or as a journey together with the interviewee (Kvale, 1996) in order to discover knowledge together. As with all data collection methods the metaphorical style is governed by the epistemological stance of the researcher and study design (Price, 2002), with the mining metaphor clearly describing a positivist stance. The post modern construction of interviews sees the relationship between interviewer and interviewee as a lens for understanding the social world (Gerson & Horowitz, 2002), and acknowledges a multitude of realities (Kvale, 1996; Price, 2002), a view congruent with critical realism (Bhaskar, 1986). Kvale (1996) demonstrates this multiplicity of realities by identifying five different ways knowledge is constructed within an interview (table 20).

Knowledge construction via an interview	Application to this study
1. Knowledge as conversation	Interviews followed a conversational style. Analysis (see 4.7) included examination of the discourse as well as content.
2. Knowledge as narrative	Each interview started with encouraging the respondent to tell their story. Analysis (see 4.7) included a focus on individual narratives and the collective narrative from all respondents.
3. Knowledge as language	<i>“Language constitutes reality, each language constituting reality in its own way”</i> Kvale 1996:43. All respondents but one spoke English as a first language reflecting the profile of the study site.
4. Knowledge as context	There were a variety of factors impacting on the context of the interview such as age and gender of the respondent and how this affected the interviewer/interviewee relationship, and the venue of the interview (see below).
5. Knowledge as interrelational	Kvale (1996) argues that post modern interviews are an exchange of views between two people conversing about a common theme. In this case the theme was the experience of living with or being in the care arena of long term conditions, and so on occasions it was appropriate to share experiences of living with or caring for long term conditions.

Knowledge construction via interviews (Kvale, 1996)

Table 20

Recruitment of respondents is illustrated in table 21, with the sampling process discussed in 4.5.1.

All patients and carers received an Information Sheet with the wording slightly amended depending on the recruitment strategy (appendices 10a-b).

With each Information Sheet was a response sheet (appendix 11) and a stamped addressed envelope, hence respondents' names and contact details were not known to the researcher until they had agreed to participate. Once the response sheet had been received the respondent was contacted by telephone and a mutually agreeable time and venue was arranged. In most cases the venue was the respondents' home. However, three respondents preferred an alternative venue with two specifically asking that the interview was

Respondent Group	Recruitment Strategy	Numbers recruited
Patients & carers	<ul style="list-style-type: none"> • Two PCTs distributed information & response sheet to individuals who had attended or were on waiting list for the EPP 	11
	<ul style="list-style-type: none"> • One PCT invited me to talk about the study at a Rehabilitation Unit, the meeting was chaired by a Trustee of the MS Society who then distributed information & response sheets at a Complementary & Alternative Therapy Centre for those affected by MS. 	4
	<ul style="list-style-type: none"> • One PCT invited me to present at a Community Voluntary Service meeting, the Chairperson of the local National Osteoporosis Society was present & offered to distribute Information & Response sheets to the members. 	4
	<ul style="list-style-type: none"> • Three people had been unable to attend the PD focus group but were keen to contribute to the study 	3
EPP Tutors	<ul style="list-style-type: none"> • One EPP tutor via the MS Society 	1
	<ul style="list-style-type: none"> • One EPP tutor via the National Endometriosis Society 	1

Health professionals	<ul style="list-style-type: none"> • One PCT distributed the Information Sheet to all GP practices. One GP & one PN volunteered. 	2
	<ul style="list-style-type: none"> • One PCT invited me to talk at a PN Forum, two PNs volunteered. 	2
	<ul style="list-style-type: none"> • One PCT had a Board member with a special interest in diabetes. He passed on Information Sheet to two GPs & one Consultant who agreed to participate, the Consultant passed on the Information Sheet to two Diabetes Specialist Nurses who agreed to participate. 	4
	<ul style="list-style-type: none"> • One PCT distributed the Information sheet to physiotherapists who had been unable to attend the focus group, two agreed to be interviewed. 	2
	<ul style="list-style-type: none"> • All female Consultant Physicians in one Trust (n=2) were informed by letter of the study and invited to participate. One agreed. 	1

Recruitment for interviews

Table 21

conducted at the University. In this instance a small room was pre-booked and the interviews were both carried out on separate evenings. Two other patients also requested evening appointments in their own home but the remainder preferred a daytime interview. One patient specifically requested that an alternative daytime venue be found near her home; in this case a room in a community centre was hired for two hours. In venues that were not the respondents' home I provided refreshments. However, having reflected on the issue I decided that it could appear patronising if not possibly insulting if I went to peoples' own homes armed with tea and coffee, in most cases I was offered a hot drink which was accepted as a norm of English cultural "ice-breaking" prior to the interview commencing.

The two EPP tutors were approached first by their respective Societies to see whether they were agreeable to receiving Information and Response sheets from me (appendices 11 & 12), when the Societies received confirmation of agreement their name and addresses were passed on to me and the information was posted with a stamped addressed envelope for reply. One EPP tutor requested an interview at the University, the other specifically wanted to be interviewed over lunch at a local pub. Whilst I expressed concerns at issues of privacy in such a setting she felt confident that a quiet corner would be found, however once there she realised that privacy was going to be difficult to ensure and so the interview was conducted after lunch in her car.

Health professionals also received an Information Sheet (appendix 13) but once I received a verbal or email expression of agreement contacted them directly to make arrangements for the interview. At their request, all interviews were carried out in a private room at the practitioners' workplace. Apart from the physiotherapists and nurse specialists the interviews were carried out during lunchtime and so I provided sandwiches and drinks. The physiotherapists and Nurse Specialists found it easier to accommodate the interview at the start of the day.

Before the interview commenced the respondent was asked whether they had any questions from the Information Sheet and were given a verbal brief about the purpose and process of the interview, this was followed by a debriefing at the end of the interview generally by asking whether there was anything else they would like to say (Kvale, 1996). Each interview utilised an interview guide (Duffy *et al.*, 2004; Kvale, 1996) (appendices 14a & b) which contained the list of topics to be covered but in order to remain as conversational as possible could be re-sequenced with the flow of the interview. The content of the guide was developed from the research questions (Kvale, 1996) and was scrutinised by supervisors for content validity (Barriball & While, 1994). Through the process of constant comparative analysis (Strauss & Corbin, 1990) as the study progressed, the focus of each interview changed slightly and new topics were added. For example, in the later interviews with the consultants and nurse specialists questions were used that explored their responses to the emotional needs of patients which was highlighted as an issue for GPs and patients in earlier interviews.

There is a great deal of literature on the skills required for effective questioning in interviews. Whilst some of the literature details the types of questions which range from introductory to interpreting questions (Kvale, 1996), or from informational to feeling questions (Charmaz, 1990), Duffy *et al's* (2004) advice not to ask a question outright appears particularly pertinent when exploring peoples' experiences. For example, asking someone outright how professionals responded to their self-management strategies may have caused some difficulties in responding, in contrast asking people to tell their story of how they cope with their condition and their story of how they get on with their doctor or nurse may reveal more. A biographical approach (Gerson & Horowitz, 2002) was used in all the interviews. In order to facilitate this an appropriate scenario was used during the interview to trigger narrative (Mason, 2002) (appendices 4b-d & 15a-b). Whilst this worked very well with the health professionals and seemed to free them up to articulate their feelings, it did not work well with the patients and so was dropped as a technique in the patient interviews early on, with a focus on their own biography far more fruitful. As with Price's (2002) own experience, my skills and confidence in interviewing developed with the study, particularly my ability at thinking on my feet and probing. Probing allows for clarification, the exploration of valuable information, maximum interaction and rapport, and can enable respondents to recall information (Barriball & While, 1994). Whilst many techniques in probing such as the use of silence, echoing or encouraging by using uh-huh are familiar to nurse researchers from their professional communication training (Price, 2002), I found probing by leading or baiting a more accomplished skill that developed with time. Using a ladder approach to the questioning (Price, 2002) was also a useful strategy, with biographical action questions (for example, what happened) followed by questions regarding knowledge (what do you know about) and ultimately questions regarding personal philosophy being asked when the rapport had developed. The latter type of questions were facilitated by the use of the scenario in the professionals' interviews (Fielding, 1993), in the case of patients it was triggered by questions such as how would you describe an ideal doctor? Many issues that potentially arise during an interview relate to ethics and will be discussed in 4.7. However, as indicated earlier the main challenge was to

develop skills to maintain the quality of the interview. Kvale (1996) describes a set of criteria for the quality of an interview that includes the extent of spontaneous, relevant and rich answers, short interviewer questions in comparison to the interviewee's responses, the degree of clarification of interpretation by the researcher during the interview, and the extent to which the interview is a story in itself. As the study progressed the audiotapes and transcripts were examined for quality and learning points responded to in subsequent interviews. Characteristics attributed to an effective interviewer who enhances communication (Fielding, 1993) were also reflected upon, and whilst sensitivity, gentleness, and openness (Kvale, 1996) had hopefully developed during my years as a district nurse this could not be assumed. Therefore transcriptions were critically interrogated and my feelings and insights articulated within the reflective journal (see 4.8).

Unlike the focus groups the interviews were transcribed professionally but to enhance reliability (Kvale, 1996) and to get a feel for the data, transcriptions and audiotapes were read and listened to simultaneously. Wherever possible interviews were spaced enough to enable an initial analysis of the previous one (Duffy *et al.*, 2004), which also prevented researcher fatigue when multiple interviews are fitted into a day (Price, 2002).

4.5.5 Observation

Whereas observation is seen as a key method in ethnography (Delamont, 2004) it is also seen as a method typically employed within a grounded theory methodology (Bonner & Tolhurst, 2002), and particularly useful when used with other methods to provide a diverse perspective (McCann & Clark, 2003c; Morse, 2003). Observation contrasts with the process of simply watching an event, with the observer proactively using a vision that is guarded from everyday familiarity (Sanger, 1996). It is seen as the method of choice where the focus of the research is to explore the experience of people, how they feel, think, act and understand their world (Delamont, 2004; Waddington, 1994), and is cited as one of the most important approaches to data collection in practice-based professions (Moore & Savage, 2002). Observation is particularly useful when there is little known about a phenomenon, there are probable differences between the insider view and outer appearance of a

phenomenon and the insider view is somewhat obscured to the outsider (Jorgensen, 1989). Within this thesis it is argued that observation was an appropriate method as the phenomenon of the expert patient was under researched and the process of developing expertise in self-management was likely to be partially hidden from an outsider. As with the other methods described so far, observation is underpinned by a continuum of philosophical paradigms ranging from a reductionist highly structured observation (Endacott, 1994) to a near total immersion within the social world (Savage, 1995). The philosophical continuum relates to a continuum of observer roles (Bonner & Tolhurst, 2002; Jorgensen, 1989; Spradley, 1980), which in turn needs to be congruent with the researcher's values and research questions. Within this study two different roles were undertaken, participant as observer and observer as participant (Waddington, 1994). As can be seen in figure 10 these stances were congruent with critical realism in that they do not lie on the extreme ends of the continuum but do allow for the acknowledgement that there is a reality that can be observed, but this reality may be one of many (Archer *et al.*, 1998).

Complete observer	Observer as as participant	Participant as observer	Complete participant
Merely stands back & observes operation	Superficial contact asks occasional questions	Forms relationships & participates but does not hide role as observer	Covert
	<i>Consultant, Specialist Nurse & Practice Nurse Clinics, Professional-led Self-management Programme</i>	<i>Expert Patient Programme</i>	

Continuum of researcher identities (Waddington, 1994)

Figure 10

As shown in figure 9, the design of the study allowed for parallel data collection via the interviews and observation thus enabling constant comparative analysis. Within the observation strand timing of the first available EPP within the study site resulted in this preceding the other periods of observation and therefore this will be discussed first.

Access to a site for observation can often be problematic depending on a number of factors. Gerson & Horowitz (2002) describe these as the formality of the setting, degree of control exercised by the participants, the socio-political and historical context of the group, and the perceived social distance between the participants and the researcher. I envisaged several problems in getting access for participant observation. Firstly I was anxious that the actual approach of participant as observer would not only cause anxiety for the stakeholders but would also prove problematic with the research ethics committee (this is discussed further in 4.7) (Morse, 2003). Secondly the EPP was seen as the flagship of public health policy (Donaldson, 2003) and it appeared that PCTs participating in the pilot phase felt protective of the programmes. Finally, only one of the collaborating PCTs had actually joined the pilot wave managing to run one course before the start of the study but were having tremendous difficulty in recruiting for another course, the other PCTs in the study site were only beginning to think about the EPP when the study started. As with so many stories of access (Gerson & Horowitz, 2002), mine was a fortuitous break when one PCT asked me to join their EPP implementation group. In effect my role was as a consultant to this group and thus with a little creativity and common sense (Waddington, 1994) it was negotiated that in return they would facilitate my access to one of their EPPs. However, this was only the first hurdle because as I had no intention of undertaking a covert observation it would be necessary to obtain informed consent from the lay tutors and course members (see 4.6), with the former asking that permission was also gained from the regional trainer. My concerns that my role as participant as observer would prove a barrier were completely unfounded and indeed actually eased my access as both trainer and tutors were most concerned about having someone sitting in with the group who would not be fully participating. Any lingering doubts from them were finally

dispelled when I explained that I was affected by a long-term condition (4.1.1) and would be using myself as a research tool, reflecting on my experiences as being part of an EPP (discussed further in 4.8). This identity also enabled relationships to be formed (Gerson & Horowitz, 2002) with the course members, with self-revelation of what I had in common with them leading to a developed rapport (Jorgensen, 1989; Waddington, 1994).

Once access had been negotiated with the gatekeepers (Hammersley & Atkinson, 1995), the PCT sent the information sheet (appendix 16) to the prospective course members. As I would use myself as a focus for the observation, it was not considered necessary from an ethics perspective to obtain written consent from each course member, however verbal consent was sought and this is described in 4.7.

To enable my participation in the EPP to be as full as possible I encouraged the tutors and PCT organiser to treat me as a member of the group.

Consequently I was given the course handbook (NHS Expert Patients Programme, 2002) and undertook all the activities. As I was fully participating it was neither appropriate nor possible to take field notes during the course which lasted for two and a half hours weekly for six weeks. Before commencing the observation I was anxious that I would not be able to write up the detailed field notes required (Delamont, 2004; Waddington, 1994) particularly as I expected the dual role of insider/outsider (Bonner & Tolhurst, 2002) to be mentally draining. To make it manageable I recorded my field notes as an audio diary, taped as soon as possible after each session. This taping often took place in my car as soon as I had left the venue, utilising a framework to trigger critical reflection (Boud & Walker, 1990) (appendix 17). The other periods of observation took a different approach with my role more as observer as participant. The rationale for this was that during the observation of nurse and consultant consultations, any active participation on my part would not be a natural part of the normal encounter. Whilst it must be acknowledged that having a third person physically present during a consultation would have some impact, I tried to be as unobtrusive as possible. For the consultants it was not uncommon to have someone sitting in on consultations (for example medical students), however both practice and specialist nurses were less accustomed and admitted that they had felt quite

nervous to be “watched” at the beginning, but by the end of the session felt very relaxed with my presence. Whilst this may be to do with a conscious effort on my part to be non-threatening and positive (Waddington, 1994), it also felt as if I began to merge into the background with all nurses admitting they forgot I was there after a while.

Patients received an information sheet when they arrived at Reception, once they had read it and agreed for me to be present they were asked to sign a consent form (appendices 18a & b). In the case of the consultant clinics the out-patient nurse collected the consent forms. This format had been requested by the consultants and was the usual process they adopted when involved with research. To address my concerns that patients would feel they had little opportunity to ask questions of the researcher I had fully briefed the nurses about the study and encouraged them to let me know if anyone had any queries. When the patients entered the consulting room both the consultant and myself gave patients the opportunity to ask any questions and to confirm their consent.

Whilst patients attending nurse-led clinics also received the information sheet from the Reception, it was I that approached each patient once they had read it to answer any queries and obtain written consent. The nurse led clinics were far less busy than the consultant clinics enabling me the time to do this between each appointment.

The professional-led self-management programme (Back Fitness course) was the last period of observation within the study. The timing was pragmatic in that it was the first available course after completion of data collection in the EPP. Access was facilitated by the same PCT that had run the EPP, the Back Fitness coordinator was part of the EPP implementation team and was aware of the study. However, initially it took time to negotiate access to an entire programme as she felt that observing one session would be enough for the study. Hence I learnt not to assume that, despite reading protocols, stakeholders would necessarily understand the particular purpose of each phase of the study. An information sheet (appendix 19) was sent to all prospective course members by the PCT and at the first session I reviewed the information with them and received verbal consent for my participation. The purpose of this period of observation was to compare with the EPP,

particularly how the relationships between group members and their relationship with the facilitator differed, whether a different milieu was created and whether any differences in outcomes were observed. Whilst the findings are described in chapter 5, it is pertinent here to justify why a different researcher role was undertaken than in the EPP. Firstly, I had felt enabled to fully participate in the EPP as I had a long-term condition, however this was not a back problem and I felt that acting as a full participant would have an element of dishonesty (see 4.7). Secondly, I would argue that using a variety of observation roles when observing self-management programmes enabled a multi-perspective to be gained, thus facilitating triangulation (see 4.8). Thirdly, data collection fatigue was a potential problem at this stage of the study and I had found the effort of being both insider and outsider of the EPP draining and whilst still being engaged the distant role felt less emotionally challenging.

Although the role of observer as participant was more distant, it did not preclude interaction with the participants. Within the clinic settings I would sit slightly away from the practitioner and patient, but the size of the consulting rooms excluded any great distance. I would record field notes contemporaneously in a small note book but tried to respond to any non-verbal cues directed at me, for example smiling back as appropriate. At times the consultant or nurse would involve me in a discussion with the patient, and if I felt it necessary to clarify an issue with any of the participants I would ask questions as appropriate. Any intimate examinations would be undertaken in an adjoining consulting room and to maintain patient privacy I would keep out of that room. My interaction with the participants on the Back Fitness course was informal and generally happened when we were waiting in the Sports Centre reception area for the course to start, here I would ask general questions such as “how has your week been?” As the weeks progressed I was accepted more and they would ask me questions in return such as “how is it (*the study*) all going?” The course was divided into two sections each week, firstly an exercise programme facilitated by a fitness trainer. During this I would sit in the corner of the large gymnasium and record field notes. The second half was facilitated by a psychologist and focused on developing life skills. This was undertaken in a small room with participants and facilitator

sitting in a small circle. If I had sat outside of the circle I would have had difficulty in being able to observe what was going on. Topics covered were sometimes sensitive such as dealing with the emotional consequences of chronic back pain, also there was a weekly relaxation exercise. I felt that it would be intrusive and possibly disruptive to sit in the circle and make field notes, hence I decided to adopt the same approach as the EPP by recording a reflective audio diary as soon as I had left the Sports Centre, using the same reflective framework as the EPP. I also used this framework to trigger more open field notes when observing the exercise element as by this stage of the data collection and analysis I was far more focused within my mind as to what questions I needed to explore (Gerson & Horowitz, 2002). In contrast I felt I needed to use a more structured approach when first observing the clinics and so used a more formal schedule (Barlow, 1994) (appendix 20). However, as my time in the field progressed and constant comparative analysis guided the process, this schedule was replaced by the reflective framework that enabled a progressive narrowing (Spradley, 1980) focussing on themes of theoretical relevance (Strauss & Corbin, 1990) such as gender.

Within a grounded theory leaving the field should be governed by data saturation (Strauss & Corbin, 1990). In the case of the clinic observation, saturation was the trigger for completing this data collection; however, the length of observation in the EPP and Back Fitness Course was equally as guided by the length of the programme. Although time spent in the field was not as great as in an ethnographic study, nevertheless leaving the setting has the potential of being painful for the researcher (Waddington, 1994). This was to some extent the case with the EPP where my emotional engagement had been the greatest. As part of the PCT policy, reunions were arranged for course participants and whilst I was invited, I deliberately did not attend in order to draw closure of my role as an insider. However, a year later, once the data collection and analysis had been completed I did attend in order to give feedback from the study. Leaving the field was personally less challenging with the other meetings, presumably due to my more outsider role. Whilst the Back Fitness participants were invited to contact me if they would like to receive feedback from the study, all the practitioners involved received a written report (appendix 21a) and were encouraged to contact me if they had

any questions or wanted further information. Patients in the clinic setting were advised to contact me if they would like written feedback of the study, whilst all patients involved in the interviews and focus groups were sent a written report (appendix 21b).

4.6 Ethical issues

Ryen states that “...*the ethical stance towards research practice varies across paradigms*” (2004:244) and develops a framework identifying values and ethics within four contemporary qualitative research paradigms (table 22).

ASPECT	NATURALISM	ETHNOMETHODOLOGY	EMOTIONALISM	POSTMODERNISM
Values	Excluded, influence denied	Ethno-indifference	Included - formative	Included - formative
Ethics in general	Extrinsic, tilt towards deception	Extrinsic	Intrinsic, process tilt towards revelation, special problems	Intrinsic, process tilt towards revelation
Field relations	Keep to research protocol, do not go native	Natural data, subjects' consent for access to data	Passionately engrossed	Researcher authority under attack
Representational practice	Loyal representation of the respondent's version as truth	Non-judgemental attitude	Innovative representations of emotions	Deconstruction, focus on representational practice.

Values and ethics in four contemporary qualitative research paradigms (Ryen, 2004) Table 22

Whilst this is a useful framework it does not take the reader beyond postmodernism, or more relevantly for this thesis to critical realism. However, using the same criteria it is possible to articulate the values and ethics within the critical realist paradigm underpinning this study (table 23). However, clarifying the epistemological basis of the ethical approach does not negate the formal research governance procedures. Within the UK, the research management and governance process was reinforced by European Union legislation (Department of Health, 2005d). Whilst the primary aim was laudable in focusing on public protection particularly in clinical trials it has not been without its critiques (Howarth & Kneafsey, 2005), and in general

ASPECT	CRITICAL REALISM
Values	Included, formative
Ethics in general	Intrinsic, process tilt towards revelation
Field relations	Engrossed but also seeking natural data
Representational practice	Focus on representing multiple realities, non-judgemental but seeking to understand contextual issues

Values and ethics within the critical realist paradigm Table 23

there has been a growing discontent with research ethics committees' responses towards qualitative research (Morse, 2003). This study went through two formal ethics processes. Firstly, as the focus groups with nurses was to be undertaken as part of a University programme, approval for this element of the data collection was obtained from the University Ethics Committee (appendix 22). The remainder and bulk of the study required approval from a NHS ethics committee which was obtained following a few minor amendments to the submission (appendix 23). Whilst this process was relatively smooth, issues around the research management and governance were more complex because the new regulations were concurrently being introduced; a learning process for all involved (appendix 24). Fortunately by the time research management and governance approval was required for the data collection within the out-patients department, the process had become less complex and time consuming (appendix 25).

When devising an ethically sound study design three main areas need to be addressed; informed consent, field relations and confidentiality. Informed consent is seen to have four main elements (Moore & Savage, 2002; Silverman, 2000), firstly, that respondents are given enough information of what will and might occur. Secondly, that this information should be understandable for them and that they are competent to make a mature judgement. Lastly, there must be freedom from coercion with participation

entirely voluntary. There is much debate in the literature as to how much information is enough with an anxiety that giving full and frank information may affect the respondents' natural actions (Hammersley & Atkinson, 1995). Information giving within grounded theory may also be problematic as the researcher may not know exactly what they are specifically wanting to find out (Glaser & Strauss, 1967). Within this study I adopted a "shallow cover" approach which whilst making the research intent clear remained slightly vague (Ryen, 2004). Whether to obtain written or verbal informed consent is also problematic, for whilst it is deemed good practice and a safeguard for the researcher's integrity, signing a consent form may be culturally inappropriate (Ryen, 2004), or may cause undue anxiety for the respondents (Moore & Savage, 2002). Written consent forms were obtained from all respondents except those participating in the EPP and Back Fitness Course. The rationale for the latter was that in order to protect the respondents' anonymity as fully as possible I should not have any of their names or contact details recorded if I did not need them. Verbal consent was obtained from the groups involved each time I was present and not having to deal with paperwork each time we met, led to a more relaxed environment (Moore & Savage, 2002). Whilst this could also be applied to the respondents in the clinic observations, the Trusts involved preferred written documentation recording consent.

Field relations are also attracting increased articulation within the literature, particularly from the feminist paradigm (Ladino, 2002). Whilst Ladino (2002) states that an involved relationship is required, and Charmaz (2002) arguing that any researcher involvement with vulnerable groups such as the chronically sick should put a caring and involved relationship at the forefront, others suggest a more neutral approach (Gerson & Horowitz, 2002). The morally correct approach within this study appeared to be to take the most appropriate approach for that particular respondent or group. Certainly there were some respondents who stated that the interviews were therapeutic (Hutchinson *et al.*, 1994), others such as one consultant and the specialist nurses actively asked for a more challenging relationship. All field relations were underpinned by three principles, respect for the respondent (Charmaz, 2004), engendering the trust of respondents by actively listening and facilitating reciprocity (Ryen, 2004). Reciprocity within this study was

provided in a number of ways. All participants were provided or offered written feedback from the study that had the potential to trigger self-reflection (Ryen, 2004) and were given the opportunity for further verbal feedback if required. This was only taken up by one consultant who wanted to pursue future research ideas resulting from the findings. Reciprocity also took the form of formal presentations to the collaborating Trusts and voluntary groups involved.

Confidentiality of respondents can be problematic to ensure particularly when reporting the research (Kvale, 1996; Ryen, 2004), but paradoxically reporting research findings is also seen as an ethical imperative (Smith, 1992a). Whilst there is always the possibility that a respondent may be recognisable to a particular reader, anonymity was potentially easier as the study site had been across a whole county. Specific NHS Trusts were not identified in the reporting and respondents' names were anonymised to a code known only to the researcher. Data was stored in a locked cabinet and laptop computer to which only I had password access. On completion of the study written data such as the consent forms are stored in a university archive facility as per usual operating procedures, but audiotapes are destroyed.

Whilst Smith (1992) advises researchers to be prepared for sensitive topics to emerge during interaction with respondents this did not occur during the interviews or focus groups. The only incident that I felt was sensitive was during observation of one consultant's clinic. On one occasion a male patient started to discuss erectile dysfunction and I immediately started to wonder whether my presence as a female would be problematic for both patient and the male consultant. I felt I had two options, firstly I could interject and ask whether they would like me to leave, however the patient did not appear to be impeded by my presence so I wondered whether it was my own discomfort that was more of the issue. I took the second option of remaining and continuing as normal. After the consultation I asked the doctor whether he thought I was impeding the communication on a potentially sensitive topic with his response being that he thought the patients were no different with me there. Consequently I stayed when this topic emerged in future consultations but continue to worry whether any of the patients might have wanted to discuss this but felt unable to do so with me there. Interestingly similar

occasions happened with the female consultant who saw patients with vulval pain. On reflection I felt no discomfort on an equally sensitive topic in an all female environment. Gender emerged as a major theme in the findings, but it is appropriate to reflect that it also affected my feelings and responses as with so many female researchers in the field (Bell, 1993).

Whilst the interviews did not raise sensitive topics, there was one occasion when I felt that morally I had to take some action. Several authors describe the tension of being both a clinician and researcher (Johnson, 1992; Rose, 1994; Savage, 1995) with the general consensus that if harm or potential harm is seen by the researcher then there is a moral imperative to take action. Whilst nothing of this nature was heard about or observed in this study, the first interview I conducted with a person affected by a long-term condition triggered me to respond as a nurse. F1 was recently diagnosed with Parkinson's Disease, she was also a recovering alcoholic. During the interview it became apparent that she had virtually no knowledge about the disease, was not following the prescribed drug regimen with both she and her husband articulating isolation and a need to understand the condition. When the interview was finished I spent time with them both answering relatively basic questions about the condition. As they had internet access I also showed them the Parkinson's Disease Society website and gave them the number of a local branch secretary. Smith (1992) reinforces the need to provide appropriate debriefing and support to respondents after the interview that hopefully was demonstrated in this scenario.

Finally, an ethically sound study should be able to illustrate that process issues have been addressed. Firstly, Kvale (1996) points out that transcription has ethical implications, particularly in remaining loyal to what was said or not said (Charmaz, 2002) and maintaining confidentiality if an external transcriber was used. Whilst I transcribed all the focus groups I did not have the typing skills to manage all of the interviews in addition. An external transcriber was employed who understood the need for confidentiality and was sufficiently removed from the research site to make it very unlikely that she would recognise any of the respondents. Once the transcripts were returned I would read and listen to the tapes concurrently and correct any errors, inserting silences if necessary. Kvale (1996) also asks whether respondents have the

moral right to have a say in how their statements are analysed but within this thesis this is seen as an integral part of verification which will be discussed in 4.8.

4.7 Analysis of data

Although the process of analysis varies from one qualitative methodology to another, there are some general principles applicable to all (Tesch, 1990). These describe the concurrent or cyclical nature of analysis and data collection, a systematic but flexible approach, and the incorporation of a reflective process. Data is also segmented into meaningful units that are categorized according to the data rather than an imposed system, a tentative process at first. The main intellectual tool used during qualitative analysis is comparison, and whilst the overall aim is to enable a higher level of synthesis, there is no single procedure to do this (Tesch, 1990). Pope *et al.* (2000) demonstrate these overriding principles in an applied qualitative research framework (table 24).

Familiarisation
Immersion in raw data to list key ideas and recurrent themes
Identifying a thematic framework
Identify all key issues, concepts and themes by which data can be examined and referenced
Indexing
Apply thematic framework to data by annotating transcripts with numerical codes
Charting
Rearranging the data according to the appropriate part of the thematic framework to which they relate, and forming charts. The charts contain distilled summaries of views and experiences
Mapping and interpretation
Using the charts to define concepts, map the range and nature of phenomena, create typologies and find associations between themes with a view to providing explanations for the findings

Applied qualitative research framework (Pope *et al.*, 2000)

Table 24

Whilst categorizing via codes or themes is the most common approach in qualitative analysis, Maxwell (1998) points out that there are two other approaches; contextualising strategies such as narrative analysis, and the use of memos and displays. In order to enhance rigour (see 4.8), all three approaches will be used and further explored in this section.

Tools that can help: to use or not to use computer packages

When I commenced the PhD study one of my personal aims was to develop the skills necessary to use computer-assisted qualitative data analysis software, in particular NUD.IST (non-numerical unstructured data indexing, searching and theorizing: Qualitative Solutions and Research Pty Ltd.). Whilst I found the process of analysis by traditional paper approaches an enjoyable experience during my masters research, I envisaged that the large amount of data generated via the PhD would be easier to manage via NUD.IST, and so it was with enthusiasm that I undertook a basic course to use the software. Yet, although I felt I had developed the competencies and could use the software with ease, the whole process felt sterile in comparison with my previous experiences, leading me to question whether I was applying it correctly. However, whilst the literature can promote the use of NUD.IST, particularly in its congruence with grounded theory analysis (McPherson *et al.*, 2004), I discovered a range of authors warning against the use of such software. Their criticisms varied from the philosophical stance of worrying about the demise of a variety of representational modes as a result of such packages (Coffey *et al.*, 1996), unrealistic expectations of the packages as theory builders (MacMillan & McLachlan, 1999) or misassumptions about them being the sole requirement for grounded theory (Coffey *et al.*, 1996). Both Eaves (2001) and Maxwell (1998) warn against reliance on software as a mechanism for rigour, however it is the argument about the loss of intimacy and engagement with the data (Pope *et al.*, 2000; Webb, 1999), and particularly the lack of seeing the whole picture (Kelle, 1997) that provided resonance with my feelings, and the rationale for returning to a more osmotic relationship (Webb, 1999) between the data, the pen in my hand and my thoughts. However, some way of organising the data so that relationships could be identified is required with data displays one approach for this (Coffey & Atkinson, 1996).

Data displays

Data displays are a compressed and organised assembly of information from which the reader can make conclusions (Ashworth, 1994; Miles & Huberman, 1994). They can take a number of forms from extended text to causal networks, but in whatever form must be supported by an accompanying narrative (Williamson & Long, 2005). Williamson and Long (2005) describe a number of advantages of using data displays described in table 25.

1. Condenses a large amount of data into a more manageable form
2. Displays different ways of teasing out promising analytical lines of enquiry
3. Enables further comparisons
4. Enables search for verification and contradictory evidence
5. May lead to the development of theoretical propositions
6. A logical chain of evidence can be created
7. Communicates study findings
8. All of above facilitates triangulation (see 4.8)

Advantages of data displays (Williamson & Long, 2005)

Table 25

Data displays will be used as a key tool to facilitate grounded theory analysis, a process that will now be explored.

The process of analysis in grounded theory

As discussed in 4.2.2 and 4.2.3 grounded theory methodology is continuing to evolve and changes in approach are reflected in the process of analysis.

Differences primarily result from what is known as the emergence versus forcing debate (Duchscher & Morgan, 2004), with the Glaserian branch being identified with the emergence of theory directly from the data, whereas the Straussian approach is described as a forcing of a preconceived conceptual description through prolonged fracturing of data and directive questioning.

Whilst Duchscher and Morgan conclude that it is impossible to merge the two branches because they are shaped by different philosophical stances, Jeon (2004) argues that it is impossible to separate them entirely as they developed from one original model (Glaser & Strauss, 1967) which was shown to be the case within this study. Furthermore, if grounded theory is to be a reflexive, iterative process then the researcher needs to take a similar approach to the

methodological literature (Jeon, 2004) and seek a process of analysis that is best suited to the research purpose (Tesch, 1990).

The first process that was undertaken in the analysis of this study was the breaking down of the data into manageable units. The preliminary stage was to separate the data generated by professionals and individuals affected by long-term conditions as they were viewed as independent but connected units (Maijala *et al.*, 2003). By the very nature of the data collection process and sequence this separation was an inbuilt feature. As focus groups formed the stepping off platform for the study design, these units were analysed first, however this was a concurrent process with data collection from ongoing focus groups as part of the comparative analysis method (see later in this section). Interviews were also treated as separate units but compared and contrasted with others within and across the professional/patient arms. Fieldwork notes were broken down into clinic sessions, and then further divided into individual consultations and events external to the consulting room such as the waiting room environment and availability of patient information literature. The two audio diaries were initially analysed separately but respectively as whole entities to follow the reflexive progression, they were then compared with each other and with the rest of the data.

Analysis of focus groups

Morgan (1997) advises against separating individual group members or the whole constitutive group as separate units of analysis but encourages the search for a balance between these two levels. Consequently, during the reading of the transcripts individual's comments were highlighted and so was the group response. This ensured that not only a continuum of views developed but also how the views changed and developed through the group interaction (Reed & Roskell Payton, 1997). Particular tools used for this were the searching for affirming or qualifying comments, and any introduction of new ideas or directions. An example of this is shown in figure 11.

This provided the initial open coding, the first stage in the process of analysis in grounded theory.

<p>F3 Sometimes it's OK, sometimes I think they think we don't know what we're talking about, having the disease isn't the answer, they have the knowledge and training and recognition, and I think sometimes you have to do it yourself, I don't know whether anyone else thinks like that?</p>	<p><i>New idea: having to try things out yourself, professionals don't think you know what you are doing</i></p>
<p>F1 Yes, of course, it's a little bit like you tend to experiment and, um... I was going to say something else, I've forgotten what it was now!</p>	<p><i>Affirming</i> <i>New direction: forgetfulness</i></p>
<p>F3 That happens a lot.</p>	<p><i>Affirming</i></p>
<p>F1 Yes!</p>	
<p>R Shall we leave you for a moment?</p>	
<p>F3 That happens a lot.</p>	
<p>F1 Yes!</p>	
<p>R Shall we leave you for a moment? You were nodding as well? Anyone else have a view?</p>	<p><i>New idea: being encouraged to experiment</i></p>
<p>M2 Well, I suppose I have been encouraged to vary what I'm taking, they'd say try a different drug</p>	
<p>R So were you left to self-manage your drug regimen, except what drug it is but they give you permission to change the dose?</p>	<p><i>New idea: encouragement/permission depends on individual clinician</i></p>
<p>F3 Not really, no</p>	
<p>C3 It depends on the consultant, so sometimes it's with guidance from your GP but some don't like you messing about at all</p>	

Example of analysis of focus group transcript

Figure 11

Open coding

Open coding was the preliminary process in the analysis of all units of data (Dey, 2004) and entailed reading or listening to the data word by word (Strauss & Corbin, 1990) moving onto complete sentences and paragraphs (McCann & Clark, 2003a). As far as possible an open mind was kept with events and actions being labelled (Duchscher & Morgan, 2004), these were then categorized both as topic areas or emerging ideas (Charmaz, 1990; Jeon, 2004), with the former being given in vivo codes from the actual language used and the latter adopting sociological constructs emerging from the data (McCann & Clark, 2003a) (figure 12). The initial codes were used to facilitate theoretical sampling (Strauss & Corbin, 1990) (4.5.2).

The process of open coding proceeds until a core category is identified. A core category is a variable that is central to other categories (Strauss & Corbin,

1990) and is an essential feature of the process of generating a theory that explains changes and dimension of behavioural patterns (Jeon, 2004).

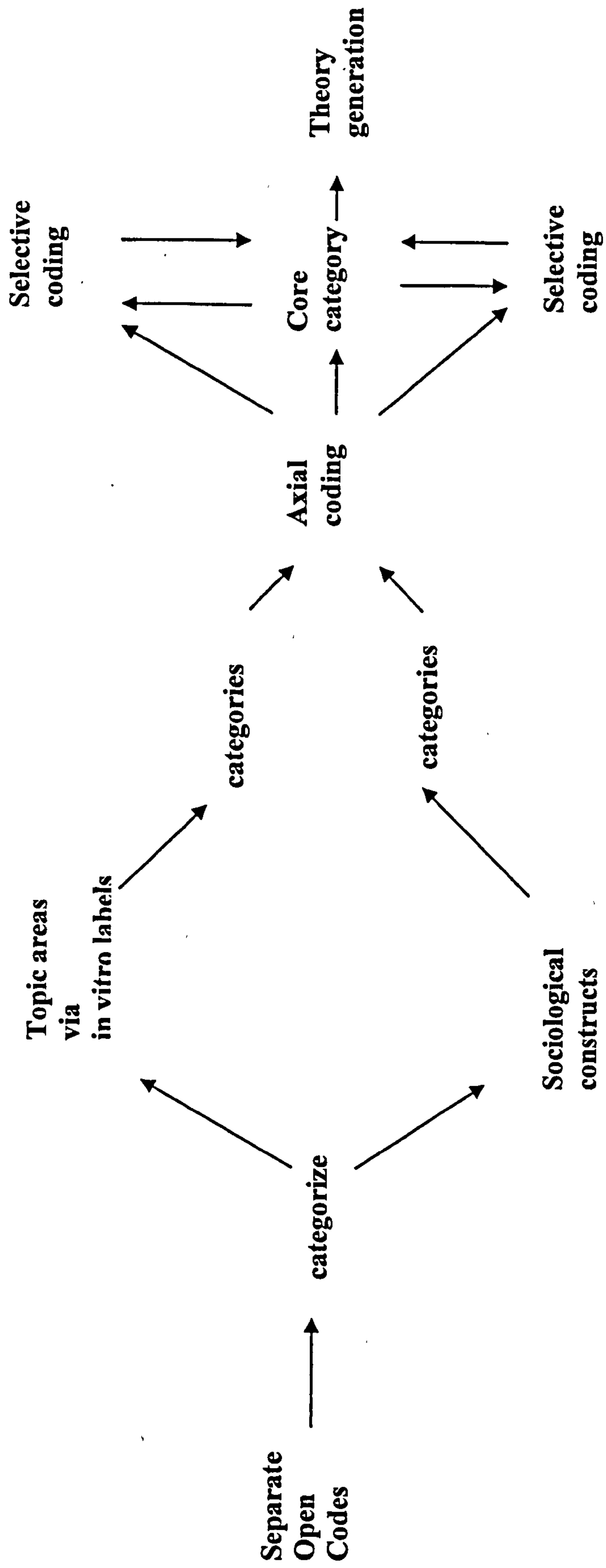
<p>Cons1 What are we here for? We are trying to help people. What are we here for? And people aren't five minutes, ten minutes, fifteen minutes, people, we're here to, to <i>(sighs)</i> help people. You can't pigeon hole somebody in ten minutes and we're not psychiatrists as yet so you know at the end of your fifteen minute interview, we can't say "Right, we'll see you next week" or whatever. I mean you do to a certain extent, em, in that you will, em, work out what sort of duration's likely to be and it may be that you do give people further appointments for, you know, a lot of what we do at the clinic is actually deferring to the nurses. They are much more flexible in what time they have, em, but you can't say "Well you know your allocated time's up so I'm not doing any more"</p>	<p style="text-align: center;"><i>Open coding</i></p> <p>Time shouldn't be an issue. You can't pigeonhole people into time slots. Defer time consuming patients to nurses Nurses more flexible in time</p> <p style="text-align: center;"><i>Emerging ideas</i></p> <p>Time resource Nurses' role</p>
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Example of open coding process

Figure 12

Advanced coding

Whilst some authors see the process of open coding neatly ending when a core category is identified (Jeon, 2004), the reality in this study was that the analysis was not a linear process but a constant moving between coding and category development via the constant comparative method (McCann & Clark, 2003a). A variety of terms to describe coding other than open can be found in the literature including axial (Strauss & Corbin, 1990), selective (Dey, 2004; McCann & Clark, 2003a), focused, substantive and theoretical (Jeon, 2004). This plethora of ideas about advanced coding may be a result of changing language (Bunch, 2004) but nevertheless does nothing to ease the confusion of a novice grounded theorist. Whilst Glaser and Strauss' (1967) original work offers a far more open approach (Duchscher & Morgan, 2004) to analysis which emphasises constant comparative analysis and theoretical sampling as the main tools, some of the processes within advanced coding have been found to be useful in this study. The whole process of developing codes, categories and the core category is illustrated in figure 13. Axial coding was found to be conceptually useful in revisiting the emerging categories, deconstructing and



The process of developing codes, categories and core category

Figure 13

then reconstructing them to see if any new links could be found (McCann & Clark, 2003a). Once the core category emerged from this process it was compared to the other categories via selective coding to determine which needed further refinement and development (Dey, 2004), thus enabling the stimulation for theory generation (Jeon, 2004). Whilst the use of codes and categories are major tools in this process there are some other essential components in grounded theory analysis, not least of which is the constant comparative method which will be discussed next.

Constant comparative analysis

Constant comparative method or analysis is a unique feature of grounded theory (Eaves, 2001) and is clearly described in both Glaserian and Straussian approaches. Glaser and Strauss (1967) describe it as a strategic method for generating theory with four stages. The first stage is to compare incidents between each category, for example one of the categories in this study was *Emotional Needs*, with an incident labelled as *crying*. This incident or code was then compared with other categories and was found in the category of *Gender* but not in the category of *Expert Patient Characteristics*. This process of comparison then facilitates the second stage of the process, the integration of categories and their properties, thus *Gender* and *Emotional Needs* merged. The third stage is described as delimiting the theory. In this stage fewer modifications are needed with the researcher looking for uniformity and a reduction in terminology. As well as constant comparison of the categories and their properties, previous theory from other literature may also be used in this stage and hence the merged *Gender* and *Emotional Needs* also joined with *Expert Patient Characteristics* to become identified with *Cultural Codes of Gender* (Gilligan, 1982). The major categories that culminated into one overriding theory are used as the section titles (as illustrated in chapter 5) when writing the theory (Glaser & Strauss, 1967), which is the final stage in the constant comparative method. Whilst the types of theory that can emerge from the analysis are described later, this section will describe other key tools used within the more micro process of analysis; memos, theoretical sensitivity, story line, narratives and metaphors.

Memos

Throughout the complex process of discovering links between codes, categories and the core categories, systematic use of memos is invaluable (Charmaz, 1990). However, whilst a Glaserian approach identifies memoing as an essential key component of grounded theory (Glaser & Strauss, 1967), the later work of Strauss and Corbin (1990) describe it as a pragmatic system of reminders. Within this study memos were found to be a necessary part of the process in order to visualise conceptual relationships and to explicate theory (McCann & Clark, 2003a). They took a variety of forms from notes made at the side of transcripts or field notes, or hand drawn diagrams. The memos were part of the reflexive process (see 4.8) and so were transferred to the reflective journal and further added to as the analysis progressed.

Theoretical sensitivity

Strauss and Corbin (1990) identify theoretical sensitivity as a personal quality of the researcher where there is an awareness of the subtleties of the meaning of the data. They list four sources of theoretical sensitivity, the first being literature is contested by the alternative Glaserian approach (Heath and Cowley 2004). However, as described in 4.2.4, a limited literature review was undertaken during the early stages of the study but whilst the subject areas did familiarise me to the phenomenon being studied to some extent, they did not appear to shape the emerging theory. During the latter stages of analysis I carried out a further review of the literature surrounding the areas of power and gender to enhance theoretical sensitivity to these emerging themes. The second source is described as professional experience and certainly my previous work alerted me to issues of power and gender merging from the nurses' data. The third source of personal experience was also very relevant in this study, with my own feelings and experiences of being affected by a long-term condition compared and contrasted to the respondents (see 4.1.1 and 4.8). Lastly, Strauss and Corbin (1990) state the actual analytical process provides insight and understanding via interaction with the data, and as previously discussed these insights were recorded as memos.

Narratives and story line

To facilitate the development of grounded theory a more abstract line of thought is required and can be helped by finding the story line of the research

(McCann & Clark, 2003a). To find the story line some general questions were asked first such as what is most striking and what seems to be the main problem (Strauss & Corbin, 1990)? This came up with answers such as people who were recognised as expert patients by professionals shared similar characteristics, and nurses appeared over anxious about active and informed patients. The story line is then developed further and helps to identify the core category by revealing which is the constant category that all others are related to. I found that the micro process of developing the story line was made easier by analysing the stories within the whole story; the narratives. Whilst the narratives became visible to me through the respondent data (Bailey Hill & Tilley, 2002) they do not originate from the respondent but have already circulated culturally to provide a repertoire (Lawler, 2002). Thus what I was reading was not just the respondent's own story but stories of the social world too, and illuminated how people saw their place, constituted their identity and connected to the broader social world. Thus through the narratives I began to make sense of how people had learnt to suppress their emotions when dealing with doctors, had learned to develop a professional identity in the consultation room and had reframed their condition almost as an on-going project that needed planning, risk assessment and implementation.

Metaphors

The reframing of the condition as a project was a frequently recurring metaphor emerging in the analysis. The use of metaphorical imagery (Coffey & Atkinson, 1996) often highlighted common patterns in the narratives. Metaphors are described as understanding and experiencing one thing in terms of another (Lakoff & Johnson, 1980), are socially shared and in common usage (Coffey & Atkinson, 1996), and can reveal fundamental values and assumptions prevalent in a particular context (Froggatt, 1998). Thus the example of the metaphor of project illuminated the professionalisation of patienthood in long-term conditions and became one of the pointers towards the core category.

From analysis to theory development

So far the macro and micro processes of analysis in this study have been described, but the ultimate purpose of this process in a grounded theory is the development of theory. There are two types of theory that can be developed;

substantive and formal (Glaser & Strauss, 1967). Substantive theory is grounded in research in one particular substantive area, in the case of this study the health care context. The substantive theory is the culmination of the identification of the core category and links to other categories and is the explanation of the story line. Whilst many grounded theories do not go beyond the substantive theory (Jeon, 2004), Glaser and Strauss (1967) see substantive theory as merely the bridge to the development of formal theory and give a step by step approach of bridging the gap. Firstly they suggest removing the substantive labels, which in this study would be the labels that are health care dependent, such as patient. However, Glaser and Strauss warn this is of limited help and suggest other approaches. Comparative analysis with other groups may help development of a multi-area formal theory, and in this study one example was to compare the expert patient group with other non-health care groups within a consumerist model. Other aids for this is the use of status passages (Glaser & Strauss, 1967) such as transitional status. I have already alluded to the professionalisation of expert patients, but professionalisation or proto-professional has connotations outside of healthcare that can be used as comparison. Finally, Glaser and Strauss (1967) suggest that formal theory can be developed by utilising other published research, greatly facilitating the development of this thesis.

Having discussed the process of analysis, this chapter will conclude by exploring issues of rigour within the study.

4.8 Issues of rigour

Whilst qualitative methodology recognises the subjective element of the research process (Mruck & Breuer, 2003; Ratner, 2002) there continues to be an ongoing debate regarding rigour in qualitative research. The debate is fuelled by the legacy of the positivist paradigm (Sanger, 1996; Tobin & Begley, 2004), a legacy that has not only led to an almost obsessive questioning of rigour (Cutcliffe & McKenna, 1999), but has also resulted in stringent endeavours to silence the representation of the researcher in the research by such methods as bracketing (Mantzoukas, 2004). However, failing to represent the researcher's self within a study denies any acknowledgement of construction and multiple realities (Mruck & Breuer, 2003) and would be

incongruent with the underpinning philosophy of this study. The articulation of researcher self is not a new phenomenon, for example keeping a journal of thoughts has been encouraged in a number of paradigms. However, these have often been private and even when presented publicly have been kept as a separate entity to the research text (Coffey, 2002). More recently there has been a move to integrate self and the research, with examples of narrative inquiry where autobiographical writing about the self is the research (Conle, 2000). This latter example typifies the first of two stances regarding subjectivity in qualitative research (Ratner, 2002), the postmodernist perspective articulating values as shaping the way we see the world and thus rendering objectivity impossible. However, Ratner (2002) suggests a second stance framed by the positivist legacy, where objectivity can be acknowledged within qualitative methodology and by a systematic organization of subjectivity the world can be comprehended as an independent reality. It is this perspective that dominates the literature, with rigour in qualitative research seen as a problem to be addressed.

The positivist legacy: problems of rigour in qualitative research

Rigour is about demonstrating integrity, competence and the legitimacy of the research process (Tobin & Begley, 2004). Three main issues are raised regarding rigour in qualitative research, firstly the implications of bias (Maxwell, 1998), secondly limitations in generalizability (Koch & Harrington, 1998), and lastly the potential for reactivity (Maxwell, 1998). The positivist critiques of these three areas will now be explored with both post-modern responses and the critical realist position of this thesis articulated.

Bias

Within the positivist paradigm researcher bias is seen as a contributor to systematic error within the research and as a negative feature which causes deviation from validity (Hammersley & Gomm, 1997). Whilst one response to this is to acknowledge bias as a purposive notion of helping to discern significant patterns or types, with a number of postmodernist paradigms such as feminism using bias to serve one particular group (Hammersley & Gomm, 1997), within this thesis an inevitable bias is acknowledged and articulated (Mantzoukas, 2004) (see 4.1.1). Nevertheless bias as a negative feature still

predominates the research arena with a wealth of literature grappling with the concepts of validity and reliability within qualitative research.

Reliability and validity within qualitative research: a tautology?

Reliability concerns the idea that if the same study were carried out in the same way, then the findings would be replicated. Whilst it is broadly accepted that this notion is an impossibility outside of the “test tube” experiment, nonetheless there are concerns raised regarding generalizability in qualitative research such as the worth of carrying out a study that is of no use to other settings or practice (Morse, 1999). Validity of a study is understood as whether a study measures what it set out to measure, and whilst the concept of measurement is dissonant within the interpretive paradigm, the validity of a study in terms of whether the outcomes were met through a rigorous process is generally sought (Maxwell, 1998; Sanger, 1996). As a response to the epistemological tautology of reliability and validity within the interpretive paradigm, many qualitative researchers have moved on to criteria developed specifically for paradigmatic congruence (Cutcliffe & McKenna, 1999; Koch & Harrington, 1998). Lincoln and Guba’s (1985) five criterion provided the basis for this development and although under constant refinement by the originators (Lincoln, 1995) and others (Beck, 1993) three key features are constant; fittingness, credibility and auditability. These criteria allow for multiple realities and a dialogue between the objective and subjective elements of the research process and hence are appropriate to apply within a critical realist framework.

Fittingness

Fittingness is also known as transferability and refers to how meaningful the study findings are for other similar settings (Chiovitti & Piran, 2003).

Chiovitti and Piran (2003) identify two methods of enhancing fittingness in a grounded theory study. Firstly they suggest that both the setting characteristics and profile of the participants are detailed enough to allow readers to assess the transferability of the findings. Secondly, by linking the findings of the study with previous theory described in the literature, the reader will also be able to judge potential transferability, which is congruent with Bhaskar’s (Bhaskar, 1989) re-description phase where pre-known theory is utilised

(4.2.7). Within this study it is hoped that the discussion in chapter 6 will facilitate the reader's assessment of fittingness.

Credibility

Credibility is described as the level of faithfulness and vividness in the portrayal of the phenomenon (Beck, 1993). Whilst Glaser and Strauss (1967) give some broad pointers to enhancing credibility such as an extensive abstract presentation of the overall grounded theoretical framework at the beginning and end of the report, and the presentation of sufficient material to facilitate comprehension, Beck (1993) suggests four specific methods. Firstly, allowing participants to guide the inquiry, which in this study was the use of participants' in vitro words and ideas to guide subsequent lines of inquiry. For example, "*looking an idiot*" (PN02) was an early in vitro code from a number of nurses, this was then used as an active line of inquiry with subsequent professionals in the study. Secondly, Beck (1993) advises the checking of the theoretical construction against the meaning of the participants' meanings, a process that is regarded as key (Paterson, 2003). As described in 4.6 this was undertaken within this study, as were the use of participants' actual words within the theory (see chapter 5) which Beck articulates as the third method. The last method is the articulation of the researcher's personal views and insights, a process that underpinned this study in the form of reflexivity. Underpinning the research process with reflexivity is congruent with Bhaskar's rejection of neutrality (Connelly, 2001) and promotion of transformation (Bhaskar, 1986) (4.2.7).

Enhancing credibility: the case for reflexivity

Reflexivity is a rather nebulous concept (Carolan, 2002), and similar to all the concepts discussed so far the definition is shaped by the philosophical stance of the definer. However, reflexivity is generally regarded as being an acknowledgment of the role and influence of the researcher within the study, with the researcher's role coming under the same critical analysis as the research itself (Rice & Ezzy, 1999). From a positivist perspective, reflexivity is cited as an aid to identifying the researcher's impact on the study and hence the possibility of reducing the impact or bias (Carolan, 2002). However, this stance is incongruent with this thesis where identifying myself as part of the data rather than distant; positionality (Ladino, 2002), is argued as lending

credibility and insight (Carolan, 2002). This increasingly common perspective (Conle, 2000) sees reflexivity as the most important characteristic of analysis (Delamont, 2004), aiding theoretical sensitivity (Bonner & Tolhurst, 2002). May (1999) describes two approaches towards reflexivity. Referential reflexivity is identified with the researcher reflecting on their actions as producer of knowledge within a social scientific community. To enable this a reflective journal was developed and was the main tool of referential reflexivity, with an excerpt from the journal shown in figure 14. Within the findings and discussion chapters I continue to present a personal, referential reflexivity.

Was invited to attend a patient support group. Was greeted at the door enthusiastically by 2 late middle-aged white men saying "we hear you are after perfect patients and we want to volunteer!" *How interesting that Expert had been reinterpreted as Perfect. Where had this come from, the consultant, the specialist nurse, or the patients themselves? Reminded me that if the person acts as per the EPP then from a professional viewpoint this is perfect!*

Excerpt from reflective journal

Figure 14

Endogenous reflexivity is exhibited by all the actors in the study as part of their social world (May, 1999). Sometimes it was possible to capture the endogenous reflexivity within this study. For example, reflexive comments from the research supervisors were noted where possible and reflected upon by myself. During the feedback of findings for respondent validation, reflexive comments were noted and used to trigger personal reflection. However, much endogenous reflexivity continues to be silent, for example the thesis' reader's reflexive thoughts, or the respondent's thoughts a day or so after an interview. Whilst often seen as a key tool in rigorous qualitative research (Coffey, 2002) reflexivity is not without criticism. Common practices of reflexivity are criticised as giving voice solely to the researcher, and as such are seen as self-indulgent, romanticising the self, and reinforcing a hierarchy of voices (Adkins, 2002; Coffey, 2002). In order to prevent some of these consequences reflexivity is advocated as a team process (Skeggs, 2002) which in this study happened via a reflective dialogue with the supervisors. In addition I have attempted to use a double loop approach (Argyris, 1991) to the process by

reflecting upon my reflexivity using trigger questions such as is this self-indulgence, am I reinforcing the power status of researcher and respondent, and is this just me being heard? In addition it must be acknowledged that if Denzin and Lincoln's (2000) historical framework of qualitative research is taken into account, then we are in the sixth or messy moment, a cacophony of voices all speaking with their own agenda (Denzin & Lincoln, 2000), and as such it is inappropriate to speak simply of the reflexive self, rather multiple reflexive selves (Coffey, 2002; Roth & Breuer, 2003; Walkerdine *et al.*, 2002), with the notion of multiple realities congruent with critical realism (4.2.7). Therefore an added question was to ask which self was I bringing to the research at that point, was it the self framed by my personal experience of living with a long-term condition, my professional socialisation, my gender or my ontological values?

Auditability

Auditability is understood as the process by which the reader can check the thought and decision-making processes of the researcher and follow the journey of the whole process (Lincoln & Guba, 1985). The idea of an audit trail is to provide evidence from which the reader can determine how well the findings are grounded in the data, whether the inferences drawn from the data are logical, and what the degree and incidence of researcher bias was (Cutcliffe & McKenna, 2004). However, whilst commonly seen as a quality assurance mechanism within qualitative research (Delamont, 2004), Cutcliffe and McKenna (2004) argue that it is a concept drawn from the idea of an external person bought in at the end of a process to assess the confirmability of the research, with the aim of reducing bias and demonstrating how inferences were logically deduced, and as such is more congruent with the positivist paradigm. Within this thesis this argument is refuted for not only does the audit trail include the reflexive element (Koch, 2004) but also is congruent with the critical realist paradigm as it will provide a way of showing the multiple realities found during the research journey. Within this thesis the evidence comprises of excerpts from the reflective journal, examples of memos (Glaser & Strauss, 1967) and data displays. However, whilst these provide three different modes of presenting evidence, the credibility of the evidence must also be supported by sufficient evidence (Delamont, 2004). One

method of ensuring sufficient evidence is triangulation that forms part of the abductive strategy of both critical realist and grounded theory methodology (4.3). The principle of triangulation is that a phenomenon can be studied via several methods (Redfern & Norman, 1994), with the aims of confirmability and completeness. Nevertheless, triangulation does not bring about a guarantee of internal and external validity but it does enhance increased confidence in the study and the facilitation of divergent results to enrich the explanation (Redfern & Norman, 1994). Whilst triangulation is inevitably criticised by postmodernists as a positivist method (Tobin & Begley, 2004), it is also seen as inadequate for a multifaceted phenomenon if it is literally translated from the geometrical concept as three sided, and thus it is suggested that the metaphor of crystal is more appropriate (Sandelowski, 1995). This appears a more apt description, particularly when reviewing the number of methods used for triangulation within this study (table 26).

Types of triangulation (Redfern and Norman 1994)	Examples of methods used in this study
Method triangulation <ul style="list-style-type: none"> • Within method: application of different types of the same method • Between methods: using different methods to assess the same phenomenon 	Observation: participant as observer & observer as participant Professional responses to expert patients: focus groups, interviews & observation
Data source triangulation <ul style="list-style-type: none"> • Multiple data sources such as different respondents, different times and at different locations 	<ul style="list-style-type: none"> • Nurses, nurse specialists, practice nurses, GPs, consultants, physiotherapists, patients, carers, EPP tutors • Over two years • University premises, out-patients departments, GP surgeries, rehabilitation centre, homes, community centres, leisure centre, car park
Unit of analysis triangulation <ul style="list-style-type: none"> • Differing types and sources of data can be analysed at differing units or levels 	<i>Observation</i> Field notes for outsider perspective, audio-diary for insider perspective
Investigator triangulation <ul style="list-style-type: none"> • Different researchers within a team 	Interrogation of data By myself and two supervisors
<i>Theory triangulation</i> <ul style="list-style-type: none"> • Assessment of competing theories in explaining a phenomenon 	<i>Examples of theory</i> <ul style="list-style-type: none"> • Health care sectors (Kleinman, 1980) • Cultural codes of gender (Gilligan, 1982)
Multiple triangulation <ul style="list-style-type: none"> • A combination of any of the above 	All of above used

Types of triangulation used within the study; crystallisation

Table 26

4.9 Summary

This chapter has described and critically explored the methodology and methods used within the study. The first half of the chapter identified the research focus via both socio-political and personal perspectives. The methodology was also presented firstly via a personal viewpoint that was followed by a case being developed for grounded theory methodology. One criticism of grounded theory is the weakness in epistemological underpinning, this position was further expanded into a rationale for critical realism to be used as an overarching philosophical stance to guide the research. The section concluded by drawing together grounded theory and critical realism into a synthesis for practical use within the study.

The second half of the chapter was concerned with the methods used, describing and critically exploring focus groups, interviews and observation. This section also detailed the sampling methods used, ethical issues and the process of data analysis. The chapter concluded with a critical analysis of issues of rigour, developing a case for quality criteria of fittingness, credibility and auditability, which included the development of a rationale for reflexivity, the use of an audit trail and the methods of triangulation and crystallisation.

CHAPTER FIVE

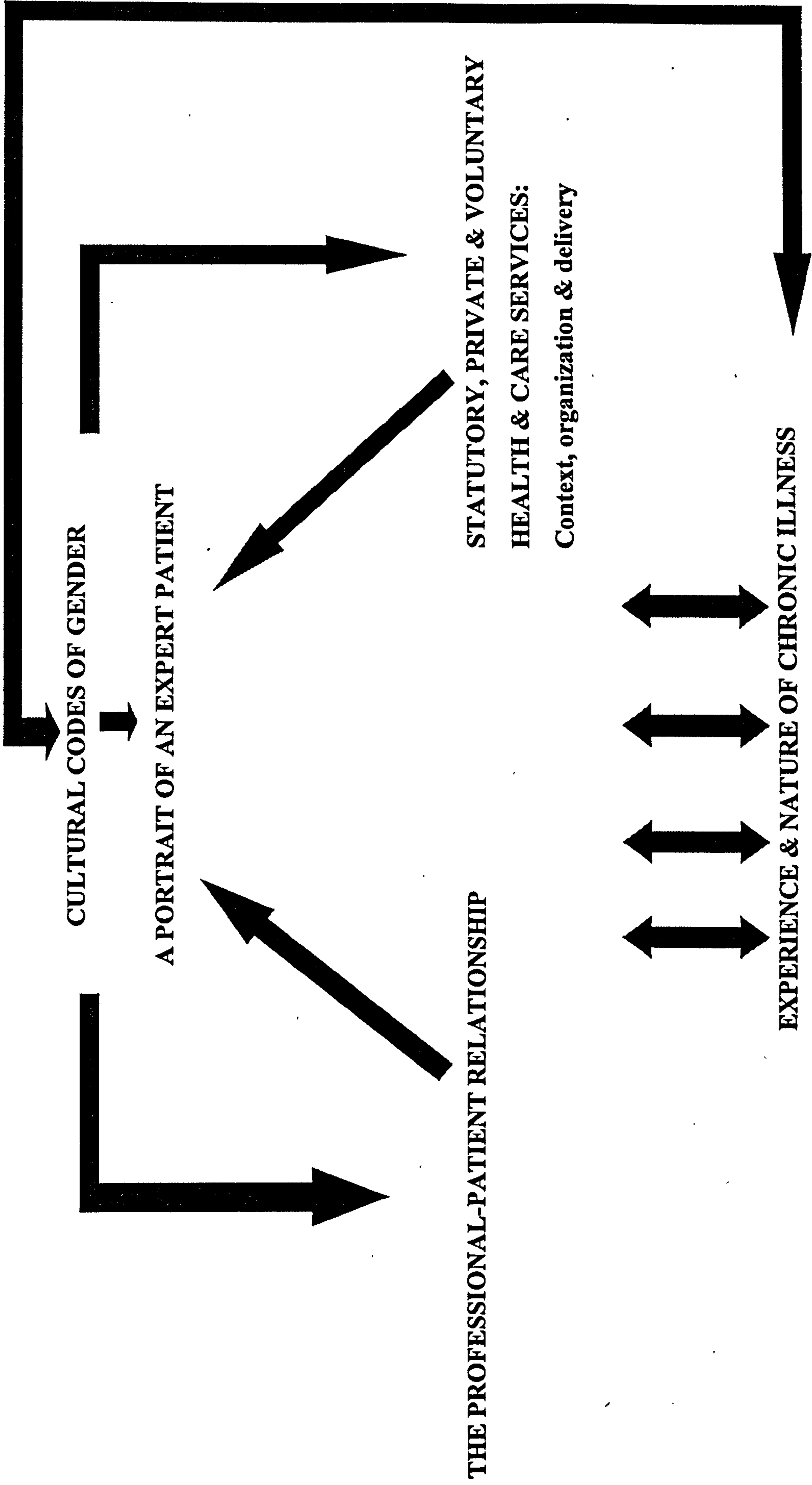
FINDINGS

5.0 Introduction

The purpose of this chapter is to present the major findings of the study. Using a critical realist framework as a guide, the chapter aims to take the reader on a metaphorical journey. As discussed in 4.2.7 the findings will be presented as a vertical representation of explanation (Bhaskar, 1986) rather than horizontal, with the expert patient identified as the higher level mechanism (Collier, 1994) and therefore described first. This will be followed by the reporting of the increasingly complex causal mechanisms which range from the direct impact of the professional-patient relationship and the statutory, private, and voluntary health and care services, to the underpinning causal mechanism of the experience and nature of chronic illness. The chapter will conclude with the presentation of the generative structure (Bhaskar, 1989), the core category (Strauss & Corbin, 1990) that connects the mechanisms or categories (figure 15). The focus of this chapter is to provide a rich description of the findings with deeper analysis and interpretation discussed in the following chapter. In order to illuminate this description, a metaphorical representation of the findings will first be articulated in the form of a storyline (McCann & Clark, 2003a).

5.1 The storyline

The findings suggest that to become an expert patient an individual undertakes a journey within the terrain of the experience and nature of chronic illness. On this journey it appears that the expert patient may be helped by a number of “signposts”, these may be enabling health professionals or user friendly services. However, the expert patient also meets a number of boulders that may block their path – these also are often in the form of inhibiting health professionals or poor services. Interpreting this imagery into a critical realist perspective, it would seem that the expert patient is the effect or higher level mechanism, with the context, organization and delivery of statutory and non-statutory services acting as the structure, whilst individuals such as health professionals and patients being the agency. Both the structure and agency act as a trigger (signpost) or inhibitor (boulder) of the effect (becoming an expert patient).



Relationship of categories to core category

Figure 15

The transformational social activity, which in this thesis is suggested as the journey towards being an expert patient, is reproduced and maintained by a generative structure (Collier, 1994). This chapter will conclude by presenting the core category of cultural codes of gender, which this thesis presents as the generative structure from a critical realist perspective. In the metaphorical terms of the storyline, it would appear that these cultural codes of gender acted as the sun on the journey, illuminating the path, sometimes obscured by nightfall, but inevitably emerging again.

The chapter will now present the data that culminated through the process of constant comparative analysis as the category of the expert patient.

5.2 A portrait of the Expert Patient

Who are expert patients? This section will present the data that revealed a portrait of an expert patient. Using health professionals' definitions and descriptors to start the exploration, the section will go on to present the analysed data that fitted the descriptor of an expert patient as identified by Department of Health literature (Jones, 2003) and negative cases that illuminate the category further (Strauss & Corbin, 1990). In order to further enrich the portrait case studies of expert patients will be presented, and as discussed in 4.7 this will be done via a combination of data display and articulation of their narrative. The section will be completed by an exploration of the data indicating an answer to the question of from what sources do patients learn to be expert patients?

5.2.1 Health professionals' definitions & descriptions of an Expert Patient

Out of all the professionals in the study, GPs tended to describe expert patients in more favourable terms as someone who took you a little further, was a positive challenge and tended to be more independent:

"Sometimes they don't present themselves as an expert patient, they haven't got it written on their forehead. So in a sense what you're finding is that they're taking you a bit further em, they're perhaps the first to mention a novel treatment, they seem to have a network that's separate to the sort of one we set up within the surgery."

Interview GPM12

Affirming comments from other professionals tended to be in terms of benefits to themselves or the NHS, such as being less time consuming and reducing cost to the NHS. However, professionals also spoke frequently in terms of the limitations of expert patients. Nurses often described expert patients stereotypically as well educated, middle class, wealthy, young patients who formed a small elite group. Consultant 01 further described this group as having their own agenda with no regard for the needs of others. Overall, expert patients tended to be described in negative terms which ranged from a refutation of their existence (consultant 01), self-unaware arrogant “*know it all*” (nurses and physiotherapists) who were often difficult to like, over demanding and needed to be persuaded against their own ideas (physiotherapists):

“...my years of experience count for nothing, they think they know better and it just counts for nothing... it is interpreted by myself as a lack of respect because sometimes people don't go about it in a nice way, they go about it in a rude way and that immediately gets your defences up”

Nurse Focus Group 2

These professionals often described feelings of being intimidated and interrogated in their encounters with expert patients:

“... it can be a bit intimidating, people coming in with this huge, you know, new technology about things that they can do for their condition...”

Interview Practice Nurse 01

Despite Consultant 01's reservations about expert patients, observation of his clinic revealed that he was comfortable with active participating and knowledgeable patients:

OP22f very informed, she knew the link between thrush and fungal infection of nails. Came to consultation with all information she needed. Had stopped nurse dilating her eyes as she had an eye test recently- assertive when she knows inappropriate action. She questions C1 on whether she should have liver tests when on gliblencamide, C1 gives an explanatory and appropriate answer. When she leaves C1 tells

me *“I’m very different from many of my colleagues in thinking it’s better for patients to be knowledgeable and know what they’d like”*

Consultant 01 Clinic Observation Fieldnotes

This ease in responding to expert patients was most evident in the doctors:

“Doctors are a lot more prone to coming through and saying “Well you know you probably do know a lot more about this condition than I do”. You know, and I don’t mind admitting that I don’t really know a lot. I know a little bit about many things but not a lot about anything in particular um, and I don’t mind admitting that the patient may have more knowledge than me, and I don’t find that that makes me lose face”

Interview GPF10

Whilst the majority of nurses described feelings of discomfort with expert patients the nurse specialists and physiotherapists articulated different responses. Whilst physiotherapists did not tend to describe expert patients in particularly positive terms there appeared to be an acceptance of their existence but with little perceived impact on their role:

“...they might be experts but what we’re expert in is our skills...”

Physiotherapist focus group 2

In contrast to other nurses, the nurse specialists welcomed encounters with expert patients:

“... I say “You know I learn from you” and get them to show me and of course they’re very enthused in showing you...”

Interview Nurse specialist 02

Whilst a pattern begins to emerge of how professionals define and describe expert patients, the responses are further illuminated by the data on the negative case; the non-expert patient.

5.2.2 The negative case: the non-expert patient

Data presented in this section is drawn from two sources. Firstly when asked to define an expert patient many professionals spent time in recounting experiences with non-expert patients. Secondly, using Jones’ description of an

expert patient (2003) who actively offers suggestions, it was possible to analyse the data from participants who did not exhibit this behaviour. Unsurprisingly, one of the most noticeable characteristics of a non-expert patient was passivity. This took a variety of forms, with lack of engagement with the condition a key feature, manifesting itself as not preparing for or asking questions at a consultation and not appearing to show any interest in the condition:

OP18mC1 Does not prepare for OPA (doesn't go for blood tests, doesn't bring diary). Does not appear to take condition seriously.

Consultant 01 Clinic Observation Fieldnotes

OP31mC2 Post excision of a benign lesion on scalp, now attending as the GP had noticed a mole on his back. He agrees to have it excised. Not really engaged with the condition, rather passive. Did not ask any questions. When asked by C2 he displays a lack of understanding about skin protection.

Consultant 02 Clinic Observation Fieldnotes

From a professionals' viewpoint, particularly the doctors, passivity was seen as linked with a lack of responsibility:

OP5mC1 Diary had minimal recordings in it, HbA1c poor. C1 appears frustrated *"we've got to work together on this, you must accept that you have a role in this too!"*

Consultant 01 Clinic Observation Fieldnotes

Passivity was seen in different terms by patients. Those who identified themselves as expert patients perceived passive patients as not having the opportunity to learn from other informed patients:

It strikes me that we're a very elite sample here because we are very used to having experts speaking to us, so we really know the game and I guess feel quite confident with consultants but there are just as many other people who don't belong to us who would accept anything very graciously

Parkinson's Disease Focus Group

Passivity was also seen as an active choice by patients:

I'm one of those who doesn't want to know!

Heart Focus Group.

Several professionals also identified passivity as an active choice by many older patients who wished to continue in a familiar patriarchal relationship with their doctor.

Lack of engagement with the condition was identified by many professionals as linked to a lack of knowledge about the condition with a subsequent failure to recognise the long-term implications. However, data from patients suggested that it was not always lack of knowledge but rather a fatalistic viewpoint that caused the lack of engagement:

Well I'm fairly fatalistic. I think 'Well so be it, nothing's going to alter it'. There's no, I mean at the best it can be held in abeyance but it, nothing's going to improve.

Interview F14

Another characteristic of a non-expert patient was their lack of skill in self-management which also included a lack of self-surveillance. Professionals rarely linked this with lack of knowledge, rather patients were labelled as wilfully non-compliant both in their treatment and their lifestyle:

...he's gonna fiddle with the dressing because he doesn't want to wear it and he's gonna say "No you can't dress it that way" and you know that every week it's a battle and you just think (sighs) 'Why do you bother coming to see me?' 'You know you don't want to listen to anything that I've got to say'

Interview Practice Nurse 03

...oh yeah, they'll get up to anything and think they can just change their INR

Nurse Focus Group 1

Communication skills of non-expert patients appeared fixed at two ends of a continuum. The patients who appeared unengaged with their condition were often unwilling or inhibited in entering a dialogue with the professional. However, this seemed less disconcerting particularly for doctors, than the opposite incarnation – the over-talkative “waffling” individual. This characteristic was both emblematic of doctors’ heart sink patient (see 5.3.5)

and as the antithesis of the ability to be succinct which characterised many expert patients (5.2.3). This feature of a non-expert patient was also linked to GPs further descriptors of a heart sink patient as neurotic, obsessive or over emotional (5.3.5). In contrast both nurses and physiotherapists identified the potential of the non-expert patient's communication style in fooling the professional into thinking the patient knew more than they actually did:

...a lot of people can have a certain amount of knowledge that would fool you into thinking they know what they are doing, until the time comes when they end up in hospital, so you'd have to make sure that they did know what they actually claimed to know.

Nurse Focus Group 2

The variation between professional groups in categorizing communication characteristics as exemplary of non-expert patients is indicative of the differing responses which will be explored further in the next chapter. This section will now develop the portrait of an expert patient further by presenting their key characteristics.

5.2.3 Characteristics of an expert patient

As described above, communication style was a clear marker of an expert patient, and these individuals were very aware of the need to communicate effectively:

... I'm a fairly good communicator, I get on quite well with most people and if you've got a long-term situation, well it's to your own advantage to create a rapport, if it's little bit by little bit so that you think of them as your friends rather than your foes.

Interview M6

The perceived need to be succinct and talk in specifics was generally recognised by these patients, and whilst many were very articulate several also used medical terminology in their conversation with the professional:

OPm11C1 uses medical jargon in his conversation. He is negotiating to seek greater self-management and has a clear agenda. He speaks as an equal, uses first names to identify other medics and to give C1 a message that he knows other medics. Very knowledgeable. States

clearly what he wants. Gives a succinct history and details of his lifestyle. OP11m to C1 "*I'd like to see you in 6 months please*" Overall characteristics: very knowledgeable, uses negotiation style, takes an equalised approach, "grown up", uses first names++, uses medical discourse++

Consultant 01 Clinic Observation Fieldnotes

During the field work it was apparent that these patients maintained good eye contact with the professional and actively questioned about current treatments. However, this approach was sometimes identified as intense with even the most assured professional commenting:

Blimey, that felt like an interrogation!

Consultant 01 Clinic Observation Fieldnotes

Whilst many expert patients thought a lot about preventing this impression of intensity (exemplified in the case studies in 5.3.3) several others justified this approach by describing perceived inadequacies of professionals. This was often triggered by stories of years of refutation of signs and symptoms (5.5.1); for example, several people affected by diabetes told of persistent visits to the GP with recurring infections, thirst and fatigue but with no investigations undertaken. Apart from investigative tests, some expert patients also felt that they needed to take this approach if they were to receive an appropriate service:

... I fight and I moan and I complain and I write and I keep going on at everybody to get it (physiotherapy) and I get there in the end because they just "Give her what she wants, she'll shut up then"

Interview F15

However, this persistence also entailed much effort:

It is rather unfortunate, as when you have got a long-term illness, you know energy isn't one of the things that you have and it's mental energy as well. You know writing letters and making phone calls but it's, it's something you have to prioritise...

Interview F15

This fighting spirit was linked to a number of other attributes such as self-reliance, the desire to take control and taking their own action in self care:

...as soon as he (husband) got onto the right medication he lost half a stone, then he's been on a diet with me and lost another stone and a half and we're much fitter...

Interview F4

Whilst this kind of self-care activity was occasionally triggered by the sense of professional inadequacy, it was more frequently a response to a strong sense of self-responsibility and ownership of health needs:

...we try to help ourselves a lot and that's another point actually that patients must help themselves

Interview F6

We're glad to know these things because we know how to go about approaching your own problem...

Interview F9

These self-efficacious individuals were neither fatalistic nor gloomy about their future. Whilst many admitted some concern about what the future may hold, particularly if there was an unpredictable nature to their condition, many were also able to articulate a positive vision for the future:

You wanna keep looking at the positive side. Like, you know, o.k. well I'll get over today and it will be better tomorrow, and if it's not better tomorrow well the next day it may be better tomorrow. You just keep doing each day, you know as it comes along.

Interview F2

This positive perspective appeared linked to a moral dimension with many patients describing a stoical approach where one had to value what you had and just get on with life with a smile or sense of humour:

One of them things isn't it? I've always been a believer there's always somebody round the corner worse off than yourself...

Interview M1

... I had to look after all these chimpanzees and they had this gorilla that hadn't got any fur and she brought out this pot of cream that was exactly the same as mine (laughs) and I thought 'Woah, there's something wrong here!'

Interview F13

I think I keep busy purposely because I don't want to have to think about myself and the pain and the joints and everything and I think if you're busy physically, then mentally you're busy and you haven't got time to think about yourself and I think positive thinking and laughter really are the two main things that really keep me stable...

Interview F11

Keeping busy was one of the many strategies an expert patient would employ. Another key strategy, triggered by a sense of needing to know either because of a perceived lack or withholding of knowledge by professionals, or more commonly a sense of comfort derived from knowledge, was actively researching about their condition. Sources they accessed for this will be described in 5.2.6, but by many it appeared an empowering device, particularly in doctor-patient consultations:

C1 *have you read anything else?* OP13m *Yes, statins. Well researched. Married to a GP so reads lots of medical journals. Tells C1 that Diabetes UK website says all should be on statins C1: They don't differentiate between type 1 & 2. Helps OP13m to evaluate information.*

OP13m asks C1 *"why haven't you got a camera?"* C1 *"yes we have but there are cost resource issues which means we use it for those who don't attend clinic, we just manually screen those who attend clinic, but new government guidelines states all should have photo taken so it will be changing"*

Consultant 01 Clinic Observation Fieldnotes

This information gathering activity was a key element in another strategy expert patients used, preparing for a doctor's consultation. In particular Out Patient's Appointments (OPA) were seen as a vital event with effort not only being spent in preparing for them, but also in accessing them and maintaining continuity by seeing the same Consultant:

I think a lot of the stress is around appointments, making an appointment, getting one, and how precious it is when you get there.

Parkinson's Disease Focus Group

Preparatory strategies for an OPA included the development of a personal aide memoir, the use of this or other personally developed material such as a pain chart or folder of information in the OPA, knowing what questions to ask and taking a bullet point list into the OPA, and mentally “psyching up”. This latter aspect had an interesting effect on some individuals, for example people affected by Parkinson’s Disease reported that the adrenalising effect of an OPA would dramatically improve their mobility for that day.

Visits to other health professionals including GPs were not viewed in the same way. In these encounters expert patients expected to have an equalised relationship and for their self-management expertise to be acknowledged (see 5.2.5).

Expert patients developed a number of skills in managing their condition. In some cases these were practical skills such as applying a pressure bandage, but more often were likely to be associated with medicine management:

I think kind of they’re (other patients) maybe a bit scared to manage it themselves so if the doctor says “Well try this dose for breakfast, and try this for lunch and try this for tea” they’ll just go away and stick to that rigidly then if they’re getting high blood sugar levels after they’ve eaten, they’ll say “Well that’s it, I’ve done what I was supposed to do, I’ll have to wait you know, for the next dose” whereas I would control it so if I do a dose and then eat my dinner say and then two hours later it’s sky high, rather than just sitting there thinking ‘Well why’s that happened then?’ or ‘I’ve gotta wait for the next time I eat’ then I think ‘Oh well that’s, you know I’ll give a bit, I’ll do myself a bit more insulin to bring it down’

R *But that’s not officially sanctioned with you? You’ve not been told?*

F5 *No*

Interview F5

Other key skills were around organization, both of condition management but also the management of complex disease and complex personal lives. To illuminate this particular skill and the other characteristics so far discussed, four case studies will be discussed. Firstly, by merit of being officially sanctioned expert patients (Department of Health, 2005g), the two lay EPP

tutors will be described. The case studies will then conclude with the two individuals that resembled the description presented so far of an expert patient whom unlike the lay tutors had had no contact with the EPP.

5.2.4 Expert patient case study: EPP lay tutors

T1 and T2 were both white, middle class women in the 35-50 year age group. T1 had a background in Human Resources but no longer worked in this capacity as Multiple Sclerosis had affected her primarily in her mobility, bladder function and fatigue. T2 concurrently worked as a teacher assistant and was affected by chronic pain caused by endometriosis. Both had children but whilst T2 was in a stable marriage, T1 had gone through a painful divorce several years earlier – this was a familiar story from many women in the study who had developed MS in their 20s and 30s. T1 had experienced her first signs and symptoms 26 years previously whilst T2 had been affected by endometriosis for the last 16 years – this longevity of living with the disease generally more than 10 years was characteristic of an expert patient. Both shared a common experience of the diagnosis period, which as will be described in 5.5.1 was typical of many of the participants' experiences. Both had made repeated visits to the GP with persistent signs and symptoms but were told there was nothing wrong with them and felt fobbed off:

I have endometriosis and one of the main symptoms is painful periods and I first went to the doctor I think, when I was about twenty two and for years they just kept fobbing me off, giving me painkillers, no-one did anything and when I look back, that makes me very angry now but still. So I wasn't diagnosed 'til I was twenty six and then by accident

Interview T2

In contrast T1 felt she was probably diagnosed several years before finding out what was wrong with her which she also did by accident:

the consultant came to see me which I thought was odd and there were medical students flying around and one of the medical students was reading my notes and I saw 'MS' printed on one of them and, because I was stupid and young, I didn't say anything, I just took it. He asked if my husband was there and he wasn't so he said "Well don't worry"

Interview T1

Both described the development of self-management strategies as a “conversion” but with different triggers. For T1 there was a realisation that self-management was actually effective for her and she was simply practising what she preached as a Human Resource trainer and counsellor. T2 had turned to self-management as a way of establishing control and saw the process as essential:

when I wasn't diagnosed, I think after that I decided I was gonna be assertive and each time I had an appointment with someone, I would have written it all down, exactly what I wanted to know and I wouldn't be ashamed. I'd go in there with my sheet of paper and I'd go through it and I never had a problem with that.

Interview T2

Both T1 and T2 shared several characteristics with other expert patients. Firstly they had spent much time researching their condition using a variety of sources (5.2.6). For T2 this process had been encouraged by a helpful GP, however T1 had been advised not to read up on MS but when eventually she did find it very comforting:

she (GP) said “Don't read anything about it, it'll only depress you. You might be lucky, you might have fifteen years before you need a wheelchair”. So I sat on it, I didn't tell a soul apart from my husband... I was tired all the time, but I hadn't read anything about it so I didn't know that you were tired with MS... and then I started living with it, started finding out about it which was actually very comforting. Only one in five people ever move into a wheelchair. Well hope at last. I'd been thinking 'That's it'. I was waiting for my wheelchair, I knew it was coming and suddenly, not necessarily...

Interview T1

Secondly, both had actively sought to remove the sense of stigma attached to having the condition with T2 talking in terms of learning not to be ashamed, and T1 describing the process as learning not to feel guilty. Both also felt a sense of ownership of the condition, with T2 speaking about the importance of

knowing your own body, even though this knowledge was often disputed by professionals:

you know the thing about the cyst and me knowing that it was the size of a grapefruit but no-one takes any notice. You know your own body, you know and then they just don't seem bothered.

Interview T2

Fourthly, both were willing to try out alternative therapies and approaches to treatment (5.4.8). Lastly, and this dealt with in more depth in 5.5, both acknowledged that emotional support was key when one was affected by a LTC:

Because there isn't anything you can do about MS but you just felt understood and (pause) cared for

Interview T1

...having a time and a place to go and talk. Whether it's with each other or with someone who understands. I think you can feel alienated quite a lot of the time, isolated perhaps, and em, yeh it would be nice just to have a meeting place.

Interview T2

Whilst their actual preparation and their experience of running the EPP will be described in 5.4.9, there are 2 key aspects from their interviews that link the EPP and the portrait of an expert patient. Firstly, both tutors saw the key purpose of the EPP to help people take back control and provide emotional support – the extent to which it did will be dealt with later. Secondly both lay tutors drew on their professional expertise (skills training, counselling – T1, teaching – T2). This trait was indicative of the way expert patients appeared to manage their condition which will be further exemplified in the following case studies.

5.2.5 Expert patient case study: M6 & F11

These two individuals are not unique within the study but have been selected as emblematic cases that richly illustrate the portrait of an expert patient. The data from which these case studies are drawn is shown as an extended data display in appendix 27.

Both M6 and F11 lived on their own but that was the only similarity in their biographies. M6 was a white, retired professional man in his late 60's who had been diagnosed with Parkinson's Disease 15 years previously. He was also concurrently affected by insulin dependent diabetes and asthma, and had undergone quadruple bypass surgery at the same time as being diagnosed with PD. His wife died 4 years ago and he was in regular contact with his children who lived away. F11 was a white female in her mid 40's who currently works as a secondary school teacher and was diagnosed with psoriatic arthritis 17 years ago. She was single and whilst her parents had retired to Italy she had an extensive network of friends living close by. However, both found living on their own compounded the issues of being affected by a LTC:

*"But living on your own with Parkinson's, is, is pretty traumatic.
You've got to make sure you've got things at hand"*

Interview M6

"...having to cope on my own which is very difficult because, if you go through what I call a bad patch, when you're swelling up and you're uncomfortable and you want something to eat or drink, there's no person who has to get it for you so you either have to make a real effort to get it yourself or you go without basically..."

Interview F11

Both were characteristic in the paradoxical nature of articulating acceptance of incurability:

"There's no specific reason why you get it. There's no actual cure and on a personal note it drives me potty but I can't do anything to make it better or to make it worse so once you've actually accepted all that, the only way is up"

Interview M6

“...if you’re being absolutely realistic and you’ve got a chronic illness, you’re not gonna be cured. You can be stable and you can make your life a lot more comfortable and there’s loads of different ways that you can do that but you’re not gonna be cured and you really, really do have to get your head round that part”

Interview F11

but also constantly seeking the latest treatment. This was achieved by both of them through ensuring they were seen by a consultant who was actively engaged in research trials:

“I wasn’t really aware that there was so few neurologists that have Parkinson’s Disease as their core subject...and A (welfare officer) said “Well there’s certain names you can go for”. I’ve got the most outstanding lady GP and er, and she’s all for it, you know if you don’t ask you don’t get. I was interviewed at length with the Professor, one of the Professor B’s registrars and then I got taken on”

Interview M6

As with the tutors, M6 and F11 described the stigmatizing effect of their conditions, and whilst the use of humour was described in 5.2.3 as part of stoicism, M6 and F11 also used it to alleviate stigma:

“I’ve got a keen sense of humour and things happen to me which, I think the easiest one to tell you when I went to get some money out of my back pocket to pay for my bread at the local baker’s and it wouldn’t come out. My hand just froze and I said “Will somebody take my hand out of my pocket?” (laughs)

Interview M6

Both M6 and F11 articulated the emotional consequences of their conditions but purposefully used strategies to alleviate these which for M6 entailed intensive information seeking whilst F11 relied not only on keeping busy but also utilising her network of friends for emotional support. Neither of them saw their relationship with professionals as one of receiving such support with both clearly describing their interactions with professionals as a partnership approach:

“... I get the best out of people because I treat them with courtesy. . But I’m not a fawning sort of person, with courtesy you tell them what you want to hear and I think basically the medics want some ground rules established, want the boundaries, otherwise you either go all on a tangent or you talk about minutia. You really want a good picture as well”

Interview M6

“...gone are the days where you go into the consultant and you sit there, you’re told what to do and you walk back out. It’s a partnership, partnership treatment really”

Interview F11

The communication skills of M6 have already been illustrated in 5.2.3 but the range to which both M6 and F11 used these skills should be highlighted. Whilst both clearly articulated these skills in terms of the doctor-patient encounter, it was also apparent that they used these skills to help other people in similar situations:

“I said “How are things with you then?” and then a voice said “Mum’s not doing too good” so I looked at Mum. I said “You did that without your lips moving”. Anyway I chatted generally and apparently this lady had fallen over a couple of times going shopping and the more she thought about that, the more she chose to stay in all the time. So, the daughter said “Well how have you been doing?” ...They were astounded how I managed to still be here with all the things that have happened. I said “Well you, if such things happened to you, you would find some inner strength after a time” anyway this lady changed dramatically from very bad to terrific. Different woman within a month and she said to A (welfare officer) “Thank me for talking with her” you know ‘cos she, she never thought that she could get out of the trap she was in”

Interview M6

Both M6 and F11 saw these skills as a gift that should be used both for the benefit of individuals:

“...it would be nice if this could have a knock-on effect I think, like in other chronic illnesses, other people feel confident enough to say “Yeh, I can stand there and say Look, I’m alive still. You know I can still lead a life”

Interview F11

and as a contribution to helping the cause for their condition:

...if I can promote it (arthritis) somehow then I will. Em, until someone famous gets it or someone that is a figure in society does something for it, it’s not gonna get the recognition it should have really”

Interview F11

“...last year I thought ‘What am I going to do for Parkinson’s? I want to put something back’

Interview M6

This ethic of citizenship was apparent in most expert patients with each actively involved in activities such as running support groups, hosting web sites or being part of PCT public involvement activities.

As with all the expert patients in the study, M6 and F11 researched their condition extensively in order to ease anxiety, obtain the best service and to reduce a sense of self-pity:

“frankly I wallowed in self-pity for a few days so I spoke to the RNIB and got everything about things...so that, you know, I know, I knew exactly what was going to happen”

Interview M6

They were also typical in using this information gathering strategy as preparation for an out-patients appointment:

“ I think for me it’s my basically enquiring mind, not because I want to, want to beat the medic at their own game, it’s just that forewarned is forearmed”

Interview M6

However, perhaps the most striking feature of these two which provides illumination on how the other expert patients framed their behaviour, was their organizational skills and the use of occupational and personal skills in shaping the way they behaved as expert patients:

“...you’ve got to be very very organised”

Interview M6

“I’m a very organised person in the sense that I know exactly what I’m doing and when I’m doing things”

Interview F11.

M6 cited his previous role as a project manager in shaping his response to living with a LTC:

“ I had a strategy meeting with my GP. “I think we’ll sort the heart out first and see if the shakes get a look in” ...

“That’s my strategy. I mean with H’s (wife) cancer, I mean em, H wasn’t feeling well on a Sunday, saw a GP on first thing Monday morning, was at the L & D to have the ultrasound and was diagnosed on the Wednesday and the following, so I got all the information on Non-Hodgkin’s Lymphoma by Friday and I sorted out a MacMillan nurse by Friday and saw the Oncologist on the Tuesday. Possibly my project management skills came to the fore” ...

“ I was a contracts manager, senior contracts manager with major construction companies moving onto jobs, then I was Director General of a trade association for three years

R *Right. So you’re able to use those skills very much in the appropriate way?*

M6 *Yes. That’s the approach I take”*

Interview M6

F11 utilised her teaching skills not only in the way she planned and managed her life, but also as a “proto-professional” expert patient:

"I did do a talk in July to the two consultants, a couple of physiotherapists and occupational therapist, I did the presentation... a brief medical history about myself, I also brought my splints with me, my pen holder and everything and showed them and they said after that talk I was inspirational and they were just bowled over by it all, they just couldn't believe it. But I just did it as though it was a lesson."

Interview F11

M6 could also be labelled as a "proto-professional" expert patient exemplified by being used to evaluate research proposals.

Whilst M6 and F11 were clearly identified as expert patients by professionals:

In fact my GP (laughs) will say "I've got a letter from Professor B. If you'll just have a look and then tell me what it means"...

"you know in many ways if you're, if you're a person like me who wants to know what's going on then you're bound to be a bit more informed than your GP anyway"

Interview M6

"I'm the type of person that when I go to my appointment, I do discuss what we're doing and everything and they're probably seeing me now in a different light because recently, a couple of weeks ago, I did a talk to em twenty other patients who were recently diagnosed and they asked me if I would like to be an expert patient and I said "Yes I would".

Interview F11,

both also described how much effort being an expert patient took, which was story repeated by many expert patients:

"I mean you've got to empower yourself, I mean obviously it's a tad difficult on your own to be focussed and it takes, takes a lot of effort but I get there in the end"

Interview M6

The case studies of M6 and F11 illustrate two individuals who had reached the summit of a journey towards being an expert patient. However, as described in

the storyline, these individuals had come across many boulders and signposts during their travels, and this section will complete with an exploration of some very significant signposts for all expert patients – sources of information.

5.2.6 What sources of information do expert patients use?

Reflecting the recruitment strategy it was unsurprising that the most frequently cited source of information was support groups such as the British Diabetic Association or MS Society. Even for those patients who had not been recruited via support groups it was the dominant source of information although mainly accessed via the Internet. The Internet whilst widely used was perceived as a source that needed to be carefully managed either to prevent overload or misinformation:

there's the dreaded internet, find a word you didn't understand and search for that word, and it's absolutely fatal because you can convince yourself, I mean I convinced myself a couple of weeks ago that I was getting massive heart failure but took 2 paracetamol and felt better!

Heart Focus group

Whilst the Internet was mainly used to generally inform about the condition it was also used by some to check on professionals' suggestions:

he (GP) wanted to give me Seroxat. I was thinking about taking it because he said it would do something for a few months and then we looked at it up on the Internet and I decided no.

Interview F16

Conversely a few individuals would also use professionals to check out information they had found on the web. When professionals were asked to identify key sources of patient information none mentioned support groups. Whilst the internet was recognised as a significant source the consultants and nurse specialist felt it was underused by patients, where as some physiotherapists were concerned that it may be misused:

with the Internet they don't, they put it in layman's term and they don't quite explain certain things so they don't really know as much as the professional

Interview Physio 02

The main congruently identified source between professionals and patients was an acknowledgement of the impact the *Daily Mail* health pages had. Whilst GPs, practice nurses and specialist nurses would highlight the increased consultations the day after an article, many patients found it an extremely good source of information.

Both physiotherapists and practice nurses felt that they provided the best source of information for patients, however the overwhelming majority of patients identified that they had never received any information from professionals:

She (practice nurse) said "Oh you'll have to work that out for yourself with the knowledge that you have" so that's not easy when you don't know what you should be eating and what you shouldn't be eating

Interview F9

Many patients cited books although often felt that material from the US was likely to raise false hope and some actively attended conferences on their condition. For the individuals affected by cardiac disease or Parkinson's Disease friends and peers provided a particularly important source of information. For the former group knowing someone who had already undergone heart surgery was deemed the best source of information. Overall, expert patients utilised a wide variety of information sources and all identified information as key. However, perhaps the most significant finding in this area was that health professionals were predominantly perceived by expert patients as not providing the necessary information, hence often acting as a boulder rather than a signpost in the journey towards being an expert patient. The chapter will now turn health professionals and the next section will particularly focus on the relationship between health professionals and patients, illuminating how the nature of this relationship can be a facilitative or hindering mechanism.

5.3 The professional – patient relationship

This section will commence by presenting the data indicative of the nature of the relationship. After the reporting of communication strategies used by health professionals, the ideal patient from a professional's perspective will be presented followed by the antithesis – the heart sink patient. In order to

illuminate differences amongst professional responses to expert patients, data indicative of role and job motivation will be reported. The section will conclude by providing the mirror image from a patient's perspective – the ideal and the non-efficacious professional.

5.3.1 The nature of the professional-patient relationship

Out of all of the professionals, doctors identified that the nature of the relationship had most significantly changed over their careers. In particular consultants identified that they were no longer paternalistic, were more at ease in being the patient's advocate and knowing the patient as a person:

I think that we did very badly by our patients when I first went into medicine and one of the best examples of this is that we told the relatives about the cancer before we told the patient, whereas now we would never dream of doing that. There was some terrible practises when I was first in medicine and even when I was first in Dermatology where you would undress the patient and go into the cubicle with them undressed... so you never saw your patient with their clothes on which was outrageous, 'cos you could never get an idea of what sort of type of person they were, which is what you get when you sit them down and have a chat with them before you get them undressed.

Interview consultant 02

Whilst GPs were generally positive about the change in relationship, there were some underlying concerns about patients being more demanding, less respectful and using Primary Health Care as a service industry:

Now it's a service industry and people feel entitled to demand it at any time and therefore general practice has had to change, to adapt

Interview GPM11

Many of the expert patients also identified that doctors had often improved particularly in their communication skills over years of encounters.

The current nature of the relationship was most often described by professionals in terms of partnership, with a mutual desire for self-care, patient choice, reciprocal respect and a non-hierarchical way of working as a complementary pair:

it's probably a fairly level playing field. I don't want them to feel there are any barriers or hurdles in coming to me. In fact I probably take them down too much, I wouldn't say it ended up with over-familiarity but there's a, there's a need for them to be able to sort of say things straight away rather than to have to scrabble around and find encouraging words to talk to me about things so I have a fairly open relationship

Interview GPM12

R Yes. So what kind of relationship are you seeking with your patients?

PN Um, oh gosh (laughs). Um (pause) I think it's one of trust, mutual trust really and respect hopefully.

Interview PN01

Some professionals went a little further by describing the relationship in terms of friendship. This was most marked in consultant 02 who was often bought gifts such as home baked cakes by patients, and spent time chatting to them in the mode of old family friend. However, whilst most spoke in terms of partnership many professionals were equally as anxious to maintain boundaries within the relationship:

...not getting too personal with them initially which really affects the way we relate to one another during treatment. If there other things that I'd like to put my foot down like 'Don't do heavy lifting' but if you're too friendly with the patient then they'll just not listen to that but really relating to them on a professional basis

Interview Physio 02

The way the relationship was juggled by professionals was most clearly illuminated by their communication strategies with patients.

5.3.2 Professionals' communication with patients

As reported in 5.2.2 and 5.2.3, communication skills were an important attribute of an expert patient but were also used effectively by many professionals. The practice nurses and nurse specialists exhibited a non-judgemental mode of communication with patients appearing to find them very easy to talk to:

PN3F02 Female white 50 year old cleaner with diabetes type 2.

PN3F02 *"It's all going out of control, I can't do exercise, I'm putting on weight, my blood sugar is really high and I'm too scared to test"*

PN03 *"often it's nothing you're doing"* Non-judgemental, tries to suggest exercise that the patient would find manageable, eg. 10 minutes 3 times a day instead of 30 minutes in one go. PN3 gives kindly, negotiated messages.

Practice Nurse 03 Clinic Observation Fieldnotes

There was a clear focus from the nurses on the patient issue rather than concentrating on the actual condition. The nurse specialists were also orientated towards teaching the patient:

NS02M03 Male white 45 year old builder with insulin dependent diabetes. Worried about a very high blood sugar reading, NS02 explained that a one off is not an issue. She went over his injection sites and explained why she wanted him to keep a diary *"you may see a pattern and I would learn too!"* Summarises all that has been said during consultation and negotiates goals with patient to be achieved before next OPA

Nurse Specialist 02 Clinic Observation Fieldnotes

NS01M07 Male white 65 year old retired, recently commenced insulin. NS01 uses a metaphor to teach *"Blood sugar is like honey on a table, if you wipe it off immediately there is no damage but if you leave it for a few months there will be loads of damage"*

Nurse Specialist 01 Clinic Observation Fieldnotes

Perhaps most noticeable in the nurse specialists were their ability to change communication styles to suit each patient and they articulated this as a discrete skill:

I've put a different role onto different patients, I'll be Mumsie to some, daughter like to others, friendlier to others or more matronly to some. Whatever I feel will work with that patient but I'm less formal I suppose than some of the doctors 'cos it is going to be a long-term

relationship because their diabetes won't go away so I'd probably say that I use more inter-personal skills and a lot of patients need to be listened to and they often don't feel they get listened to by the doctor...

Interview Nurse Specialist 01

As already indicated, consultant 02 was adept at linking her communication to the personal and she was also skilled in using language that was appropriate for each patient. Consultant 01 was also very clear that communication was central but approached it differently with each patient. He was particularly skilled at putting patients who appeared to be anxious at their ease, and at engendering celebration with them if blood results were good. However, as will be reported in 5.6.2 this was most noticeable with female patients:

OP10f worried about her control: C1 *"it's not something you're doing, it's to be expected"* gentle, soothing mode. Lots of validating her actions *"top of the class"* *"almost too good"* Joke shared re Eastenders, friendly banter, kind.

Consultant 01 Clinic Observation Fieldnotes

He had initiated a system where each patient would receive the same written summary sheet as GPs which contained details such as biochemistry results. In order to be time efficient he would type results and his assessment onto the computer during the consultation. Unfortunately for many patients this appeared to cause some difficulties, particularly as the computer's positioning meant he spent a large proportion of the consultation with his back to the patient:

OP17m: C1 in silence for whole of last 5 mins of OPA whilst he writes up computer notes. He creates the silence by stopping interaction, no eye contact etc.

Consultant 01 Clinic Observation Fieldnotes

This appeared most problematic for the least confident patients and for those who did not speak English as a first language. It seemed likely that this group had a particular need for non-verbal communication such as eye contact and facial expression in order to be able to grasp what was being said by the

consultant. However, whilst this lack of eye contact and periods of prolonged silence appeared problematic it had been reframed by many other patients as a sign of thoroughness, with the majority feeling it was worthwhile in order to receive a comprehensive feedback sheet:

...my consultant's quite good because he'll sort of send me a print-out of all the results as well after each appointment. So you know I know what my HbA1C is and if I've had liver tests and things like that, he'll put it all in writing and whatever he sends to the G.P. I get a copy of that

Interview F5

Nevertheless, for many patients this focus on physical measurement such as the HbA1C reading did cause difficulties. It was apparent that this reading would frame the discourse of the consultation, if out of range there would be a disciplinary atmosphere as opposed to a celebratory one if the reading was in range:

OP1M. C1 focuses on high HbA1c *"control not so good, why do we think that?"* No eye contact. Uses checklist to focus communication. HbA1c frames consultation but when OP1M's on the spot test was very low and home recordings very low, C1 accepted that HbA1c reading may not be totally reliable *"it's a puzzle, doesn't make sense"*. Then revisited sweating at night – HbA1c affected by low grade infection or the lab *"may have got it wrong"*. C1 to OP2F lots of positive feedback *"HbA1c is 'brilliant!'" "patient of the month, patient of the year!"*

Consultant 01 Clinic Observation Fieldnotes

Whilst this effect of physical measurement on communication was most apparent in consultant 01, it had a significant impact on the relationship of all professionals with their patients as will be described in the next two sub-sections.

5.3.3 The ideal patient

Being well-controlled as evidenced by a physical measurement test result was described by all professionals as one of the characteristics of an ideal patient. This was strongly linked to the idea that an ideal patient would be someone who made progress, recovered or was turned round from being poorly managed. It was also connected to the predominant thought that an ideal patient is quick, easy and succinct:

How would you describe an ideal patient?

...a patient comes in with a simple back pain, who comes because they have maybe poor stability and er bad posture. That is quite an easy patient to treat because they don't have any other neurological symptoms, no er broken bones or anything like that so that patient I think is an ideal one, yeh, you just tell them to correct their posture, and they're on their way.
Interview Physio 02

...once they feel they can make the necessary checks for their blood sugars to me they can then start going back to work or they later on end up having families or moving on or start doing their normal activities. I think they're the patients that give you a bigger buzz because they start off so low and then they work so hard. Interview Nurse Specialist 01

One that doesn't waffle too much, that kind of gets to the point because you've only got a certain amount of time, you've always got other patients waiting so really going back when you say you know "How long has this been going on for?" and they say "Thirty four years" and then proceed to tell you the entire thirty four years, that's always a bit upsetting (laughing). You have to try to condense it whereas you don't really like to interrupt them but you know, so I would say patients who are relatively succinct. Interview GPF10

Well a real em winner, a sort of fast quick winner would be somebody who comes in with a little nodule that bases them on the face, that I can see when they walk in, er that they're a person who's er, you know is relatively articulate, er where I can see the lesion, I don't even have to get off my bottom and find my magnifying glass. They give a clear history and I just book them in to have it removed and I know that's a real easy one, yes. Interview Consultant 02

...it's the one that you can come in, deal with quickly and get rid of again so you can catch up
Interview Practice Nurse 01

As can be seen in the above quotes, the ideal patient was equated with notions of easiness which was reinforced in the eyes of the doctors and physiotherapists if the patient was articulate and intelligent. Another positive attribute was seen as being cheerful, giving positive feedback and embracing life with the chronic illness:

They seem to just be sort of celebrating life even with their condition and that's feel good.

Interview GPM12

Being compliant with instructions was seen as a prerequisite for an ideal patient by physiotherapists whereas other professionals spoke more in terms of taking responsibility for health and successfully self-managing:

...they're actually sort of taking responsibility for their own health and er, those make me happy

Interview Practice Nurse 02

However, it was apparent that professionals would actively judge how successful a patient was in self-management and consequently whether this patient could be defined as an expert patient.

5.3.4 Judging patient expertise

Many professionals, but in particular nurses, felt that patients should never be simply trusted in their self-management:

I actually, em, I don't trust what patients say at all... I listen to what the patient says but I need to, in my own mind, process it, have the evidence and then I come back

Interview Practice Nurse 03

Consequentially patients were actively tested and as previously described a physical measurement was the main mechanism for this:

...there are some patients who think they are expert, I have one and yet her HbA1C shows that she's very far from it

Nurse Focus Group 3

Whilst it was acknowledged by the Nurse Specialists that the parameters set by these physical measurements were often unrealistic for patients, nevertheless assessment of patient's expertise and knowledge would take place over a long period of time often involving setting some tests:

NS02M02 white male 55 year old, type 2 diabetes commenced insulin 5 weeks ago as adjunctive therapy. NS02 checks his knowledge regarding Metformin. Asks very technical questions that he finds difficult to understand. Finally he defines the action of Metformin as "*softening my blood*".

Nurse Specialist 02 Clinic Observation Fieldnotes

It was clear during the fieldwork that patients were very aware that they were being tested, with one patient commenting when the nurse specialist was out of the room *I feel a complete failure when I have to see the diabetic nurse.* Thus, although the ideal patient could be described it was in terms of not only how easy they were, but their levels of trustworthiness. This will be further illuminated by the reporting of the findings illustrating the antithesis – the heart sink patient.

5.3.5 The heart sink patient

The heart sink patient was a term familiar to the doctors and nurses in the study as describing the unpopular patient, for physiotherapists the term “yellow flag” patient was a more typical label with the same meaning. Professionals had little hesitation in describing patients they found difficult and all were able to base the descriptor on an individual currently on their caseload. A recurring feature of a heart sink patient was the complexity and insolubility of their health needs:

...patients who are referred perhaps again and again and again for a similar condition and they, they come, you treat them, you advise them, em, they go away and perhaps six months later they're back with the same, same thing

Interview Physio 01

It's going nowhere. It's where a considerable amount of my time is spent running in circles and I don't technically think there's a personality type or problem that's heart-sink. I think it's when your relationship shows a heart-sink. In other words you're unable to sort of kind of negotiate some progress and therefore you get into cycles of seeing things round and round and round in circles and I think that isn't very good time management

Interview GPM12

somebody who has recurrent problems but does not want to be helped

Interview Consultant 01

someone with multiple chronic problems that you know you're not going to be able to help, that they're going to come in, possibly with something trivial, that you know whatever you suggest they've already

tried it, they've already been there, they've already done that and that's never worked before.

Interview Practice Nurse 01

Heart sink patients were also characterised as sad, depressed or complaining:

Well for me it's their body language. They'll come in and I'll say to them "How are you?" and it's "Oh you don't want to get old dear". You know if anyone said that to me I would think 'Well you're very lucky that you have got as far to get old'

Interview Practice Nurse 02

Some people are just chronically depressed and make everybody around them feel that way em, they seem to know no other way em, they use the surgery more like a public toilet I think. They come in and offload and er, I suppose they go out feeling better

Interview GPM11

they're very angry and it's all your fault and it's your, and nothing's their fault and they won't take any responsibility and that's very hard to work with them because everything's your fault.

Interview Nurse Specialist 01

This set of psychological characteristics of a heart sink patient was uniquely taken a step further by the GPs in the study who described their problem patient as over emotional and generally female:

...hysterical, somebody immature, manipulative, who comes because they want an antibiotic, it might be something else, but they have their expectations, they know what they want from you but they're not gonna ask for it...it's usually ladies I'm afraid

Interview GPM11

Exclusively the nurses in the study also described their heart sink patient in terms of being too knowledgeable and informed:

I suppose you think 'Oh gosh I am the nurse, I should perhaps know a little bit more'

Interview Practice Nurse 01

He's challenging our medical knowledge, what causes asthma, how we can control asthma

Nurse Focus Group 4

These informed patients were perceived as problematic by the nurses because they were a drain on their time resource:

...you've got a big clinic and they'd want to know this that and this and that, and you'd give them that answer but it's not good enough and you have to give them that answer and that answer

Nurse Focus Group 2

In contrast the other professionals in the study only perceived the heart sink patient as time consuming because they would keep returning with the same problem rather than asking too many questions. Indeed doctors, physiotherapists and the nurse specialists (uniquely out of the nurses) saw lengthy consultations as an initial investment that would save time later, with nurse specialists particularly describing a heart sink patient as someone who did not give their condition enough time including OPAs.

The section will now go on to present the mirror image from the patient's perspective, and in order to directly reflect the above, patients' perceptions of a bad or unhelpful professional will be reported first.

5.3.6 Brusque and incompetent: a portrait of the bad professional

There were two main areas underpinning the descriptions of bad professionals. Firstly a number of characteristics were described that stemmed from the professional's communication style whereby patients perceived them as rude, derogatory, callous, impatient, brutally frank with a lack of respect for the patient. These defining features would result in the patient feeling "*awkward and rotten*" :

I saw this female doctor that I'd seen before and she was really horrible to me. She did not want to give me any time I felt. You know, she was thinking "You're allocated five minutes" ... "I haven't got time for this" where I've got this long list of questions 'cos I would always go in with a list to my doctor and I'd just been diagnosed with MS. I'd seen the neurologist but didn't really want to know 'cos you're in shock afterwards anyway. You then need to absorb a bit and then go back don't you? She didn't want to know, I mean it was just horrible experience to see her...

Interview F15

This appearance of being too busy to care was a major issue for some patients:

it would have been nice for someone to talk you through rather than just fire prescriptions at you basically, and how much time do you get with the doctors, and they say to you have you got any questions for me, but you're so taken aback can't think fast enough to get the questions together before off they go

Heart Focus Group

However, whilst many patients seemed to accept that professionals were often too busy to give them the time they needed, what they found most disturbing were situations where they felt labelled and demeaned:

I started talking about people with MS had been shown to have low levels of (laughs) which he didn't like at all. He said "Well for all you know, you might have low levels of blood rhubarb" (laughs)...He put me down. Don't be smart about having MS, you're just making a fuss...

Interview T1

He (Consultant) said "If you get any inkling of this again" he said "Don't hesitate, go to your GP". Well it re-occurred and I felt blooming awful...So I had to see this doctor...Anyway I went to see him and he was derogatory from the start and he queries "Why are you here on an emergency?" ... "Oh you don't come to the doctors when you've got a little cough"

Interview M5

The second area of characteristics that for many patients defined a bad professional was to do with their levels of competence and skills. Many patients told stories of misdiagnosis and mismanagement (see 5.5.1). What particularly concerned a number of patients was a perceived lack of ability

particularly by GPs to link a number of problems together to aid diagnosis, specifically when posters in Surgeries stated patients were only allowed to discuss one problem per consultation:

I said "I'd like you to look at something else" and she said "Only one thing at a time" (stern voice) and I said "Oh no, I'm not coming back another two times" and so she said "Oh, alright then", now somebody else who wasn't quite so stroppy would of gone away and those two things would have been missed.

Interview F13

It is terrible because you may have 2 different symptoms but they may be connected, but you can only talk about 1 at a time

Heart Focus group

Whilst most of the above descriptors were used by patients to describe their idea of a bad doctor other professionals were also described in negative terms. Even though nurses were never perceived as rude or patronising they were often described in terms of incompetence. In particular, many patients with diabetes felt that Practice Nurses did not have the necessary skills to manage the condition and hospital nurses were specifically identified as lacking basic knowledge about a range of chronic conditions and being a major barrier in self-management:

I just think it is the training of nurses nowadays, they are not bang on like they used to be, particularly for Parkinsons they just say "well, there's a bell there" and I said he can't even ring the bell! If you put the bell there he can't move! And they can't seem to understand that he would need help to go to the loo, so I said you must keep your eye on him because if he gets distressed in the night he's not even going to be able to ring the bell to let you know, and that is very frightening

Parkinson's Disease Focus Group

He (consultant) said to them, er to the other em nurses "Look he's diabetic. He knows what he's doing. Let him give his own injections and take his drug himself", and they weren't happy to hear that

Diabetes Focus Group

There was one other area that patients (particularly female) identified as indicative of a poor professional; inappropriate responses to emotional distress. However, as this reaction directly contributes to the core category the data for this will be presented in 5.6.

Whilst patients' perceptions of a bad professional have been presented above, unlike the professionals the majority of patients appeared to find it easier to discuss their ideas of a good professional which will now be reported.

5.3.7 The ideal professional

The majority of patients were able to describe their idea of a good professional with the descriptors drawn from three main areas. Firstly personal attributes and communication skills were seen as key. For many patients kindness and a caring attitude were identified as a prerequisite of a good professional, plus the ability to respond with ease and kindness to emotional distress (5.6).

Now their (continence nurses) attitude was so different. You were treated like human being, you weren't a nuisance and a bore and the whole fiddling with your bits (laughs) dealt with so nicely. They understood, whereas the other woman, "Now come along, it's perfectly alright" (stern voice) you know "Have you never looked down there before". You know, belittling me all the time whereas these people just treated me so nicely

Interview T1

Participants particularly appreciated being recognised as a person rather than a patient and valued being able to share pleasantries or humour with the professional.

I think he finds the pair of us quite amusing you know because we... go in and he's "Oh, is it you two again?" ...he's respectful of our views and we're respectful of his

Interview F6

The ideal professional is someone who they felt able to share either concerns or strategies with and as such were trustworthy and gave confidence. The result of dealing with such a professional was feeling good about the interaction, not getting the impression of being perceived as a nuisance and being facilitated in keeping their condition in proportion.

... he had the ability to diagnose what your feelings are, what you are experiencing and you'd walk out of there feeling 10 feet tall, without doing anything to you.

Parkinson's Disease Focus Group

She committed suicide because she couldn't use her hands and then panic sets in because you start thinking the same ... so you have to sort of try and ... that's why I said my G.P. was very good because he sort of said to take a step back, that's the worst that can happen

Interview F2

Integral to these attributes was the ability to be a good listener who was also able to both draw out and provide information:

she really listened and followed what I was saying about my everyday activities I did and actually pinned down what was going wrong, gave me specific exercise to help it so she was excellent

Interview F3

...he was giving me information and he was listening to what I was saying 'cos I'd um been reading up on things and that's when he said "If you've got any problems, just don't hesitate". And that was all I needed was for somebody to say come back and talk

Interview F2

Openness to alternative therapies and patients' suggestions for treatment was also valued, particularly if there was validation of an individual's effort to self-help. This validation was seen as a sign of respect from a professional and as indicative that they did not perceive the patient as stupid:

...he said something to me "Oh well you're an intelligent enough person I can tell" and he did talk me through things and say what was

happening and was honest about fertility. Em, so yes he was a good guy

Interview T2

He(GP) said to me "I would be doing exactly what you are doing if I had it" you know to go down every avenue

Interview F7

The second area of descriptors of a good professional surrounded perceptions of clinical competence. Doctors and in particular consultants were often praised in terms of their intelligence, knowledge of the condition and clinical skills:

the new neurologist that I've got now, he is fine and he does examine me and I do feel that he looks me in the eye and he listens to me and he takes on board what I'm saying and he writes things down

Interview F15

Clinical competence was also identified as the speed and type of response to diagnosis with immediate action or referral by a GP identified as a positive behaviour. In addition any professional whose actions were likely to make things easier for a patient were deemed ideal. One female respondent labelled this as a "tame" doctor and saw the process of "taming" a professional to respond in certain ways being based on trust and developing over time:

I went downhill right in the end of December and I thought I'll ring in January, that's enough time to go on the Prednisolone again'. Left her (GP) a message 'Having an attack, could she leave a note' and I go that afternoon and she's left it out. I mean some GP's may say 'Oh that's irresponsible' but then I've had it (MS) for nineteen years...I mean they don't leave me a note saying 'Come in and see me', they just leave me enough tablets ...

Interview F8

The third area used to determine the efficacy of a professional was connected to the environment in which they worked. Patients frequently identified accessibility to a professional as a key indicator and also perceived continuity as vital. Accessibility is indicated in the above quote where the respondent was able to access a prescription from the GP with minimal effort. Continuity was

seen as essential as all respondents saw that a relationship with the ideal professional could only develop with time:

I'm on his list anyway but I'll always double check you know that "I am seeing him aren't I?" 'cos I don't wanna be pushed to go and see one of the registrars again...he'll take time out and you can ask what you want and you know he'll explain things to you and even to the extent you know I'll say "Can I try this?" or "Do you think I should do something in a certain way?" and he'll say "Well, you know, it's your, your condition, you're in charge of it, what do you wanna do?"

Interview F5

Whilst patients perceived personal attributes and continuity as important factors in shaping the good professional, this section will now go on to explore whether professional's roles and motivation also had an impact on the professional-patient relationship.

5.3.8 Professionals' roles and job motivation

Following on from the above set of findings it was clear that some professionals had chosen their career path motivated by an appreciation of patient care continuity:

With General Practice you've got a lot of chronic disease management because you're managing patients with, you know in General Practice that's what, they keep coming back. In Dermatology there were also a bunch of patients that I got to know because they had chronic diseases like psoriasis and eczema and you actually got to know them and their family, much as you did in General Practice and that's actually quite different to most other hospital specialties

Interview Consultant 02

It was also apparent that some professionals were motivated by a sense of vocation, particularly doctors:

...it was a vocation, that is what I always wanted to do from as far back as I can remember. If you were to theorise and come up with ideas as to why I should be struck down by that thought and that ambition then um ... well you could go on about being a compulsive care giver

Interview GPM11

Interestingly the other professional groups did not cite continuity or vocation as job motivation and there was a continuum of views. Whilst some nurse specialists and physiotherapists discussed the influence of previous professional experience on their current role, practice nurses had often selected their job to fit in with their home life:

I think it's a little bit 'Well anything's better than what I'm already doing' (laughs) and of course the added bonus of the em, not working weekends and nights when you've got family so that was the main reason. Terrible isn't it really?

Interview PN 01

As can be seen in the above quote there was some reticence in describing this as the main motivation for the role and nurses were more likely to talk in terms of career progression. Nurse specialists in particular felt that their role offered one of the few opportunities to work in a high grade job and maintain patient contact:

...at least with diabetes you feel that you can make a difference and it's also more inter-personal as well as the fact that you can go higher up the grade and also feel the inpatient contact

Interview Nurse Specialist 01

Physiotherapists more commonly described their motivation as selecting it as a career most likely to suit their personality whilst still at school:

...careers advice from school and I looked at remedial gymnastics and I thought 'Yes' you know 'That, that suits me' and it, it's about it, I basically went to college, qualified and I've worked more or less ever since

Interview Physio 01

For many nurses the roles of practice or specialist nursing offered more autonomy than general nursing, but for some GPs their role had been chosen as they did not have great ambitions to reach the top of the medical profession.

On analysis of the data it was also apparent that there were similarities and differences in the way professionals described their own role. The consultants, nurse specialists and physiotherapists more commonly spoke in terms of educating and supporting the patient, whereas GPs and practice nurses regarded information giving and helping patients to evaluate information as key aspects of their roles. GPs specifically articulated that assessment, diagnosis and subsequent treatment recommendations were their key skills:

...make a diagnosis, find out what's wrong with them and then to really release them into the world to go and decide what treatments they want to do

Interview GPM12

All the doctors described themselves as risk takers and decision makers particularly when compared to other professional groups:

...my expertise if I had any, is er, is as a risk taker really. Sizing up what risks you can safely take and em, where you can't get away with it and er, need to be a bit more rigorous em, 'cos in a day, well necessity, you're always making decisions and taking risks. Em, if you weren't willing to take any risks then you're in the wrong job basically

Interview GPM11

Physiotherapists and general nurses were more likely to speak of strategies to facilitate compliance as part of their role:

...if somebody doesn't comply then you, you keep telling them of the importance of complying with the exercise programme and, and em what to do and what not to do because if you, you actually sometimes you actually have to tell them the worst case scenario

Interview Physio 02

Interestingly it was only the nurse specialists and female consultant (02) who described their role as knowing the patient as a person, but only the former linked this with intuitive skills:

I'd learned at the beginning that you actually don't worry about the little things about the diabetes initially, build up a relationship with

them... you need to know more about the background. Get to know the patients family, get to know just little bits...

Some of them feel I may be a bit of a school teacher type which I find a bit embarrassing and I don't, I don't intend to but I think it develops. I will develop a school teacher type to that person who sort of, er and then I'll develop the other personality with somebody who's actually, I don't know, I don't know how you do it but you do

Interview Nurse Specialist 02

Whilst some professionals, particularly the general nurses appeared to have difficulty in describing their own role, this reticence dissolved when describing their perceptions of other professionals. Nurses and physiotherapists were more likely to speak negatively about doctors and these descriptors matched closely to patients' notions of a bad professional (5.3.6).

...doctors are not very good at giving up their power, and they're not very good at seeing things from other people's viewpoint, yes they listen, but they don't always hear what someone is saying about how they feel, how the illness affects them

Nurse Focus Group

Whilst nurse specialists also had a tendency at labelling doctors as poor listeners they were likely to link this to how busy the doctor was which fitted with one consultant's view that these nurses' role was to deal with the time consuming patient. Consultants tended to describe nurse specialists in positive terms but within the parameters that the nurse knew and kept to their boundaries as a care manager rather than diagnostician. There was far less regard from doctors regarding general nurses and again these negative descriptors matched patients' notions of a bad professional:

...they (nurses) really want to know exactly what's happening and they really don't like the patients to do their own thing at all and they really have issues with it... probably now it's kind of gone the other way whereas I think probably years ago it was probably vice-versa, you know the Doctors and Nurses whereas I think the Doctors, I mean

personally I would say I'm a lot more relaxed and I'm a lot more willing to allow patients to make their own choice

Interview GPF10

However, the majority of doctors were keen to link the descriptor of an over controlling nurse to their training and the nursing culture:

...their training doesn't cover that so it, whereas we are trained to make decisions and trained to stand by those decisions. That's not really a part of general nursing code so it, it takes time and I think the organisation also, the nursing culture is you know, right to the top is, is bad and is against this because the em, the nursing bodies are always giving the message as 'Well you're on your own. There's nobody to support you. If you get litigation and you've done something, the Trust won't support you, your Consultant won't support you. You're on your own, you're going to be up the duff as it were

Interview Consultant 01

Interestingly, when asked what hindered their role nurses, with the exception of those who had not undertaken extended prescribing, never cited limitations of their training, but did describe their fear of litigation as a major barrier in their enablement of patient self-management:

I document everything, I know its computerised but you have to document, it's almost like covering your back and it's a bad way to practise I think...we'll get blamed for their self-management

Nurse Focus Group 2

Whilst nurses felt vulnerable from litigation because of poor support within the health organization, they also assumed that patients would be very quick to blame the professional for any errors in self-management:

You want patients, you want them to take responsibility for themselves but they're so quick to point the finger

Interview PN03

Neither doctors nor nurses described physiotherapists as having a significant role in enabling a patient's self-management. Whilst this may be understandable as the nurse specialists and consultants specialised in conditions unlikely to utilise physiotherapy skills, nevertheless bearing in mind that physiotherapists had been theoretically sampled as patients

identified them as having a key role, it was surprising that GPs, general and practice nurses did not include them when discussing self-management. Physiotherapists equally failed to link enablement of self-management with nurses and spoke in negative terms when describing doctors:

...coming in with a big list of questions is a nightmare for doctors but not for the patient, and it shouldn't be, if we're properly patient centred it shouldn't be a nightmare for professionals

Physiotherapists Focus Group 2

Lack of resources resulting in a cut back of suitable qualified nurses and increasing rationing of diagnostic tests were the most common mechanisms perceived by doctors to hinder their role. Resource rationing was also identified by physiotherapists, particularly the cut back in patient group teaching as a major barrier to their role in enabling self-management. However, these mechanisms fall more easily into the category of health and care service delivery, organization and content, and it is to this category that the thesis will now turn. As in the above sections, signposts and boulders provided by the organization and delivery of care as enabler or hindrance in the journey to being an expert patient will be highlighted.

5.4 Statutory, private & voluntary care services: Context, organization & delivery

This section will deal with two major areas. Firstly there will be an exploration of the hindering mechanisms within service delivery both in the statutory and non-statutory organizations. Secondly, the signposts or facilitative mechanisms will be presented, which whilst spanning all the sectors will also include a specific focus on mechanisms that particularly enabled self-management.

5.4.1 The NHS as “dangerous” territory

For a minority of participants, the NHS was perceived as a boulder large enough to be termed dangerous:

I said to the consultant (private) “If we hadn't got it sorted out, I'm not sure D (husband with asthma) would have survived either one” and

when I said it to the consultant he just said "He was very bad when I saw him" and we have had to always pull out of the NHS

Interview F4

However, the most common complaints regarding the NHS were more likely to be about the lack of speed in accessing non-emergency services, and as reported in 5.3.6 experiences involving perceived incompetence of health professionals. The most frequent response to unhappiness with the NHS was to access private health care, however this was not a totally problem-free event.

5.4.2 The problem with going private

With the exception of a few, the majority of patients accessing private care were uninsured and spent at the very least the amount of money they would normally allocate to holidays. For some it was simply not worth the money but the major issue for many of the participants was the moral dilemma of accessing private care. This appeared to congruent with the moral ethic of citizenship described in 5.2.5 and caused some dissonance for some:

I don't really believe in private medicine in terms of jumping the queue, which I did, ... I still think it's an unfair advantage over people that really do need operations. I mean we could afford it, you know, I'm not saying we couldn't but I just don't think it's right and not that we're socialists or anything like that

Interview F6

It was not only private health care that was sometimes viewed as immoral as there were also concerns stated regarding the ethics of voluntary support groups.

5.4.3 Latching on to you: The problems with support groups

Whilst the vast majority of participants were very positive about the value of support groups there were a minority who were concerned that these organizations tended to latch on to people simply to access money, and that meetings were attended by too many negative individuals to be of any use:

I think this is the trouble if you've got something wrong with you and these Societies and that, they latch onto you because you're a source of

income aren't you? You know I know they need to get the income but, as soon as they know you've got something, you're pestered and it's money they're after

Interview M5

I'm going to be really catty and say there's sometimes a meridian of them going on and on and on 'cos I think they take health much more seriously, or their own health

Interview F14

However, whilst patients did identify a number of hindering mechanisms there was an overall tendency to link these with constructive suggestions for improving service delivery.

5.4.4 Suggestions for improvement – the patient viewpoint

Patients' suggestions for improving services ranged from simple practical measures such as providing better parking facilities at hospitals to more philosophical notions such as the promotion of holistic individualised care. A voucher system which could be used to access statutory, private and complementary services was one suggestion for the latter. Time was a major focus of suggestions, particularly the need to cut waiting times and to be given more time for OPAs. Training to improve professionals' interpersonal and clinical skills was also suggested with the latter seen as particularly needed with the shift to primary care:

I'd be happier going to someone who I know is a specialist in that particular field or that area whereas I can say the G.P. fair enough they're good enough at what they do but they've gotta know a lot about everything and you can't possibly, if you have to know lots about everything, you can't possibly be on the ball one hundred percent, up-to-date on every single thing that's going on on every single condition 'cos you'd be a robot if you were that

Interview F5

Patients were far happier with primary care if they felt the GP or Practice Nurse had extra training in the relevant long term condition.

Communication between sectors was also identified as an area for improvement, patient-held records and an email system which included the

patient were suggested as possible mechanisms for this. Psychological support was perceived as needing much development. For example, people who had undergone cardiac surgery identified the gap between discharge and the commencement of cardiac rehabilitation as a period which needed but lacked psychological support from health professionals. Indeed, the whole area of improving patient support was also recognised by professionals as a focus for improvement.

5.4.5 Suggestions for improvement – the professionals' viewpoint

Consultants were particularly keen to enable more support via such mechanisms as telephone support services and opening up direct access for patients to secondary care. However, whilst the doctors were willing for patients to be able to directly self re-refer they felt it unlikely that Trust bureaucracy would sanction this:

I see patients in the clinic and I know that I'm only bringing them back because if I discharge them, they won't be able to get back in and I know that if I had a little card and the nurse's telephone number and I had the money to set up a little nurse helpline, I could really discharge masses of patients. Um, that would be so cheap and cheerful to do. Then I could fill up my clinics with new patients and just see the follow-ups when they needed. And the other thing is we have stupid bureaucratic systems whereby if it's longer, a patient with psoriasis is longer than six months, they have to be re-referred with a GP letter. Daft. Why aren't we joining everything up and then if it's longer than six months, they have to be re-referred with a GP letter and we can't put them straight onto the nurse led clinic until we've got that letter. All bureaucracy. Patients who are sensible with psoriasis should be able to ring in, talk to or be seen

Interview consultant 02

Increasing access by walk-in and Saturday clinics was suggested by both the doctors and nurse specialists, with practice nurses also proposing that patient education sessions should be held at times which would fit with peoples working lives. In tandem with the patients' views was also the suggestion from nurse specialists and physiotherapists that specialist services should be more

available in primary care by increasing domiciliary visits. Improving integration between primary and secondary care was recognised as a need by GPs and nurse specialists, but it was only the latter and the female consultant who specifically suggested improving psychological support for patients. So far this section has reported boulders within service delivery on the journey towards being an expert patient, and has described some of the patients' and professionals' suggestions for reducing these. However, as with their views on professionals, patients were far more likely to describe the positive or signposts of service delivery, and it is to these that this section now moves.

5.4.6 Always there or speed & ease? The case for the NHS and private care

The NHS was seen by some patients as all that is needed and providing constant reassurance. However, the majority of patients would either identify its particular strengths as supplying safe emergency care or dealing with life threatening disease, or in the case of people with heart conditions being better placed as providing longer term rehabilitation:

...if you go private you might have the same doctor but you don't know anything about rehabilitation, what you're supposed to do...

Heart focus group

People who had used private health care were more likely to talk at length regarding the positive aspects which were a direct mirror image of the perceived shortfalls of the NHS and its health professionals. In particular speed of access, length of time at OPAs, an increased sense of control over the situation and the competence both in clinical and interpersonal skills of the professionals were identified as the key positive features:

...well we are private, but he (consultant) said there's no reason for you to see me privately at the hospital, and so we did it once and never again! Well, it's not as if we are going regularly, once or twice a year I think is well worth the money, cos everyone says you never, ever see the same doctor, the waiting is horrendous, and we saw a young woman... and we had already been waiting for 2 ½ hours

Parkinson's Disease focus group

Whilst patients identified the positive aspects of both statutory and private health care, it was the voluntary sector that was most frequently identified as a helpful mechanism on the road to being an expert patient.

5.4.7 Support groups – being understood

Support groups were described by some respondents as the only place where they felt understood and it provided a family-like feel:

...when I went there I thought 'Oh I'm not gonna like this, it's cliquey' because everybody knew each other and everybody was asking about each other's children and things like that. I thought 'Oh I don't know. I don't know anyone' but within a couple of weeks, they're so friendly...

It is like a family and if someone goes missing, everyone's worried

Interview F8

However, people not only valued their group for the emotional support but also identified it as the greatest provider of information via other members, formal presentations and the organization's own written material. This information was seen as vital in not only helping people to get over the shock of diagnosis but also to find out what were normal experiences of the condition, and to provide a checking mechanism for possible professional bad practice. Support groups were also identified as having a macro influence through fundraising activities for research and new treatments, and by raising the profile of the perceived "less glamorous" conditions such as arthritis. However, one of the major outcome for individuals attending these groups was awareness-raising about self-help and an encouragement to explore complementary and alternative medicine (CAM).

5.4.8 When all else fails – the case for CAM

Whilst a few participants had used CAM as a philosophical preference to conventional medicine, the majority of users had accessed it as a perceived quick fix or because conventional treatments had offered little. Although people with chronic back pain identified positive health outcomes from CAM the majority of users described the relationship with and knowledge of the CAM practitioner as a major attraction:

...this girl (Alexander Technique practitioner) is quite um sympathetic. I'm more inclined to her because I know she works in hospices and things like that, her attitude is one of caring

Interview F14

...he (osteopath) was extremely helpful and er, em it was quite different treatment to how I expected but I did feel that he knew something at his fingers of what was wrong with my back which I thought, of all the consultants and their high faluting status, I don't think any of them have really got down to the nitty gritty of what was actually going on in my spine.

Interview F3

The above quotes illustrate the mirror image of CAM in relation to the perceived weaknesses of conventional practitioners regarding their interpersonal skills and clinical competence. However, respondents did have reservations about CAM itself, particularly the safety of unregistered practitioners, the lack of an evidence base, the cost, and again highlighting the moral ethic, CAM being perceived as self-indulgent. Patients were also likely to identify one characteristic of a good doctor as being open to the possibilities of CAM and whilst the doctors within this study stated they had no problem with it many patients reported that they actively chose not to discuss their use of CAM with their GP or consultant to avoid disapproval. Whilst physiotherapists had mixed feelings about CAM ranging from seeing it as a patient right to concerns regarding the evidence base, overwhelmingly the nurses had worries about the latter, and as discussed in 5.3.8 this was linked to concerns regarding litigation:

...without the evidence I don't believe in a jar of honey to manage the condition and needing a jar of honey to apply it...(honey for wounds) I probably would never have initiated it and I'd be worried about and if I hadn't got the research, reliable research I'd be worried about the litigation side of it.

Interview PN02

For many patients, CAM was an integral part of their self-management but as seen by the above quote nurses in particular were very reluctant to sanction this as legitimate. This section will now move on to look at mechanisms

specifically designed for the development of self-management strategies and will report findings to illustrate how these mechanisms did enhance or in some cases inhibit the development of self-management skills.

5.4.9 Enhancing self-management – what helps and what does not

As discussed previously, expert patients were motivated to self-manage by a realisation that as time was so limited with professionals it was an essential activity, and a comprehension that it worked for them. Whilst nurse specialists and physiotherapists were likely to mention patient education groups the majority of professionals perceived enhancing self-management skills as a one to one activity between professional and patient. During the observation of clinics it was noted that both doctors and nurses utilised written information such as an explanatory sheet on what HbA1c is, or providing specific tools such as real-size photos for patients with atypical mole syndrome. Doctors tended to give one to three key messages and used long-term prognosis as a motivation strategy whilst the nurses used more active teaching approaches such as the use of metaphors and planned, small steps in teaching the patient:

NS01M02 a very sad looking man whose wife had died recently. He had type 2 diabetes but was not controlled and so had been put on insulin a year ago. He has gradually improved his control but had no conception of how a proposed long-haul holiday may affect his control.
NS01 facilitative, kind, lots of eye contact, explaining to him in short sentences and checking out his understanding. After he had left NS01
“this chap needs to be drip-fed information slowly”

Nurse Specialist 01 Clinic Observation Fieldnotes

Patients rarely mentioned any experiences of being taught by a professional on a one to one basis, however the one exception appeared to be encounters with physiotherapists:

A couple of weeks ago I trapped a nerve so she said “Well, I won’t interfere with you this week”. She went and got a model skeleton, wheeled it over, showed me what I’d done, very helpful.

Interview F8

As stated earlier, physiotherapists and nurse specialists clearly linked condition specific group education to the enhancement of self-management and one such programme – the Back Fitness course was observed as part of this study. However, none of the professionals in the study could describe the Department of Health’s flagship self-management programme or had suggested to any patient that they could access the EPP. The remainder of this section will now present the findings on group self-management courses, comparing and contrasting professional-led and lay-led programmes. The content of the Back Fitness Course (BFC) and EPP were similar in many ways (see appendix 26 for full content). Both used weekly goal planning as a tool and both had a content that covered stress management, relaxation and management of pain, however the EPP also covered a number of other topics. In addition whilst the EPP comprised of 6 sessions, the BFC was made up of 8 and therefore the depth was more but breadth of topics less in the latter. Whilst the lack of depth impacted on the superficiality of the EPP, the depth of the BFC was not always facilitative of lay understanding:

Session 5

The bulk of the session was on depression and how to manage it.

Several things arose for me –

1. I realised that I had never suffered with depression – particularly obvious as 2 participants’ LTC was clinical depression.
2. Whilst the differences between feeling low and depression were acknowledged it was all dealt with at such a superficial level with no opportunity to explore differences between reactive and clinical depression it simply did not feel as if it was working
3. The participants affected by clinical depression appeared to feel that they had to reinforce this difference to the group but the response from others was that it was all about “*turning your life around*”, and they rather preached at the 2 with clinical depression
4. The conflict this engendered was dealt with the lay tutors by an acknowledgment both of the different types of depression and the inadequacy of the teaching material to deal with this.

Observation EPP reflective diary

Session 5 – what is pain?

In depth information given on gate theory. One participant (nurse) appeared to make great effort in demonstrating her knowledge to the rest of the group, but the level and depth of knowledge did not appear to make any sense to the rest of the group, one person commenting “*do we really need to know this?*”

Observation BFC reflective diary

Because of the range of topics covered in the EPP, participants also described how it felt too rushed:

It was very very squashed together and a lot of the more elderly people, I should imagine, had trouble taking it in

Interview M4

Another significant difference between the courses was that whilst the BFC’s participants had similar conditions, the EPP as a generic programme had people affected by a range of LTCs. Being able to share experiences of back pain was important for the BFC participants whilst the generic nature of the EPP had the potential to create a competitive culture of whose condition was “*worse*”. However, the majority of EPP participants felt that the generic nature could be a strength through sharing common experiences irrespective of the condition and learning about other health issues:

...a lot of different age ranges, em, different medical conditions, er, different walks of life but we all got on well because we’re all in the same boat. We seemed to just click

Interview M4

The referral system was also different between the programmes. Participants for the BFC were referred by their physiotherapist or orthopaedic surgeon whilst the underlying philosophy of the EPP results in self-referral being the preferred option. This appeared to directly impact on participants’ commitment to the programme with the BFC significantly affected by sporadic attendance and less active participation in group activities:

The majority of the group were silent. There was no group discussion and there did not appear to be the same onus on participants to fully engage with the process when compared to the EPP.

Observation BFC reflective diary

However, participants appeared to develop similar informal roles in both programmes, both had male “comics” who attempted to inject humour into the sessions, very quiet members who whilst giving the content their full attention did not verbally participate significantly, garrulous ones who tended to dominate the discussion, and people who responded negatively to the exercises and suggestions. These latter participants appeared to have a direct impact on programme outcomes, particularly in the EPP. Their negativity regarding the possibility of improving their situation tended to pervade the group and denigrate any potential feel-good factor:

...they were spilling out their problems to us and I was taking them on and feeling sad and I felt worse and I'm thinking 'I don't want ... I've got enough things going on with me - I don't need to think about other people's problems as well.

Interview F2

These people also caused problems for the lay tutors and were their heart sink participants:

The person that doesn't seem to want to be there, doesn't see the good in what everyone else is saying and then tries to pick up the negative things. They will never say "Oh yeh, I hadn't thought of that, I'll try that". It's always "That won't possibly work". Very defensive I think. Negative and defensive

Interview T2

Whilst the negative impact of these people was significant, so too was the potentially positive impact of the group facilitator. The BFC observed was led by a psychologist experienced in facilitating groups. Her facilitation skills and subject knowledge was significantly greater than the EPP lay tutors and yet this appeared to be negated by the participants' perception of her lack of credibility:

I walked behind a couple of participants as they left the session. They were clearly a little disgruntled about the material regarding the psychological element of pain and I overheard them say *“well, it’s alright for her to say that but she doesn’t have to live with a bad back”*

Observation BFC reflective diary

In contrast whilst the lay tutors had comparatively poor teaching skills and read the course material verbatim, their credibility as someone with a LTC themselves outweighed this:

The last session and everyone was asked to evaluate the course. A. states that for him the best thing was the tutors *“ at last we weren’t being talked at by professionals, at last someone who really knew what it was all about was there”*

Observation EPP reflective diary

The outcomes of the two courses varied considerably. Participants on the BFC developed knowledge about back pain and learnt specific practical strategies to alleviate it, with the input of the Fitness Trainer and the gymnasium work seen as the main strength of the programme. Whilst the EPP did develop some practical strategies, particularly relaxation techniques, outcomes were more of a psychosocial nature when compared with the BFC. The reduction of a sense of stigma was identified by many as an outcome and integral to this was validation of their illness experience:

...I think knowing that my fatigue wasn’t laziness

Interview F13

Some reported improvement in their confidence when dealing with doctors, but equally this was tempered by a perceived lack of change in the way professionals responded to them. For many participants reduction of a sense of isolation was the main outcome, however this was negated if there was no ongoing support after the completion of the course:

...what are we going to do after and er, I think we’d been sort of left out on a limb

Interview F3

Ultimately the EPP had the potential to inspire people and spur them on to further action such as information seeking or joining a support group. This potentiality was reduced if the impact of negative members was too great, however when compared to the BFC sustainability of self-management behaviours appeared stronger via the mechanism of the EPP:

If we don't do it, nobody else is going to' and it's giving you back that control which you feel so out of control...you feel completely lost with what you're supposed to do and suddenly you're in this room (EPP venue) and you start feeling confident that 'Yeh, it's up to me and I can make this decision. Yes, what works for me is the best thing to do'

Interview T1

Thus it would appear that the EPP and the practical elements of the BFC could provide signposts on the journey towards being an expert patient. Whilst professionals often felt they were providing signposts and the observation data suggesting that they did actively employ strategies for this, it was more likely that respondents would identify other sources as their main guide towards self-management.

This chapter will now move onto the findings illustrating the journey terrain – the experience and nature of chronic illness.

5.5 The nature and experience of chronic illness

This section will present the data illustrating the experience of living with a LTC. The majority of narratives started with the pre-diagnosis phase and diagnosis event and this will be reported first. The effect on life and metaphorical imagery used to describe this will then be conveyed, and the section will be completed by the narration of acceptance, view of the future and the strategies people develop to live with the condition.

5.5.1 Achieving a diagnosis; shock, relief & validation

Getting a diagnosis was an achievement for many as often respondents had spent years of visiting the GP with signs and symptoms only to be told there

was nothing wrong with them. For many this period was described as the worse:

...it was pretty horrible because all the time that they were doing the tests, they kept saying to me "Oh yes, we're doing this but we don't think you've got that", "But we don't think you've got that", they kept saying that

Interview F15

Diagnosis was seen as a vital event because it validated the individual's belief that something was wrong with their body. Nevertheless there were mixed reactions to the diagnosis. For some the diagnosis was expected either because they had worked it out themselves or knew people or family with the condition, often there was associated frustration that doctors had refuted their suggestions that this could be the diagnosis:

I had a draggy leg and well it just got me down really. Anyway I went to the doctor, er, and I said to him "I'm thinking of MS" and he said "Oh no, no, no"

Interview F7

However for others the diagnosis came as a complete shock although this was more likely to be the case in conditions where there was an acute onset of symptoms such as heart disease. For those with a longer onset although the diagnosis was often a shock it also often bought a sense of relief by not being what they feared most, and for the majority of people this was cancer:

...the tragic thing for me was I was put in a bed next to a nice girl my age who had a brain tumour and was going to be operated on three days hence. And she had the same symptoms as me and my father had died of a brain tumour at forty five when I was nine, so putting two and two together and making twenty, I thought 'Well this is it. I'm dying. I've got a brain tumour'...

'It's something very similar to multiple sclerosis' and it was such a relief I thought 'Oh'. I could have kissed him. I said "Do you die?" I didn't know anything about multiple sclerosis. I said "Is it fatal multiple sclerosis?" "Oh no, no, no, people go on for years"

Interview F8

The majority of patients described communication of the diagnosis by the professionals at the very least poorly given or “*diabolical*”. There were some respondents who had initially been misdiagnosed and a few still had not received a diagnosis:

...they still can't find anything, er, so basically at the moment I'm being shunted from pillar to post, trying to find out what's actually causing the pain

Interview M4

Any relief regarding the diagnosis was often followed by slump in emotion and a phase of anger and denial. Reaching an acceptance of the diagnosis needed time and also appeared linked to the level of validation it bought and type of illness. Examples of the latter included people with heart disease not perceiving their condition as long-term but totally curable with surgery, and this idea of increased acceptability of conditions amenable to surgical intervention rather than long-term drug therapy was articulated by many:

...the diabetes, that's the next biggest thing in my life I suppose, em, it's not as, it's not as acceptable as the cancer because you're never gonna get rid of this whereas I do, touch wood, hope that I've got rid of the cancer

Interview F9

5.5.2 More than just an illness; the effect on life

The impact of a LTC varied between respondents but at the very least would have some impact on their life plans. For many the loss of spontaneity meant that the condition became a prison, shackling them to home or the medication regimen. This was recognised by the nurse specialists who described diabetes as a complex mathematical equation that patients spent most of their life concentrating upon. Whilst many respondents spoke of their experience of the condition as a journey, this journey had often been unpredictable and intermittent. For some the condition had been silent, creeping up upon them, for others it was a living nightmare:

...so it's just been an absolute honest nightmare. I mean I've had fifteen years of my life has just been totally, I've had no quality of life you know, it's just been absolutely awful

Interview F16

Managing the condition was recognised by the majority as hard work but the reward for the effort might be some sense of control, this was seen as key as the majority most feared their condition as out of control.

The bulk of the respondents articulated some sense of stigma arising from their condition. For some this arose out of the effect the disease was having on their body:

I find it very difficult at the check-out and somebody pushing a trolley, I can't say I'm sorry I've got Parkinsons, I just say I'm sorry I'm very slow, and I keep thinking I should say I've got Parkinsons because that's the only way people will know how it affects you

Parkinson's Disease Focus Group

For others the stigma arose from the perception that they were being labelled by others. For example, participants affected by arthritis or osteoporosis felt labelled as old before their time, whilst those living with ME described being identified as depressive.

Closely associated with the stigmatizing effect of having a LTC was a sense of losing rights. This ranged from loss of privacy:

"Oh hello" she said "I've been doing your job for a week, you've been on holiday haven't you?" ... "You've got MS haven't you? My mother died of that" ...and that's the only time I've lost my temper, I went into my boss and everybody was scared stiff of my boss, but I wasn't. I went in, shut the door and said very quietly "Please, I would appreciate it if you would not discuss my personal life and health with your hired help..."

Interview F8

to being refused surgery because of the condition, or practical issues such as the impossibility of getting travel insurance. However, counterbalancing this loss of rights was a sense of elevated moral status which often off set the stigmatizing effect:

...not even any of the five years have I thought "Why me?". I've just thought well I've got it and that's ... you know and of course every time you read a book and it always says in there it says the first

question people say is "Why me?" and I thought "Well, I never did say that, I never did"

...when friends phone up they say "how are you?" I say "I'm fine" you know. I could be sitting at home 'cos I can't move ... and the same with my Mum because I don't want to worry, I don't wanna to worry my Mum

Interview F2

Respondents sometimes articulated a sense of being punished by professionals and being seen as too much hard work.

Unsurprisingly, many effects on life were bought about by the symptoms of the condition and whilst these obviously varied fatigue, pain and loss of mobility appeared to have the most significant impact. Common to all LTCs was the relationship people had with medication. For some it was just part of life and the least of their concerns, for others there was a real fear of taking medication

I keep on having these bouts of sickness don't I? And I think one lot of pills are fighting against the other.

Interview F1

For some groups of patients medication had become a focus of their life. For example, those affected by Parkinson's Disease described the skills needed in balancing all the medications and how vital medication was:

F *I think sometimes they will try something just to see what happens and you get a reaction, cos they said to me you should have To stop the pain in my arm, and/*

M *well mine you see was for burning feet/*

F *well, they do use amitriptyline as a pain control drug/*

M *it also played havoc with my mouth and had a dreadful experience, and bits coming off my tongue, and a dirty taste*

M *from the amitriptyline?*

M *and err, I reduced it myself and I got, and didn't take it any further, the other symptoms kind of died off, it's a tightrope!*

Parkinson's Disease Focus Group

he gave me a pump and that made an enormous difference, got rid of the peaks and troughs and it was a steady input, a steady flow of the amber nectar to keep me going and I've been on that since then

Parkinson's Disease Focus Group

5.5.3 No answers – the reaction to incurability

Although dealt with more fully in 5.6.1, at this point it should be highlighted that one consequence of living with a LTC was the emotional responses it brought. Feelings such as anxiety, anger and depression were not only a reaction to the impact the diagnosis and condition had on peoples' lives, but also as a result of the feeling that there were no answers. This sense of no answers was compounded when there was very little ameliorating treatment available such as in MS, or professionals were found to give conflicting advice. Whilst the outcome was often negative emotion it could also result in a stoical reaction; *"just put up and get on"*.

5.5.4 What will happen to me? Fear of the future and how it was dealt with

All participants described going through a period of anxiety regarding the future and how they would cope with deteriorating health. For some, especially those with Parkinson's Disease, rheumatoid arthritis and MS, this was an ever present fear:

...how bad is it going to get?

Interview F2

For others, such as those with diabetes or coronary heart disease there was a sense that once the condition was under control, either through medication or surgery, the condition should be forgotten and life should be got on with. As described earlier, the reaction of those affected by CHD was different to others as they perceived themselves as cured despite long-term drug therapy:

I did have trouble getting travel insurance ,but I eventually persuaded them that I'm cured and, they cover me for anything

Heart Focus Group

Whilst incurability was accepted by the majority of the other participants there was little sense of giving in to the disease. Many actively sought to try a variety of treatments which as described in 5.4.8 often involved CAM. One

other key strategy to maintain a feeling of hope was to always say yes to participating in treatment research and consequently there was a preference for being under the care of a specialist centre:

...I thought 'Well if there is any clinical trial or a cure, at least they've got my name'

Interview F8

This section has described the experience and nature of chronic illness – the terrain of the journey towards becoming an expert patient. The section concluded with an overview of people's responses to living with a LTC. As these responses form an integral part of the core category they will now be explored further.

5.6 The core category: culturally gendered context & responses

During the analysis of the data and development of categories a pattern began to emerge. Whilst this pattern was the framework of the metaphorical journey described in 5.1, it also provided the gestaltic image of the expert patient. Both patient and professional behaviours fitted this pattern and organizational structure and context was illuminated by it. This pattern has three main features; emotion, culture and gender. Although the underlying sources of the pattern are explored in depth in the next chapter it is pertinent to explain here that these three aspects intertwine to produce a particular way of thinking, responding and organizing services that are characterized by concepts of masculinity or femininity. Thus within the development of the core category gender is not defined as a biological concept but a cultural code (Gilligan, 1982).

To follow on from the previous section there will first be an illustration of how emotional consequences of chronic illness fitted this pattern. The section will move on to report how the core category was revealed in the professional-patient relationship and the shaping of service responses. Finally there will be an exploration of how an expert patient adapted their behaviour to fit with this pattern. The section will conclude by linking these findings together in a coherent whole providing the basis for theory development.

5.6.1 Emotional consequences of chronic illness

As described in 5.5.1 for the majority of patients the pre-diagnosis phase was a traumatic time. The “not knowing what was wrong” period brought three major concerns. Firstly there was anxiety of potential suffering from a pathology that would rapidly and significantly reduce life-span. However, for many the pre-diagnosis phase was particularly stressful because the uncertainty resulted in feelings of not being taken seriously. The longer this period went on the stronger the sense of a loss of respect from the professional:

At first he (GP) pulled out all the stops. Everything was fine, he was very very helpful... That seems to have died down a bit now, in fact he, in the last three months he's sent me to a Psychologist to see if it's all in my mind and the Psychologist said "Well why the hell has he sent you here? I can't understand that" and she wrote him back a nasty letter saying 'What are you doing wasting our time?'

Interview M4

Thirdly, the uncertainty brought frustration in not being able to take action or plan ahead. In order to speed up the process of diagnosis some patients would resort to using emotion to underline to the professional their sense of desperation:

I said I thought I was stressed and he (GP) said "You're not stressed" because I don't probably give the impression that I am you know. I'm not one to go in tears and, and you know, I sort of swallow them down if it's anything really and, and so he didn't really realise that until this, this you know and then he suddenly realised that, what it was like...

Interview F10

Once diagnosed this frustration would continue and build up if there was a perceived lack of appropriate management of the condition:

And there was no tablets or anything like that you could take and I can't get any advice from ... see I have a Miss P.... who is a general surgeon, she was going to operate but she went on holiday so I went into hospital. I spent a fortnight in hospital, she'd already gone on holiday and I didn't have any treatment except in the bed rest.

Interview M2

Emotional responses triggered by the effect the LTC had on a person's life are described in 5.5.2, however particularly pertinent to the core category was the effect the condition had on roles such as being the main income provider or being a wife. Interestingly only women respondents shared how the condition had impacted on their relationships with several recounting painful divorces or at the very least unsupportive husbands:

R If you had one message you wanted me to take away about living with a long-term illness, condition, whatever you want to call it and how people can be helped with that, what do you think's the key thing?

P I think it's persuading your partner that you need help

Interview F13

None of the female respondents articulated any impact of the condition on their role as a mother, however many had gone against medical advice in starting a family and felt that they had to appear a *super mum* in order to counteract any criticism of their choice to have children:

I always was showered and dressed when the midwife came and I didn't want her to think 'Oh, not coping, got MS'. When my best friend's had babies later, I was amazed to go round there in the evenings to find them still smelly, still in their dressing gowns, not done a thing all day and just laying there moaning

Interview F8

For respondents who continued to be in a stable relationship it was noticeable that they appeared to have joint ownership of the condition and were both actively involved in its management. This is exemplified in the following quote from the wife of a person affected by PD:

Well, we see our GPs are very responsive to our suggestions we make but of course we wouldn't know in this example whether he would have heard of Botox injections or such things but I mean his mentality seems to be quite willing that he would refer us to a consultant, whatever, he's not an obstacle in the way, he's generally willing to try and be helpful, so we're content with him in that respect

Parkinson's Disease Focus Group

For many of the male patients concerns centred on being able to continue in employment. This was a particular issue for those in non-professional jobs

PN2M4 53 year old male with CHD. He was very angry as the DVLC had removed his bus drivers licence following diagnosis of a stroke. *“I know it wasn't a stroke, it was a bad migraine, I've had them for years”*

Practice Nurse 02 Clinic Observation Fieldnotes

However, many professionals had managed to adapt their work patterns to accommodate the condition:

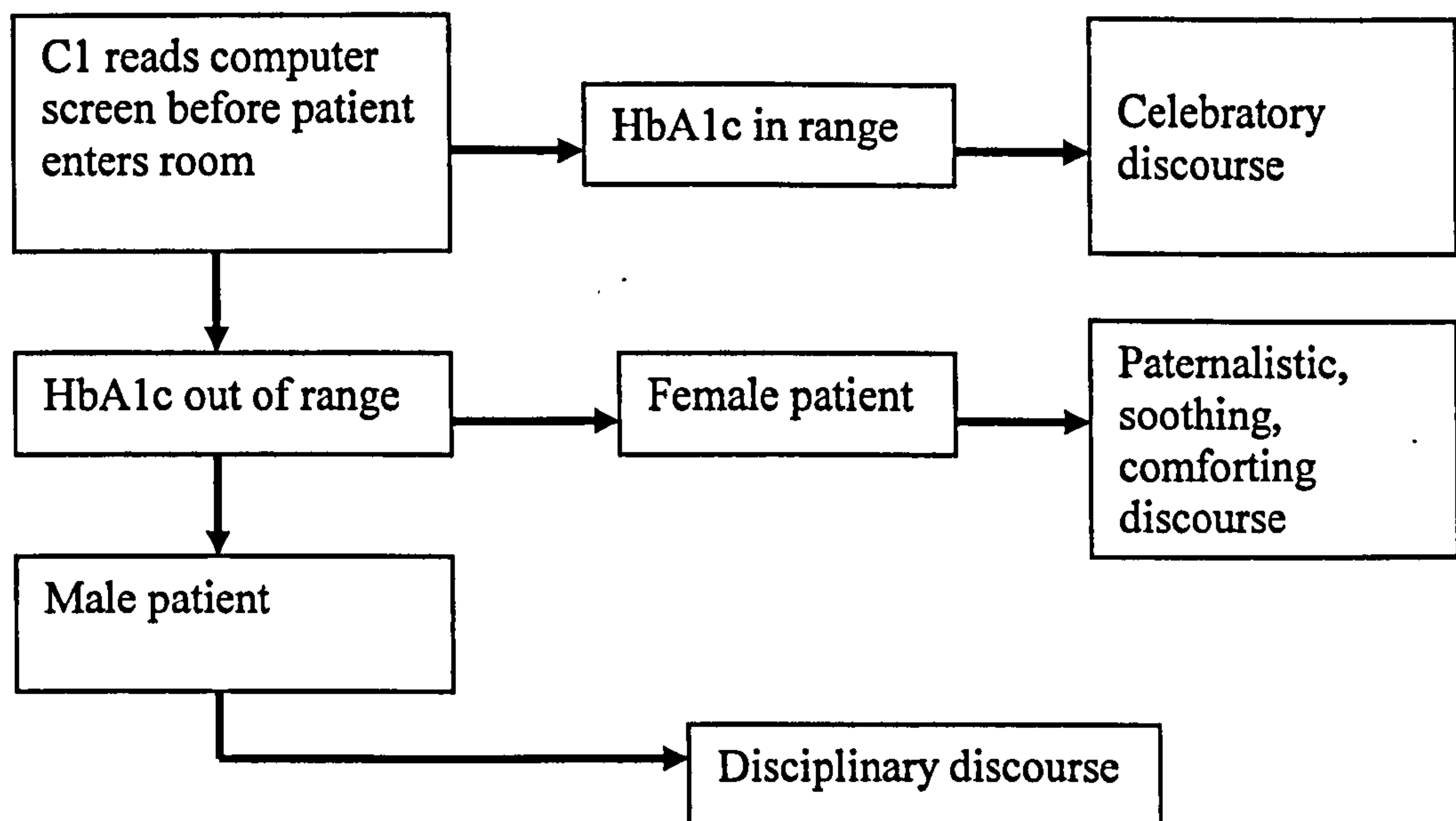
...the left leg was dragging, I didn't drive anymore and I hired a chauffeur and he ferried me around all over the place

Parkinson's Disease Focus Group

Whilst the emotional consequences of the condition were influenced by its trajectory, support of significant others and impact on employment, it was also linked to the nature of the relationship between patient and professional.

5.6.2 Cultural gendering of the professional-patient relationship

The relationship that was most overtly framed by gender was the one between consultant 01 and his patients. During the observation period it was noticeable that he was more likely to use a disciplinary discourse with male patients, with a more comforting tone used with female patients throughout the age range who appeared with a very similar biochemistry profile to their male counterparts. However, when interviewed he did not articulate this as a conscious strategy but referred to the impact, for example, pregnancy may have on diabetes. Thus with consultant 01 a clear pattern could be predicted in most cases as to the framing of the consultation (figure 16).



Consultant 01 pattern of consultation discourse

Figure 16

There was one negative case to this pattern:

C1OPM18 a 32 year old white male lawyer, enters the consultation room wearing a club rugby shirt and looking cheerful. He had not had any blood tests done nor had he brought his diary with him. C1 “*bad boy!*” jokingly. There is none of the usual telling-off, instead they enter into a friendly banter about rugby.

Consultant 01 Clinic Observation Fieldnotes

It appears in this consultation that the usual response was negated by social class and a commonality between professional and patient.

Whilst physical measurements were likely to influence the consultation between all professionals and patients, the nurses also appeared to have a certain pattern in their responses. However, unlike consultant 01 this was less likely to be framed by a physical measurement and more by perceptions of patient vulnerability. Thus if patients were perceived to be in need of being *looked after* the nurses appeared able to enter into a more natural response with increased use of non-verbal communication and therapeutic touch. Whilst independent patients were listened to, nurses seemed less relaxed in posture or allowing silence. This was consistent with the interview and focus group data which indicated the majority of nurses’ unease with active patients. There was

also congruity between the observation and interview data of nurse specialists whose articulated ease with expert patients appeared confirmed by their consistency of behaviour to different patients, this was also the case with consultant 02.

Patient and professional definitions of a good relationship were often defined differently. For the majority of professionals it was identified as one of mutual respect (5.3.1), whereas many patients described it as a caring relationship which encapsulated the ability to reduce emotional distress (5.3.7).

Unfortunately, as indicated in 5.3.6 many patients had experienced a lack of emotional support:

I started to cry in the surgery, he (GP) said "I always thought you were such a, you know, someone with common sense, I didn't know you got upset like this" and put me on tranquillisers...

Interview F3

However, as will be discussed in 5.6.4, the relationship had been reframed by the majority of expert patients. The findings also suggest that this cultural gendering extended beyond the professional-patient relationship and permeated service organization and delivery.

5.6.3 Cultural gendering of services

The NHS services that provided the backdrop to this study revealed a number of gendered characteristics. Firstly, the vast majority of nurse respondents felt relatively powerless within the organization resulting in feelings of vulnerability, and an inability to facilitate patient self-management:

we've even tried to get our GP's to let us wear ordinary clothes, we are a health centre for 20,000 people and 1 practice allows their nurse to wear ordinary clothes, but our side, oh no and it's purely a medical, GP line, you are nurses and you, you will be seen as such

Nurse Focus Group 2

... my consultant would have a heart attack on the spot if a patient said I'm going to use this (self-monitoring)

R Right, so what are the reasons he wouldn't do it?

G Well, he doesn't have to justify himself

R *Well what do you think?*

G *Um, I think the reason he gives is safety. Yeah, that's the only argument I have ever got from him...*

Nurse Focus Group 1

As illustrated in 5.3.8 there appeared a direct correlation with perceived sense of professional autonomy and feelings of ease with self-managing patients. Patients too often felt powerless within the NHS environment:

...it was very upsetting actually and very difficult to try and repeat it back to somebody. I mean I can talk to you easy but it's so difficult to talk to the medics...to say "Look I think they've actually damaged me". They think they're, you know they think I'm neurotic or something...

Interview F3

Patients felt powerless too because of a sense of not meeting certain criteria and therefore denied new treatments or surgery. Whilst physical status was often cited several older patients felt discriminated against particularly when refused access to a drug trial because of their age. In order to regain some sense of control many patients opted for private care (5.4.6) or would pay for new drugs privately.

In direct contrast to the NHS services so far described was the cultural gendering of voluntary services. Patient led groups such as support groups and the EPP often provided an antithesis to the service experienced elsewhere. In particular support groups provided a sense of connectedness and emotional support (5.4.7). Accessing such groups was one strategy expert patients used to ameliorate the consequences of experiencing culturally gendered statutory services and professionals. However, this was not their sole strategy and the other ways they adapted to this pattern will now be reported.

5.6.4 Adapting to the pattern – the case of the expert patient

As described above, expert patients did not expect to receive emotional support from doctors and this appeared to result from their identification of the relationship as one of mutual respect and partnership, echoing health professionals' interpretations. Instead they not only gained psychosocial

support from voluntary organizations but also through their own voluntary work:

I thought 'What are, you know, what can you do? You're not well enough to work' but I thought 'Well what are your skills?' and I thought 'Well do some charity work' as they were recruiting for the MS Society, em, I went along and I'm now Secretary of the one in H... MS Society. I've met a few people. From that I met a guy my age who'd got it, he's actually worse than me...

Interview F8

As described in 5.3.5, characteristics of heart sink patients were described by professionals as being chronically depressed or unable to communicate concisely. Expert patients appeared aware of these perceived flaws and as demonstrated so far in this chapter were often stoical. They had also developed communication skills that were professional-like, rational, objective and able to summarise salient points (5.3.5). For a few such as M6 (5.2.5) this had been a natural response from the onset of symptoms, but others such as T1 and T2 (5.2.4) could map out their conversion to this kind of approach. The development of these characteristics was linked to the reframing of the condition from stigmatizing traumatic experience to one where guilt or feelings of shame were replaced by a “just get on with it” approach. Occupational or personal skills were drawn upon to facilitate the process of “getting on with it” and this activity appeared characterised by distinct phases of assessment, planning, implementing strategies and evaluation. Extensive information gathering underpinned the assessment and planning phases (5.2.5), and implementation strategies often involved moving beyond those advised by the doctor and included, for example the use of CAM. Evaluation of treatment and therapies often utilised the experience of other people affected by a LTC in order to develop some sense of outcome criteria. Whilst the majority of expert patients had a professional background the sample also included respondents with other backgrounds, what they had in common was this structured, rational approach to self-management. Harnessing or developing this behaviour by expert patients was the trigger for a number of responses both from professionals and health services which will now be described.

5.6.7 Linking it all together – the expert patient as a culturally gendered phenomenon

Figure 17 attempts to draw a diagrammatic representation of the pattern described in this section. The data suggests that statutory services often fail to provide the emotional support people with a LTC commonly require. The NHS and Social Care services also perpetuate feelings of power imbalance between patient and professional, and between professionals themselves. The latter was clearly illuminated by the differing responses to expert patients which appeared congruent with professionals' sense of self-autonomy and role definition. However, the EPP was unique within statutory provision by being patient-led which appeared to result in a sense of emotional support and validation of personal experience. Paradoxically it also appeared to function as a reinforcer of expert patient characteristics such as developing a rational approach to self-management. Whilst some expert patients in the study had accessed the EPP the majority had developed this behaviour pattern by drawing on other mechanisms such as private provision or voluntary groups. These mechanisms provided an outlet and support for emotional responses and also increased the individual's sense of control. Thus, although a number of patients could describe their early relationship particularly with doctors as one of feeling labelled as neurotic, they had learned to act in a certain way to be granted expert patient status. This status brought a number of rewards such as ease of access to services and open, equalised relationship with professionals:

...there's the rheumatology nurse, if I'm going through a bad patch, I ring up the nurse...she's got a bleeper number as well. I can ring her up and I can say "Look, I need to see Doctor B. or I need an injection" or whatever and then she'll get back to me which is good and I've also got the number of the secretary of the consultant and she's pretty good as well. Em, and I can ring her up and say "Need a repeat prescription" and then that's just put through the post... but I mean, only, 'cos I've been in the system for so long, that I know how to get round it.

Interview F11

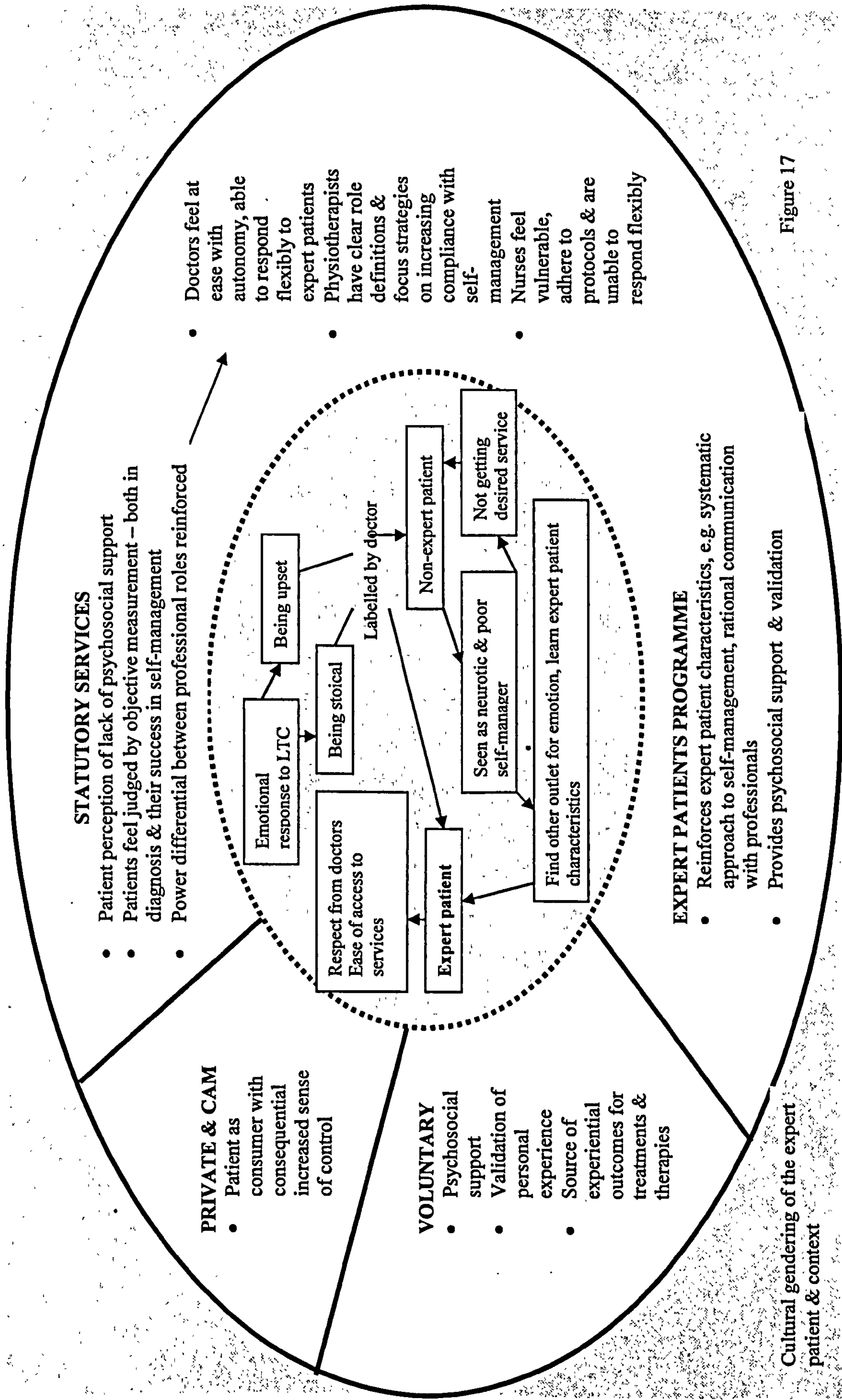


Figure 17

Cultural codes of gender was a discourse that pervaded the expert patients' experience of clinicians and services, and as suggested in the storyline appeared to be the generative structure. However, from a critical realist perspective this discourse and generative mechanism merits further examination. In the next chapter the experience and responses of the "travellers" or expert patients in the centre of figure 17 will be explored further and I will present a typology of expert patients. This will provide an analysis of why some expert patients found the journey easier.

While the core category of cultural codes of gender illuminates the discourse of the expert patient arena, I will argue in the next chapter that submerged beneath the discourse is the persuasive medical division of labour.

5.7 Summary

This chapter has presented the major findings of the study. It has attempted to present these as a metaphorical journey through a landscape of the experience of chronic illness towards being an expert patient, and data surrounding professional responses, statutory, private and voluntary services have been reported. Throughout the chapter a critical realist framework has been utilised to indicate which mechanisms an expert patient encountered inhibited or facilitated their journey. The chapter has culminated in the presentation of the core category, arguing that cultural gendering has produced a pattern that not only permeates the context but also shapes the phenomenon of the expert patient. The thesis will now develop an explanatory framework for these findings, ultimately arguing that the structure, agency and generative mechanism described so far are shaped by the medical division of labour.

CHAPTER SIX

DISCUSSION

6.0 Introduction

Findings from the study have been presented suggesting that whilst the experience of having a long term condition is subjective, experiential and entwined with emotional responses, the expert patient projects an image of being rational, objective and theoretically knowledgeable. This chapter will explore this paradox more fully and will develop a case for the following key concepts of the thesis. First, there is a typology of expert patients. Second, expert patients are shaped by the medical division of labour commonly resulting in the notion of an ideal patient as a set of characteristics determined by the medical paradigm, including the ability to speak the language of the masculine, rationalistic world. Third, this shaping is encouraged by state sponsored mechanisms such as the Expert Patients Programme. Fourth, the relative powerlessness of nurses results in expert patients evoking particular feelings of threat to that discipline. Finally, expert patients have learned that their narratives about their chronic illness experiences are neither recognised nor engaged with by the majority of health professionals. Expert patients' strategies to deal with this lack of engagement often entail significant emotional work for them. Set in a critical realist framework the nature of expertise in the expert patient will first be discussed and the chapter will elaborate the triggers and inhibitors of the expert patient as a concept.

6.1 Where is the expert in the expert patient?

As discussed in the introduction to this dissertation, combining the terms expert and patient has caused some consternation particularly within the medical profession (Shaw & Baker, 2004). The roots of some of these anxieties are made clearer if traditional definitions of expertise are explored. The notion of the expert as understood by most people today, developed from the Age of Enlightenment when there was a growing belief in the ability of "man" to apply scientific rules and analysis in order to solve the problems of life (Appleyard, 1992). Identifying "man" as the expert is purposeful here as

traditional masculine traits such as rationality and objectivity (Caron-Flinterman *et al.*, 2005; Popay & Williams, 1996) are seen as key attributes of an expert (Kitzinger & Williams, 2005). The notion of expertise is closely related to exclusivity of knowledge and maintenance of authority (Code, 1991), with authority born out of a societal need for experts who in return for fulfilling that need are awarded respect, commonly good remuneration and a monopoly over a particular field of expertise (Code, 1991; Higgs & Bithell, 2001; Kitzinger & Williams, 2005). For example, Kitzinger & Williams' (2005) analysis of how experts' views regarding the embryo stem cell debate demonstrate the underpinning masculine discourse of expertise but also illuminate how the discourse is being expanded within post modern society to include emotive elements in order to reinforce the rational argument. Many of the expert patients within this study did behave in ways congruent with the above description demonstrating a rational, objective approach to managing their condition (5.2.5), suggesting a link with traditional assumptions of expertise. However, whilst there was an acknowledgement of the emotive element of their lives this was rewritten to be dealt outside of the professional-patient interface (5.6.4), which will be explored later in this chapter. The congruence and tensions in definitions of expertise between traditional experts and expert patients can be illuminated further by exploring the elements of professional expertise more closely.

6.1.1 The elements of professional expertise

The distinct elements of professional expertise have been defined as four aspects (Fox, 2005; Higgs & Bithell, 2001). Empirical knowledge is seen to be gained over a number of years normally via pedagogic instillation of theory. Aesthetic knowledge or craft is usually attained via apprenticeship (Lupton, 2003), whilst personal knowledge is drawn from life experience. In the case of the medical profession recruitment continues to be predominantly from the middle class (Lupton, 2003) hence lessening the chances of a kaleidoscopic range of personal knowledge. Finally, professional expertise is seen to have an ethical element which will guide the professional to act in the "right" way (Dreyfus *et al.*, 1996). Some theorists have included a fifth element of professional expertise – intuitive knowledge (Benner *et al.*, 1996). Intuitive

knowledge poses challenges as by its very nature it cannot be voiced (Polanyi, 1967), and it is closely identified with the relatively marginalised and feminized professions such as nursing (Carpenter, 1993). However, tacit knowledge is often recognised by people belonging to the same community such as a particular profession and is central to the mutual ability to negotiate meaning and understanding (Walker, 2001; Wenger, 1998).

The professionals within this study demonstrated all these elements of expertise. The doctors particularly emphasised the empirical, aesthetic and ethical elements of their work when interviewed (5.3.8), as to a lesser extent the physiotherapists did. Nurse specialists were unique in attempting to articulate their intuitive knowledge particularly in regard to communicating with patients (5.3.8). However, to what extent are these elements of professional expertise evident within expert patients?

6.1.2 Patient expertise; a typology of the expert patient

As previously discussed in chapters two and three there is a wealth of literature on the labour involved in living with a long-term condition and the development of self-management strategies. The focus in this section will be an exploration of the specific elements of expertise (table 27) which underpins a typology of an expert patient drawn from the findings.

The most contested area of patient expertise is within empirical knowledge. Some studies have suggested that lay empirical knowledge is very limited (Prior, 2003) and there are assumptions of an unbridgeable competence gap between patient and clinician (Tuckett *et al.*, 1985). Prior (2003) argues that the lay person has limited thinking about disease and aetiology, are poor risk assessors and tend to base their empirical notions on one or two experiences, the media or the internet. Prior's concerns echo those of many of the professionals in the study, particularly nurses, that patients over-estimated their empirical knowledge (5.3.4). However, there is a body of work suggesting that lay empirical knowledge is increasing through a better understanding of basic science (McClellan & Shaw, 2005) leading to the ability to formulate sound theories of aetiology and prediction of risk (Popay & Williams, 1996). There is little doubt that access to information, particularly

Sources of expertise	Acquirement	Examples of evidence
Empirical knowledge	<ul style="list-style-type: none"> • Researching literature & internet • Attending conferences and health professionals' presentations • Voluntary organizations' dissemination of research & guides on condition • Commercial information such as pharmaceutical companies • Some one to one teaching from health professionals 	<p>Parkinson's Disease focus group ability to describe role of neurotransmitters in development of condition.</p> <p>F7 (MS) describing the effort put into researching the condition and the need to "<i>constantly evaluate the information</i>"</p>
Aesthetic knowledge	<ul style="list-style-type: none"> • Trial and error/experimentation • Other people with the condition (friends, support group, web chat room) 	<p>F5 (Type 1 diabetes) described how she had learned to adjust her insulin outside the prescribed amount to accommodate any changes in diet.</p> <p>F13 (MS) had learned to take cat naps and pace herself.</p> <p>F8 (MS) had learned to ration use of walking aids to prevent over-reliance on them.</p> <p>F11 (psoriatic arthritis) had installed phone extensions in each room for ease of use.</p>
Ethical knowledge	<ul style="list-style-type: none"> • Cultural norms • Life experience • Milieu of voluntary organizations' and statutory services' drive for patient & public involvement 	<p>F9 (diabetes type 2) & M5 (rheumatoid arthritis) members of PCT Public involvement forum.</p> <p>F8 (MS) acting as unpaid secretary for local MS Society.</p> <p>F11 (psoriatic arthritis) teaching professionals about condition because of "<i>wanting to put something back</i>"</p>
Personal & experiential knowledge	<ul style="list-style-type: none"> • Life experiences living with the condition • Vicarious experience via support groups 	<p>M6 (PD) learning to deal with doctors to get best out of consultation.</p> <p>F4 (type 2 diabetes) learned that personal stress resulted in poorer control of her diabetes.</p>
Tacit knowledge	<ul style="list-style-type: none"> • Knowing one's body 	<p>Heart focus group described instances of when they knew something was wrong with their cardiovascular system but could not describe why they knew.</p> <p>T2 (endometriosis) described how she knew something was wrong with her body but could not say how she knew. Originally refuted by doctors, the "<i>gut feeling</i>" turned out to be a large ovarian cyst.</p>

Expertise of an expert patient

Table 27

via the internet, has had a significant effect on lay empirical knowledge. However, in contrast to Prior's (2003) conclusion of the internet developing erroneous ideas in the lay person, this study (5.2.6) and others (Hardey, 1999; Rogers & Mead, 2004; Ziebland *et al.*, 2004) suggest that lay people generally have the ability to critically evaluate the information they encounter on websites. During the interviews and particularly the focus groups it was apparent that many expert patients had a significant level of empirical knowledge and were, for example, able to discuss the problems of neurotransmitters in Parkinson's Disease with relative ease. Although this specific medical knowledge may be learnt from interactions with health professionals (Kirk *et al.*, 2005) this study suggests that it was often self-taught (Coulter, 2002) and commonly developed at a group level (McClellan & Shaw, 2005) (5.2.1) where use of this body of knowledge was not only permissible but encouraged.

Aesthetic knowledge in expert patients was utilised to maintain contextual health (Thorne *et al.*, 2003). Expert patients described the craft of living with the condition such as tailoring their home environment, making therapeutic adjustments to their drug regimen, or reorganizing daily activities. The aim of this craft work was to maintain a sense of control (Paterson *et al.*, 2001) over both body and quality of life.

Ethical knowledge is regarded by some as the hallmark of an expert, with Dreyfuss *et al.* (1996) describing ethical comportment as the ability of the expert to act in a similar way to another expert. This idea can also be applied to the expert patient, with a strong moral code evident (5.2.5). Data from the focus groups suggested that an expert patient may manage their condition differently to another expert patient with the same condition; however there were strong similarities in the ethic of citizenship with the majority of expert patients talking in terms of putting something back into society and helping others.

Personal and experiential knowledge is widely seen as forming the major element of patient expertise (Coulter, 2002; Department of Health, 2001a; Fox, 2005; Paterson *et al.*, 2001; Prior, 2003; Thorne *et al.*, 2003). The narratives of many patients within this study suggested that much of their expertise was based on cumulative experience, not only their own but also

vicarious experiences gained often via support groups (5.4.7) or web chat rooms.

Intuitive knowledge was described in terms of knowing one's body but not being able to articulate what exactly one does know. An example of this can be found in 5.2.4 where one of the lay tutors (T2) described how she knew something was happening to her body beyond endometriosis, this was refuted by doctors until the evidence became visible; a cyst the size of a grapefruit. Whilst the examples from each element of expertise indicates that the expert patient has multiple-level knowledge (Kivits, 2006), interestingly it was the discourse of empirical, aesthetic and ethical knowledge that featured most prominently in the data. This reinforces the supposition raised in 5.2.5 that many of the expert patients described in this study are proto-professionals (Caron-Flinterman *et al.*, 2005). In particular their communication style (5.2.3, 5.2.5, 5.6.4), organizational approach (5.2.3, 5.2.5) and rational, non-emotive encounters with the health care context (5.2.4) appear more closely aligned to the traditional assumptions of expertise rather than that more commonly described in terms of almost exclusively experiential knowledge (Department of Health, 2001a). However, whilst all expert patients demonstrated multiple levels of knowledge, exhibited an ethic of citizenship and took a rational approach to self-management, there were a number of variables within this descriptor. These variables can be charted on two axis; acceptance – challenge and covert – overt. The variables fall within four categories; responses to NHS services, expression of emotional responses, motive for knowledge seeking and style within the medical consultation. These variables and characteristics are displayed in figure 18 and create a typology of the expert patient as represented in the data. A selection of data exemplifying each type is presented in appendix 26.

I have already shown that M6 and F11 fell quite clearly into the overt-acceptance quadrant. On the whole they were very satisfied with the services provided within the NHS but would also use their knowledge of the system (such as actively seeking referral to a centre of excellence and knowing the consultant's secretary) to get the best out of it. Whilst they could both articulate the emotional consequences of their condition they perceived that the patient-doctor consultation was not the arena to vent these emotions and

Typology of expert patients

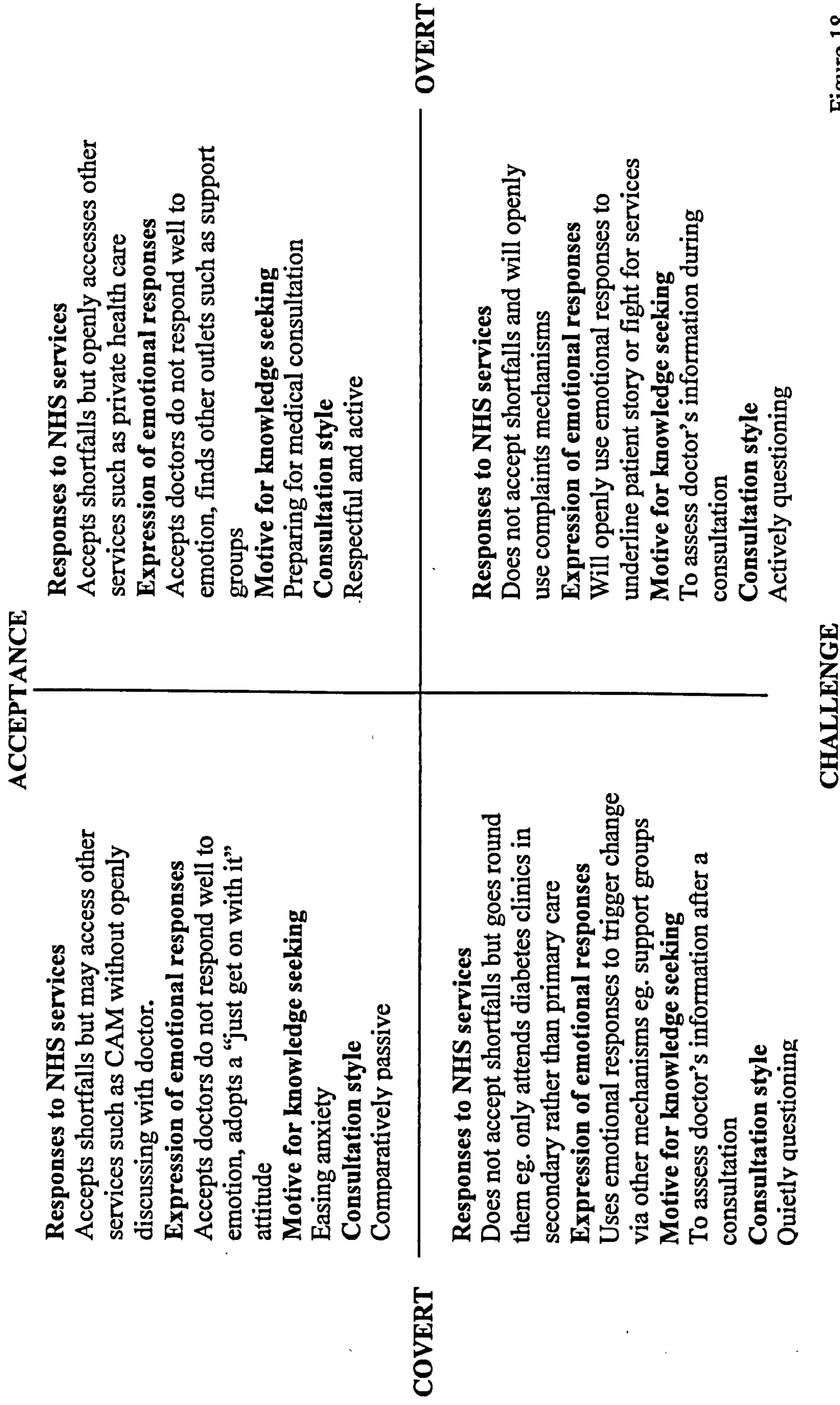


Figure 18

instead utilised friends, family and support groups. Their motive for knowledge seeking was to ensure that they could ask the right questions at the consultation for which they prepared rigorously. They described the consultation as one of mutual respect and active discussion.

An example of an expert patient within the covert-acceptance quadrant was F2, a 47 year old lady with Rheumatoid Arthritis. Despite not regarding the promotion of Hormone Replacement Therapy by her Consultant as “bad advice”, she nevertheless decided to use alternative therapies but kept this hidden from the Consultant. Although she felt enabled to have a more open discussion with her GP she described continuing unease in medical consultations, finding it easier to adopt a comparatively passive style.

F5 a 30 year old lady with diabetes type 1 was an example of a covert-challenger. Having lived with diabetes since childhood she was an expert self-manager, well able to self-adjust her insulin dose but feeling unable to share this with the consultant (5.2.3). She was particularly concerned about moves within the NHS to shift specialist diabetes care from the secondary to primary sector. Her few encounters with a practice nurse diabetes clinic led her to question the competence of practitioners leading this service; however she did not openly complain but simply ignored reminders to attend her annual primary care review. She also went to great lengths to remain under the care of the consultant she trusted, for example she had not told the hospital of her new address which was out of the catchment area and continued to use her parents address in all correspondence with health services. The information she sourced was used after a consultation, particularly with “non-specialists” such as the GP and practice nurse to check on their advice.

The stereotypical “heart sink” patient particularly of nurses were overt-challengers. F4 was a middle aged teacher diagnosed with diabetes type 2 a number of years ago. She had felt unwell which the GP had diagnosed as being related to work stress and had undertaken psychotherapy with her. Unfortunately these sessions did nothing to help and indeed made her feel worse. When she saw another professional she found out that the GP was not

appropriately qualified to undertake this type of therapy. Discussions between the GP Practice and F4 and her husband did not reassure them that the GP would cease these activities and so the couple felt compelled to make a formal complaint. She described breaking down in tears when asking her Member of Parliament what could be done to protect the public from GP practices who allowed partners to conduct treatments outside of their qualifications, thus underlining her story and mission to prevent this happening to someone else. This issue and subsequent perceived failings to do with her husband's treatment made F4 feel that the NHS was dangerous, with private health care a safer option (5.4.1). However, she continued to be registered at the same GP Practice, who had recently invited her to become part of their patient forum, she ascribed these actions to both she and the GPs preferring to "*deal with the devils we know*". Nevertheless, consultations with F4 were highly likely to be characterised by active challenging and questioning by a patient who had extensively researched the health need for which she was attending. Whilst the expert patients in this study fell into four categories the discussion will now explore how this typology compares to presentations of expert patients within the literature.

6.1.3 Assumptions regarding the expert patient

The rise of lay expertise and the way this had been reflected in policy has been charted within chapters one and three of this thesis. This section will particularly interrogate how the typology presented above fits with the expert patient role currently articulated in the literature.

Expert patients are commonly portrayed in two ways within health care literature. Firstly they are described as desirable patients because there is an implicit assumption that the expert patient is compliant with treatment and therefore will have better health outcomes (Donaldson, 2003). Secondly there is a growing body of work particularly in medical journals that identifies expert patients as potentially effective teachers of professionals (Shah *et al.*, 2005; Stacy & Spencer, 1999; Wykurz & Kelly, 2002). In this teaching role expert patients are seen as specifically suited to teaching professionals skills such as communication and passing on the experiential knowledge they have gained through living with their condition. Although an overt-challenger such

as F4 would be more likely to use emotion to underline her story, this study suggests that the other categories of expert patients had learned to keep emotional expression out of the doctor-patient consultation thus not providing any real challenge for doctors to change their responses to emotion within consultations. It is also significant that a substantial proportion of expert patients are likely to keep the full extent of their self-management practices hidden from professionals (Stevenson *et al.*, 2003), again curtailing the possibilities of the professional learning vicariously through the expert patient's experiential knowledge.

Unsurprisingly the closest portraits of expert patients as described in this study are to be found in the literature by expert patients themselves. Lynn Faulds Wood, a broadcaster and expert patient having lived with bowel cancer identifies four key roles for the expert patient (Faulds Wood, 2003). Whilst two of these roles are congruent with the literature described above (teacher of professionals, curriculum development) and the third relating to the EPP (teacher of other patients), it is the last role that seem to most closely fit the expert patients in this study. She describes expert patients as "uniquely informed patients" who are in a key position to improve the patient journey and services. Their years of experience of both the chronic illness and health services enable an insight that would be invaluable for service providers. There is growing evidence that expert patients are attempting to actively shape services for the benefits for patients with a range of chronic conditions (Association of the British Pharmaceutical Industry, 2002c; Mayor, 2006), with this study suggesting that this was a prime motivation for expert patients within all four quadrants of the typology. However, there is comparatively little written by professionals extolling the virtue of this fourth role, a tension that now will be explored.

6.1.4 The tension between professional and patient expertise

There has been a growing acknowledgment of the value of experiential knowledge in lay expertise (Prior, 2003) but as discussed in this section so far less recognition of the other forms of knowledge held by an expert patient. Whilst in theory a lay person now has the same access to information as clinicians (Kivits, 2006) there is a continuing belief that the general public

lacks knowledge and understanding about science and risk (McClellan & Shaw, 2005). I would argue with others (Popay & Williams, 1996) that this is not necessarily the case with many expert patients having multiple levels of knowledge (Kivits, 2006; McClellan & Shaw, 2005). In contrast it could be argued that professional knowledge is restricted and impoverished by an absence of knowledge derived from living with the condition. Kirk *et al.* (2005) suggest that tension arises when the expert patient or carer combines their levels of knowledge to create individualised strategies whereas the professionals often rely solely on knowledge that may be espoused as empirical. This conflict often gave rise to perceptions of the expert patient as self unaware, arrogant and over-demanding (5.2.1). The challenge to the dominance of empirical knowledge also contests the supremacy of the medical profession and the notions of power and masculinity that go with it. The chapter will now turn to an exploration of power and gender as applicable in the shaping of the expert patient.

6.2 Power and the division of labour in health care

There is a wealth of literature charting the rise of medical power and dominance and the effect this has had not only on patients, but also on professions working closely with medicine such as nursing. This section will present the major themes from the literature and link to the findings of this study for further illumination.

6.2.1 Sociological critiques of medical dominance

Medicine is both an art through its virtues as a skill and a science. Following a series of key discoveries in the seventeenth and eighteenth centuries such as the circulation of blood (Baggott, 2004), the science of biomedicine has risen to dominate the descriptions of medicine. Biomedicine employs a rational, reductionist approach towards health and disease, with the former being identified as an absence of the latter. During the twentieth century reductionist methods of defining, measuring and isolating biological changes heralding disease culminated in the adoption of randomised controlled trials as the gold standard in biomedicine's assault on disease (Baggott, 2004). However, whilst the medical advances biomedicine brought may have made a dramatic

improvement in peoples health (Williams, 2001) there has been an ever growing array of critical commentaries on medical dominance.

In the first half of the last century medical dominance was on a steep curve upwards, and in the UK this was enhanced rather than impeded by the advent of the NHS (Klein, 1990). The functionalist school of thought emerging in sociology during the 1950's amplified this dominance by emphasising the requirement of dominant doctor and passive patient for efficient running of the state. The seminal work of Talcott Parsons (Parsons, 1952) and his identification of the sick role suggested that the role of a profession is that which is of functional significance for the wider social structure (Saks, 1995). In order to return to being a productive citizen as soon as possible an individual submits themselves to the medical profession and complies with the treatment given. If return to productivity is impossible, sickness is verified by the doctor and the individual is absolved from productivity responsibilities. Whilst the functionalist approach emphasises the relationship between the state and medical profession, it is also underpinned by a frequently critiqued assumption of altruism of doctor to patient (Saks, 1995). The functionalist approach is also criticised as over simplifying the power issues within the doctor-patient encounter and ignoring organizational constraints on doctor-patient behaviour (Lupton, 2003).

Criticisms of the medical profession started to emerge in the 1970's as part of neo-Weberian approach (Saks, 1995). Freidson's (Freidson, 1970) work on professional dominance focused on the relationship between the state and profession and highlighted the monopolistic hold of doctors. Freidson suggested this has been gained through legal protection against the encroachment from other professions, autonomy in terms of work, a code of ethics to enable trust between the public and profession, and sole access to knowledge and skills (Freidson, 1970). Supported by the power of the state, the medical profession is able to recreate the patient's world, defining illness in terms of the profession's biomedical knowledge base (Salvage, 2002).

However, Freidson's critique of the medical profession has been criticised for overly ignoring any altruistic motive (Saks, 1995) and failing to ignore any success of biomedicine (Lupton, 2003). Navarro (Navarro, 1986) and other Marxist commentaries on medical dominance have continued the sociological

critique of the medical profession by linking it to capitalism in two ways. First, professionalization in medicine has led to specialization and hierarchicalization, hence echoing the capitalist division of labour. Second, medicine is identified as a commodity and whilst this is less obvious in the UK than the US there is still seen to be considerable influence by the pharmaceutical industry in the former (Navarro, 1986). However, Marxist critiques of the medical profession fail to recognise any value in non-Marxist societies and do not take into account radical factions within the medical profession itself (Saks, 1995).

More recent sociological critiques of medical dominance have arisen out of the social constructivist school of thought, particularly influenced by the work of Foucault (Foucault, 1976). Foucault sees power as omnipresent within every interaction between people (Porter, 1998), operating by what Foucault terms panopticism which literally means all seeing (Wilkinson, 1999). He argues that the medical profession has objectified the patient since the Age of Enlightenment (Peerson, 1995; Wilkinson, 1999), subjecting people to the “clinical gaze”. For Foucault the body has become the ultimate site of political and ideological control, surveillance and regulation (Lupton, 2003). Whilst social constructionism is not without critics (see 4.2.6), particularly the potential for relativism and nihilism (Lupton, 2003; Porter, 1996), as with the perspectives described above it nevertheless provides a useful looking-glass on the medical profession (Wilson, 2001).

Finally, as in the discussion on the notion of expertise (6.1) the issue of gender is inextricably tied to the idea of medical dominance and the division of labour. This manifests itself in a number of ways. At a theoretical level the characteristics of a profession such as autonomy (Freidson, 1970), exclusionary closure (Saks, 1995) and self-regulation (Salter, 2004) are closely related to traits traditionally masculinised (Code, 1991; Gilligan, 1982). Illness is strongly linked to femininity by notions of passivity and weakness (Lupton, 2003), relinquishing control of the patient’s body to the doctor. Whilst there is a volume of work exploring the effect of this bipolarised and gendered power differential between doctors and female patients (Asbring & Narvanen, 2002; Koch *et al.*, 1999; Kralik *et al.*, 2001), there is less work on the effect on a male patient of “*relinquishing control of his body to another*” (Lupton,

2003:28). Out of all sectors of an economy, health care's division of labour appears to be the most divided by gender (Riska, 1993). This not only manifests itself within medicine (Brooks, 1998; Elston, 1993), but is strongly echoed in the professions surrounding medicine such as nursing (Davies, 1995).

Having provided an overview of the major theoretical discussions surrounding the medical profession and its dominance, the discussion will move forward to the manifestation and revelations of medical dominance within this study.

Three areas will be critically discussed; first how it was expressed within the doctor-patient relationship, second manifestations within the relationships between professionals and last how medical dominance was replicated in the nursing/physiotherapy-patient relationship.

6.2.2 Medical domination and the impact on patients.

Traditional assumptions of the doctor-patient relationship are predominantly described in terms of a paternalistic, authoritarian and active "heroic doctor" whose aim in the encounter is to promote patient compliance with the prescribed treatment (Salter, 2004; Scherman & Lowhagen, 2004; Werner *et al.*, 2003). Within this relationship non-compliance is seen to be caused by a problematic patient (Anderson, 2005) who either wilfully or negligently fails to comply with their best interests as defined by medical direction. However, partly as a response to the public's loss of confidence in the medical profession (Coulter, 2002) (explored more fully in 6.3), the rhetoric of the relationship has moved on to accommodate the acknowledgement of the independent agency of patients. The term concordance is now used to denote encounters where patient and professional act as equal partners in the decision-making process (Royal Pharmaceutical Society of Great Britain, 1997).

However, despite the rhetoric and curriculum developments (Thistlethwaite *et al.*, 2003) there is evidence that doctors continue to find it difficult to adapt to this new paradigm (Raynor *et al.*, 2001), and it has been suggested that it will take a great deal of time for medicine to make the cultural shift (Anderson, 2005). In addition, patients continue to need doctors to exercise authority in validating their illness experience for societal recognition (Broom &

Woodward, 1996; Nettleton, 2006), for if there is no validation there is the potential for greater stigmatization (Asbring & Narvanen, 2002).

The doctors within this study espoused the new paradigm of active patient (5.3.1). Indeed they had agreed to participate in a study titled the “expert patient” so it was highly likely that the accounts within the interviews would be presented as favourable to the notion of active and informed patient and this was confirmed by the interview data. It was not possible to observe GPs interactions with patients affected by chronic disease as these particular clinics were run by practice nurses. However the consultants in the study continued to lead their own clinics, with observation of consultant 01’s work revealing that whilst he was comfortable with expert patients (5.2.1) his comfort levels did not extend to the overt-challenger (6.1.2). Tuckett *et al*’s. (1985) study of medical consultations suggested that whilst patients who overtly sought information and questioned the doctor were more likely to be listened to, it generally created a consultation with more tension. I would argue that there has been some shift in this position for while overt-challengers still created a sense of tension in the doctor, overt- acceptors did not. Although overt-acceptors would actively seek information they utilised approaches that did not create tension. Doctors clearly described their ideal patient as one who fitted the overt-acceptor type, often reasoning that these patients were easier to deal with due to the open relationship, ease of communication and the positive feel to the consultation.

Whilst it is understandable why the “easiest” patients were the most popular with doctors, data from the observation of the consultants’ clinics reveals that there may be a more underlying set of reasons. First, communication is always easiest to conduct with people similar to ourselves (Hogg, 1999). The majority of doctors are from a middle class background (Lupton, 2003), and it was clear that consultant 01 related more to white middle class male patients to such an extent that it would negate his usual disciplinary discourse (5.6.2). He also stated that he found it particularly difficult to relate to patients from a black and minority ethnic background. Consultant 02 also appeared to engage more with white, middle class female patients, particularly those in a similar age group to her. Overt-acceptor expert patients were more likely to display communicative symmetry in terms of being articulate. Second, it was evident

that the new discourse of concordance was not all it seemed (Wilson, 2001). Consultant 01 emphasised patient responsibility for self-management within the disciplinary discourse he particularly employed with male patients whose HbA1c was out of range. During the interview he rationalised this as reinforcing the fact that the majority of diabetes management is self-care (Department of Health, 2001b) and hence the need for patients to take the responsibility for this. However, this can also be seen as a reformulation of the authoritarian paternalistic relationship of traditional medicine (Salter, 2004) with the potential added bonus for doctors in shifting responsibility totally to the patient (Broom & Whittaker, 2004) who thus become blameworthy for when things go wrong (Maseide, 1991). Consequently, overt and covert-acceptors and to a lesser extent covert-challengers do not cause feelings of discomfort for doctors because they are relatively easy to deal with within the interactional rules and boundaries of the traditional medical encounter. Equally these patients are acceptable to the medical profession not only because they are relieving the doctor of some of the less preferred work (Ovretveit, 1985) in chronic disease management, but also because responsibility can be shifted to them for failings in medical knowledge exemplified by the lack of cure in chronic disease.

It would seem that despite notions of patient partnership and concordance medical domination persists within the doctor-patient relationship. Thus, I argue that medical dominance is still being reproduced and replicated in doctor-patient encounters despite the apparent paradigm shift towards concordance. Indeed, there appears to be a continuing need for patients to use subtle methods to avoid conflict (Stimson, 1978) and problems if the patient viewpoint was not explored or acknowledged (Tuckett *et al.*, 1985). The discussion will now turn to explore the effect of this domination on the other professionals in the study.

6.2.3 Medical domination; a problem for the physiotherapists?

Physiotherapy is defined as the promotion of health and prevention or rehabilitation of dysfunction or disorders in movement (Higgs *et al.*, 2001). Compared to medicine and nursing, physiotherapy is a comparatively young discipline within health care. The evolution of UK physiotherapy into what is

known today began in the 1940's with the establishment of the Chartered Society of Physiotherapists (Sparkes, 2002). However, as with nursing, physiotherapy has been considered a paraprofession (Freidson, 1970), and although received state recognition in 1960 this was only under the auspices of the *Professions Supplementary to Medicine Act* (1960). Until the 1970's physiotherapists could only practice under the direction of a physician (Sparkes, 2002) but since 1977 have been able to work as first contact autonomous practitioners (Chartered Society of Physiotherapists, 2004b; Larkins, 2002).

There are similar debates within physiotherapy as in nursing regarding professional status (Sparkes, 2002); however the rhetoric within physiotherapy suggests that it can cite a number of factors in staking its claim to professional status independent from medicine. First, unlike nursing, physiotherapy can articulate discrete skills. These are massage and manipulation, electrotherapy, and exercise and movement (Chartered Society of Physiotherapists, 2004a). These core skills direct the knowledge base, education and practical application of physiotherapy, and are specific and measurable (Dalley & Sim, 2001). Although physiotherapy is said to overlap occupational therapy, chiropractic and osteopathy, nevertheless it is distinct in its deep and broad understanding of movement (Higgs *et al.*, 2001). Second, physiotherapy in the UK has a far longer history of degree education than nursing and so practitioners are almost exclusively graduates resulting in a potentially firmer grasp on developing evidence based practice (Palfreyman *et al.*, 2003). Finally, as autonomous practitioners physiotherapists have had far more success in establishing private practice than nurses (Higgs *et al.*, 2001). However, despite these characteristics of autonomy, discrete body of knowledge and extensive training, there is evidence that medical domination continues to impinge on physiotherapists.

Despite the enablement of self-management being a key aim of physiotherapy (Chartered Society of Physiotherapists, 2002) it was interesting to note that neither the doctors or nurses in the study mentioned physiotherapists in the context of the expert patient (5.3.8), it was almost as if they were invisible to their colleagues. This invisibility may contribute to low self-confidence in multidisciplinary teams (Atwal & Caldwell, 2005), lack of a profile as a

desirable career when compared to medicine (Bithell & Greenwood, 2005), and a lack of professional involvement in the policy arena (Jones & Santaguida, 2005).

Notwithstanding autonomous practice none of the physiotherapists in the study took self-referring patients. Whilst patients were referred to them by consultants or GPs there is a growing move within physiotherapy to work as first contact practitioners (Chartered Society of Physiotherapists, 2004b). It is argued that removing the gate keeping role of medicine would reduce the workload of doctors (Holdsworth & Webster, 2004), however it is also likely to reduce the power of medicine as a filter to the other professions (Annandale, 1998). Physiotherapists in the study had mixed feelings about direct referrals with the majority fearing an increase in work. Congruent with descriptors of expert physiotherapy practice (Shepard *et al.*, 1999) it was likely to be the more experienced physiotherapists in the study who were in favour of direct referral.

Despite a rapidly extending scope of practice and increasing numbers of qualified practitioners (Chartered Society of Physiotherapists, 2002), there appears a tension between the masculinised rhetoric of a rational and discrete body of knowledge and being a predominantly female occupation (Higgs *et al.*, 2001). Indeed attrition rates of male physiotherapists outstrips that of females (Higgs *et al.*, 2001), emphasising the lower pay and status a feminised profession brings (Kazanjian, 1993; Porter, 1995).

6.2.4 Medical domination; the effect on nurses

The doctor-nurse game (Stein, 1967) with its features of medical superiority within a hierarchy where nurses were to be found at a lower level, is a description seen to encapsulate the problematic nature of medical dominance for nursing (Porter, 1995). Within this game nurses would have to learn the skill of communicating recommendations without appearing to make them, and doctors equally would learn to request recommendations without appearing to ask for them. Reinforcement of medical dominance not only by other professions (Stein, 1967) but also by the state (Klein, 1990) has created medicine into a template to which others, particularly nursing, aspire (Salvage, 2002). In many ways this is perverse as nursing emerged within the

Nightingale movement as a relatively powerful profession (Black, 2005). Indeed in the early days of nursing there was a clear identifiable body of knowledge in the form of *Nightingale's Notes on Nursing* and relative autonomy particularly in district nursing (Manthey, 1992). The demise of autonomous nursing is linked with the advent of relatively unqualified nurses as a response to the increased need for nursing created by the second world war (Manthey, 1992). In the UK this was quickly followed by the creation of the NHS with state sanctioning of medical power (Klein, 1990).

A counter-rhetoric regarding nurses' inferior position to medicine has begun to emerge over the last few decades, with changes in nurse education cited to be the vehicle for change in the doctor-nurse game (Stein *et al.*, 1990). Nurses emerging from higher education and different ways of working such as primary nursing (Manthey, 1992) are seen as the catalyst for nursing to enter a collegial relationship with physicians on a negotiated but equal footing (Allen, 1997; Svensson, 1996). This seeming rise in the professional fortunes of nursing appears backed by the state by creation of a range of new roles (Boaden *et al.*, 2005; Department of Health, 2005i; Health Technology Assessment Programme, 2004) including those traditionally seen as medical (Dowling *et al.*, 1996), extended prescribing (Department of Health, 2006c), and encouragement of an NHS culture based on meritocracy (Doyal & Cameron, 2000).

The nurses who participated in this study all exemplified these new extended roles. The practice nurses were running their own clinics and were observed ordering investigations. The nurse specialists had developed an in-depth knowledge regarding the management of diabetes and were observed commencing patients on insulin therapy including selecting which insulin would be appropriate. Nurses in all the focus groups were also in similar roles, with many such as the Anticoagulation nurses undertaking work that had previously been the remit of doctors. However, the findings suggest that apart from the two nurse specialists, the nurses in this study did not perceive themselves to have a relationship of professional equality with doctors, evidencing examples from being compelled to wear a uniform to not being informed of the rationale behind medical decisions (5.6.3). Whilst the nurse specialists articulated a discourse of autonomous practice, this too was

tempered with feelings of being consigned by the consultant with the more time-consuming “problematic” patient. These “problematic” patients were defined as those who had difficulty or reluctance in understanding self-care in diabetes and were consequentially non-compliant with the treatment regimen. Observation of the diabetes clinic also revealed a clear hierarchical order with the consultant leading the team. This echoes the picture of a dominant medical profession that governs the division of labour (Coombs & Ersser, 2004; Goldie, 1977), passing on aspects of work that they do not wish to deal with (Cott, 1997; Ovretveit, 1985) and allowing nursing autonomy at their discretion (Salvage, 2002).

The doctors within the study espoused appreciation of the nursing contribution to care management, however there was an emphasis from doctors for nurses to confine themselves to management rather than extend into the discrete set of skills that doctors identified as their own; diagnosis and risk taking (5.3.8). When presented with data exemplifying nurses’ feelings of disempowerment doctors responded by either attributing it to nurse education, perceiving there was a lack of emphasis on autonomous practice when compared to medical training, or on “*the nursing bodies*” (5.3.8) who failed to provide any support or backup for the profession. Whilst none articulated it as a response to medical dominance, a few doctors spoke in terms of nurses, particularly non-specialist, as wanting authority but not being prepared to take the associated responsibility such as accountability for treatment decisions.

Manthey (1992) explores the dichotomy of responsibility and authority within nursing, but unlike the doctors in this study argued that this tension was created by an organizational imposition of responsibility but not corresponding authority.

Much literature continues to reflect this rhetoric of nursing autonomy in tension with the continuance of medical dominance and organizational constraint (Carpenter, 1993; Cott, 1997; Daiski, 2004; Woods, 1999). Whilst there was no evidence of this in the study, some nurses may rebel against this dominance by specialising in alternative “non-scientific” therapies (Glazer, 2001), attempting to emphasise a cure-care dichotomy (Kottow, 2001). This reflects what many attribute to the power differential between doctor and

nurse; the gendered nature of professions, work and organizations (Davies, 1995).

The Victorian values of gender and class continue to be reflected in nursing (Salvage, 2002), in particular the notion of doctor/husband/father as wise, firm and kind, and the nurse/mother/wife in the background as dutiful and attending to the man's needs (Porter, 1995). This is compounded by the continuing association of science being associated with rationality and masculinity and caring with emotion and femininity (Hochschild, 1983; Larson, 1999), with the discourse of caring and compassion seen as invalid, unreliable (Ceci, 2004) and not particularly valued by society (Smith, 1992b). Davies (1995) identifies four areas of gendered responses within the NHS with the findings suggesting that these responses were identifiable within this study (table 28).

Masculinity of organizational life (Davies, 1995)	Examples of responses within the study
<i>Gender on the surface.</i> Males in management role, women as workers	Three out of five doctors within the study were male (60% male). All nurses (80) in study were female (0%). Three out of thirty two physiotherapists in study were male (10%).
<i>Gender and the logic of organization</i> Hierarchical. One must be totally committed to the job with no outside distractions such as child care responsibilities.	The female GP was unmarried and could commit totally to the job. The female consultant was a dermatologist – a less prestigious area of medicine with a higher than average ratio of female doctors mainly due to lack of on call duties (Elston, 1977; Elston, 1993).
<i>The gendering of bureaucracy</i> Based on the patriarchal role	Doctors as leaders of the multidisciplinary teams. Practice nurses speaking in terms of their GPs looking after them. Doctors creating job descriptions and protocols for the nurses.
<i>The gendering of profession</i> Formalized training based on science is central to claim for professionalism. Nursing as adjunct to a gendered concept of profession.	Nurses felt their work was controlled by doctors. Nurses felt vulnerable if they stepped outside of this carefully controlled work.

Gendered responses within the organization

Table 28

It should also be noted that increasing numbers of female doctors have had little impact on these responses (Brooks, 1998), suggesting that it is gendered characteristics rather than the sex of the clinician that has the effect. Other work has suggested that feelings of powerlessness and vulnerability in nursing leads to oppressed group behaviour (Daiski, 2004) with nurses displaying “horizontal violence” (Roberts, 1983) against each other as a way of relieving the tension. There was no evidence from the nurses’ data that this was a perceived issue but it was clear that the majority of nurses perceived themselves as working within a “blame culture” environment. I argue that this tension appeared most in the interaction between expert patient and nurse.

6.2.5 The amplification of medical values in the nurse and physiotherapist-patient relationship

The most striking similarity between doctors, nurses and physiotherapists was the commonality in their descriptions of heart sink patients (5.3.5), focusing on the notion of negative affect in the patient (Gill & Sharpe, 1999; Tandeter, 2006) with whom there was little sense of making progress in health outcomes (Mathers *et al.*, 1995; O’Dowd, 1988). This latter descriptor is strongly aligned to the acute model of care which continues to frame the rhetoric of health professionals (Anderson, 2005). There are a number of differing assumptions between acute and chronic illness (Thorne *et al.*, 2000) and it is the differences in the ongoing nature of the health need plus the significantly greater proportion of care managed by the patient that makes the use of the acute care paradigm unsuitable in long term conditions (Assal, 1999). Nevertheless, ideas of a heart sink patient being one whose problems cannot be cured are resonant of the acute care model.

Within nursing it has been repeatedly recognised that there has been a lack of engagement by the profession with the needs of people with chronic conditions (Gibbon, 1994; Kratz, 1978; Nolan & Nolan, 1995), with the preference for acute care indicative of health professions’ utilisation of medicine as a template (Salvage, 2002). Equally patients, with for example chronic back pain, described physiotherapists in terms of being a “bully” and perceived they were of little help. These patients were likely to be the “yellow flag” (equating to heart sink) patient who are judged by professionals to have

stronger psychosocial variables as the cause of their pain rather than medically explained variables (Newton-John *et al.*, 2001). With these patients physiotherapists were likely to adopt a traditional authoritarian relationship (5.3.8) with a focus on compliance, a major reinforcer of professional power (Porter, 1998). An ultimate sanction was available to physiotherapists who were able to discharge patients with relative ease if they perceived there was no possibility of achieving any improvement in the patient's mobility needs. Whilst expert patients have been deemed as too demanding on time (Bastian, 2003), it was only the nurses (with the exception of nurse specialists) who clearly voiced this as an issue. Nevertheless, all professionals described the ideal patient as someone who is quick and easy to treat.

Perhaps one of the most surprising echoes of the medical paradigm was the majority of nurses' disregard of the importance of supporting patients' emotional needs. This element of care is seen as the core of nursing (Coombs & Ersser, 2004; Crowe, 2000; Ersser, 1998; Kitson, 2002; Smith, 1992b; Speed & Luker, 2004), and it is argued that it requires significant skill (James, 1993) and effort (James, 1992). Described as emotional labour (Hochschild, 1983; Smith, 1992b) it is suggested that nurses manage their own behaviour and emotional responses (Dingwall & Allen, 2001) in order to make patients feel they are in an empathetic, therapeutic relationship with the nurse (Smith & Gray, 2001). Although emotional labour has been criticised as being an ethically dubious activity because it involves a level of acting on the nurse's part, it is counter-argued that the emotional labour of experienced nurses is focused on the management of emotions that benefits both patient and nurse, and is underpinned by altruism (Smith & Lorentzon, 2005). Patients participating in this study identified this part of care as highly important (5.3.7) and often gave examples of nurses being specifically skilled in this (Wilson *et al.*, 2006), contrasting with patients' frequent opinion of doctors failing to provide emotional support. This perception was supported particularly by GPs participating in the study who described their heart sink patient as one who was "over-emotional". However, although denial of the importance of emotional support was particularly voiced in the nurse focus groups, observation of the practice nurse clinics revealed that they were skilled

in enabling a supportive relationship (5.6.2), but it was only the nurse specialists that clearly articulated it as a skill (5.3.8).

The doctors in the study appeared to have reframed the expert patient as an acceptable phenomenon that could be to their advantage, similarly physiotherapists perceived an expert patient as knowledgeable and therefore easier to deal with in terms of compliance (5.3.3) and of no threat to their specific skills (5.2.1). However, apart from the nurse specialists, nurses appeared to find the expert patient far more of a threat.

6.2.6 Expert patient as threat; the case of the nurses

The majority of nurse respondents regarded the patients presented in the scenarios (4.5.3) (appendices 4a-c, 15b) as a threat to their sense of professional integrity. In contrast to the other professionals there was also a tendency by nurses to articulate value judgements regarding the scenarios. For example, it was frequently suggested that the patients from the anticoagulant and diabetes scenarios over-consumed alcohol and that was their major reason for wanting to self-manage. However, it was also apparent that the nurses often articulated feelings indicating a lack of autonomy when compared to the other professionals. Whilst the nurses often described the scenario patients as “heart sink” patients, the doctors and physiotherapists were far more at ease with them. Having reassured themselves of patient knowledge and understanding the doctors were invariably happy for self-management, and whilst physiotherapists appeared to have more reservations they did not perceive the patient as being a long-term issue as their professional intervention was time limited. In contrast the nurses voiced feelings of being referred the patient who wanted to self-manage, but according to the nurses would not be allowed to by the doctor. This appears to suggest that although nurses’ work boundaries had been expanded, for example, in running nurse-led clinics, these boundaries were predominantly established and maintained by medical practitioners (Goldie, 1977). In the pursuit of a negotiated and stable working relationship with the doctor (Allen, 1997; Coombs & Ersser, 2004; Rafferty *et al.*, 2001) the nurse was unlikely to challenge normal protocols and enable the patient to self-manage.

Nurses often described situations of the “problem” patient being passed on to them by the consultant or GP, with consultant 01 clearly identifying the nurse specialist role as taking on the more time consuming patients. This appeared to be a clearly acknowledged role within this team which appeared to achieve a sense of coherence for the nurses (Housley, 1999). However, a significant number of the nurses appeared to feel they were consigned by the doctor with the more time consuming patient, often reframing them as the difficult “*know-it-all*”. Albeit that these referrals may be the passing on of patients whom the doctors found difficult to work with (Ovretveit, 1985), it is also a reflection of the increasingly tight physiological targets viewed as the markers of optimal control in conditions such as diabetes (Pill *et al.*, 1999). Nurse-led clinics are increasingly being used to target patients who would need to make multiple lifestyle changes in order to meet these targets (Wallymahmed *et al.*, 2003) and consequentially nurses were seeing proportionally more “heart sink” patients. Many of these patients had different priorities to the professional in self-management (Tuckett *et al.*, 1985), often bringing a sense of frustration to the nurse or doctor because of the perception of making no progress in terms of physiological health outcomes (Mathers *et al.*, 1995).

Although it was apparent that all the nurses in the study were carrying out an extended role within CDM, for the majority this was characterised by a clientele with conditions that required significant lifestyle adjustments in order to maintain optimum physiological control. The emphasis on physiological control such as ideal HbA1c or INR ranges often resulted in the nurse’s role being governed by protocols (Colyer, 2004), and it was the very nature of these that appeared to inhibit the facilitation of self-management. Whilst the doctors and more experienced nurse specialists exercised more professional judgement and flexibility (Colyer, 2004), the majority of nurses appeared too imbued in the bureaucracy of their organization to be independent professionals (Manthey, 1992). An example is nurses working in anticoagulation, a comparatively new role taking over work previously carried out by a consultant haematologist. The key role for these nurses is to initiate patients onto oral anticoagulation and continually monitor and manage the patient’s INR via protocols or computerised programmes (Connor *et al.*, 2002). Nurses’ effectiveness in these roles are normally evaluated by

maintenance of anticoagulant control and efficiency of the clinic; measures that emanate from the medical paradigm (Connor *et al.*, 2002).

Consequentially, with their competence being evaluated against these measures, nurses frequently voiced concern when patients wished to self-manage their own condition. The nurses ascribed their concerns to perceived litigious vulnerability (Vaughan & Pearson, 1998).

6.2.7 The myth of litigation in self-management

There was a marked difference in the attitudes towards litigation between the professional groups. Whilst the physiotherapists acknowledged it as a possibility they were confident that as long as they could explain and rationalise their actions it would not be an issue. The doctors were even less concerned, with the majority expressing that other professionals' concerns were disproportionate. The doctors appeared to have two criteria regarding litigation, firstly that they were dealing with competent adults, and secondly that appropriate levels of information given from the professional could be demonstrated.

In contrast, although many of the nurses highlighted the need to document the information giving, the majority expressed concerns that this would not be sufficient if the patient made an error in their self-management. Whilst it is acknowledged that there is an increasingly litigious public (Dowling *et al.*, 1996; Vaughan & Pearson, 1998), nurses appeared to believe that expert patients were likely to "*twist things*" and be "*very quick to blame the nurse*". However, when questioned this belief was never based on personal experience but on assumptions. Whilst the patient was seen as the primary instigator of litigation against the nurse it was also apparent that the nurses felt vulnerable as victims of organizational blame (Annandale, 1998) regarding self-management issues – "*we'll get the blame*". Despite working in a supportive team, one of the nurse specialists described her first year in post as being one of sleepless nights through worry about litigation. This anxiety reflects the culture of nursing where right from initial training nurses are exhorted to "cover their backs" and document everything. It appears that nurses were transmuting this blame culture onto expert patients.

Although UK law is based upon the notion of active professional and passive patient it is possible to interpret it through the new professional-patient

relationship of an active partnership (Martin, 2004b), with self-management seen as a right (EPDA, 2003; Martin, 2004a). Within the European Community this right is embedded within the convention of human rights and fundamental freedoms, with irrational responses to patient self-management making individuals and organizations potentially vulnerable in the UK under the Human Rights Act 1998 (Martin, 2004a). While there continues to be a residual duty of care from the professional for the self-managing patient it is unlikely that a court would expect the professional to remain fully responsible for the treatment when a competent adult has taken on self-management willingly (Martin, 2003). Although much work is still required in this area, it would appear that for litigation to be successful against a health professional it would need to be demonstrated that they did not:

- respond to the self-managing patient to the standard of other reasonable members of the profession,
- logically defend their actions,
- practise to the standard expected of their post,
- recognise evidence based practice.

It would also need to be established that any harm resulting from self-management was a consequence of the professional's negligence rather than the patient's behaviour (Martin, 2003).

The myth of litigation that appeared to shape nurses' responses in enabling self-management is a symptom of the effect of the division of labour in health care. The totality of labour that managing a chronic illness requires is made up of a series of sequential and simultaneous tasks. This arc of work (Strauss, 1985) is usually initiated by a doctor via the diagnosis and treatment plan, however the tasks are distributed among professionals, the patient, family and carers as the illness trajectory proceeds. Tasks are distributed amongst the workers in differing ways (Corbin & Strauss, 1993; Strauss, 1985), for nurses the work in chronic disease management (CDM) is often delegated from the doctor. Patients may also be delegated work by the doctor or it may be negotiated, and patients who wish to self-manage may simply assume the task overtly or covertly (Strauss, 1985). However, Strauss (1985) emphasises that the division of work does not necessarily equate to the division of rights and it

would appear that in CDM the comparative lower level of rights (such as the right to practice autonomously) of nurses when compared to doctors affects the way nurses respond to self-managing patients. The relative powerlessness of nurses not only makes them feel particularly vulnerable to litigation (Annandale, 1998) but also may result in nurses imposing tasks (Corbin & Strauss, 1993; Strauss, 1985) on patients such as complete abstinence from alcohol that are different from the patient's own self-managing strategies. This section has explored the effect of the medical division of labour and the chapter will now turn to explore the political acknowledgment of power differentials and the attempt to enable patient power.

6.3 Empowering the citizen

Chapter three explored the policy agenda surrounding long-term conditions, and in particular those aimed at enabling self-management. This shift in policy paradigm was partly triggered by the acknowledgement of a democratic deficit within the NHS (Baggott, 2004) and a medical dominance that was no longer acceptable following scandals such as the paediatric heart surgery services in the Bristol Royal Infirmary (Coulter, 2002). To address the power and democracy deficits policies were underpinned by patient participation and public involvement initiatives. Patient participation and public involvement is also seen to have the added bonus of improving health outcomes (Murray *et al.*, 2001), quality (Pickard *et al.*, 2002), and being desired by the majority of patients (Nordgren & Fridlund, 2001). In addition and as discussed in the last section, patient participation in health care is seen as a human right (Guadagnoli & Ward, 1998).

Despite the clear policy focus on participation and involvement there appears to be a continuing tension between the way it is defined at the Department of Health (Department of Health, 1999b; Department of Health, 2002b; Department of Health, 2004d; Department of Health, 2004e), and health care professionals' definitions. It has been suggested that participation and involvement is operationalised purely at a tokenistic level (Guadagnoli & Ward, 1998; Pattison, 2001; White *et al.*, 2004), and that it may be hiding a continuing professional agenda (Daykin *et al.*, 2004) focusing on compliance (Henwood *et al.*, 2003; Wilson, 2001). In addition the potential for conflict

between patient preferences as an integral part of participation versus the current emphasis on evidence based medicine and health care has been raised (Nolan, 2005). Beyond this tension of semantics and ideology other issues in participation and involvement have been highlighted. In particular, it is questioned whether all patients want to participate (Sanders & Skevington, 2003) particularly in conditions that need urgent and often complex treatment such as cancer (Kenny *et al.*, 1999). Equally it is asked whether it is a viable option for all, especially when health literacy levels are low (Gazmararian *et al.*, 2003; Pickard *et al.*, 2002).

Despite these issues and concerns regarding patient participation and public involvement, the tsunami of policy initiatives aimed at activating the user within the NHS is reshaping the terrain of health services (Harrison & Mort, 1998). Part of the focus of this study has been on expert patients and the EPP, with the former contributing to the force triggering the tsunami and the latter being heralded as the new terrain resulting from the policies (Department of Health, 2001a; Department of Health, 2004d). Sang heralds this new landscape as synthesizing *“the values of consumerism and citizenship, and which challenges public authorities, professions, and the public themselves to rethink their relationships, roles and responsibilities in relation to health-care delivery and service planning...”* (2004:187). This section will now move on to examine more closely whether as a key exemplar of the new paradigm (Sang, 2004), the EPP does empower the patient and address the power imbalance.

6.3.1 The Expert Patients Programme; a vehicle for patient empowerment?

Data presented in 5.4.9 suggested that the most overt strategy of both the EPP and BFC was to instil systematic approaches and enhance participants' knowledge, particularly by the setting of weekly goals and action planning. Such strategies are seen as an effective mechanism for self-efficacy (Farrell *et al.*, 2004) and teach individuals to set realistic goals that are more likely to be achieved (Bodenheimer *et al.*, 2002a). Action plan review was a central and often lengthy group process at the start of each EPP session, with lay tutors reframing any unachieved goals into a focus on what had been achieved. The

ultimate aim of action planning was to routinise self-care practices and as a tool was popular with EPP participants who often kept up the process post course. However, whilst a popular tool the course material also appeared to articulate (Corbin & Strauss, 1993) the medical division of labour by educating the participants about their role in chronic illness as defined by the medical paradigm.

Although rather reliant on the abilities of the lay tutor (Rogers *et al.*, 2005a) the EPP inherently promoted succinctness via the rigid time limits kept on each topic (5.4.9). However, whilst there was limited time on topics such as anger, fear and depression, the encouragement and modelling of peer support by the lay tutors provided a strong element of emotional support for participants, evidenced particularly at tea breaks when much of the mutual support was carried out in an informal way between participants. Thus the EPP instilled expert patient traits (5.2, 6.1.2) and in addition appeared to provide a safe environment to discuss the emotional consequences of living with a long-term condition. This provision of a “second person” (Code, 1995) (discussed further in 6.4.3) with whom participants could engage and identify with was indicative of the paradoxical nature of the EPP. Although there was an encouragement of expression of feelings, the concurrent content emphasising a rational approach towards patient- doctor encounters reinforced the discouragement of emotional expression within the medical consultation, thus enhancing the medical view of the expert patient (6.2.2).

The contradictory nature of EPP content both promoting and inhibiting the acknowledgement and importance of the individual’s feelings within the experience of chronic illness is indicative of the critiques that have been levelled at the programme. Wilson’s (2001) policy analysis suggested that the EPP had a Foucauldian potentiality of medicalising self-care practices within an individual’s previously hidden home life. This hypothetical seeping of medical power into all corners of an individual’s life via the EPP has been linked with the continuing language of disease and paternalism still present within the programme (Davidson, 2005) and it has been questioned whether the EPP can empower patients when so heavily reliant on the medical model (Fox *et al.*,

2005). Empowerment also becomes problematic when there is a focus on changing an individual's behaviour rather than societal structures (Anderson, 1996), with this study indicating that at the very least EPP graduates continue to face health professionals who are disinterested in dealing with active patients (5.4.9). Furthermore, the likelihood of such programmes promoting a white, middle class privileged position has been raised (Anderson, 1996; Rogers *et al.*, 2005a) and reaching minority groups has been an ongoing problem for the EPP (Griffiths *et al.*, 2005; Rogers *et al.*, 2005a; Wilson & Mayor, 2006). It has also been suggested that active self-management is such a complex set of skills (Thorne *et al.*, 2003) that generic approaches are unlikely to reach the depth required to develop these skills (Davidson, 2005). Rogers *et al.* (2005) process evaluation of the EPP indicates that a number of participants, particularly those with diabetes, would prefer a condition specific approach in order to acquire detailed information. However, this was not perceived as a particular issue by the respondents in this study (5.4.9). Nevertheless, whilst superficiality was often apparent within the EPP observed it often served to fuel a thirst in individuals to find out more. Hence, the EPP appeared to encourage the development of overt-acceptor characteristics (6.1.2); the ideal patient within the medical paradigm. However, the EPP reaches relatively few people with chronic illness (Bury & Pink, 2005) and therefore makes comparatively little impact on meeting the emotional needs of the vast majority of people with chronic illness.

The thesis will now focus on the individual's need to have their emotional responses to their chronic illness responded to and supported.

6.4 Where is the experience of living with chronic illness acknowledged?

"Sickness is a threat to rationality, for it threatens social life and erodes self-control" (Lupton 2003:93). Rationality is one of the recurring themes in this thesis for it underpins the medical paradigm and is a characteristic of the expert patients described in 5.2.5. It is also one of the defining features of positivism (Code, 1991) which has shaped the medical profession's notion of

objectivity and the authoritative status of biomedicine (Code, 1995). Rationality pervades the discourse of health care professionals, with on the whole physiotherapists and doctors voicing a rational discourse, and the majority of nurse respondents in the study often replicating this dialogue. This rational discourse often eclipsed the actual experience of having a long term condition (Ironsides *et al.*, 2003).

It was suggested in the previous section that the EPP paradoxically acknowledges the subjective experience of chronic illness but simultaneously reinforces rationality. An example of this reinforcement is the use of the Prepare, Ask, Repeat, Take action (P.A.R.T model) (NHS Expert Patients Programme, 2002) – a logical sequenced approach to patient preparation for and communication within a medical consultation. This kind of approach emphasises the ethics of logic (Gilligan, 1982) and reinforces a masculine orientated desire for action (Davies, 1995) and autonomy (Code, 1991). However, the findings suggested that even when this model was applied there were often negative responses from the doctors, particularly if the “Ask” element was informed by an emotional reaction to the chronic disease (5.3.6).

6.4.1 The emotional aftermath of chronic illness

The emotional consequences of having a long term condition were a recurring theme from the respondents (5.5). Many of the study participants went through a range of emotions including anger, denial and fear which disappeared and reappeared during the condition trajectory (Baker & Graham, 2004). For many, particularly women respondents, these emotions were compounded by the “emotional baggage” of being the carer – either as a mother (van Mens-Verhulst *et al.*, 2004) or wife (Werner *et al.*, 2003). Thus the illness experience appeared to differ between male and female respondents dependent on their social roles (Reynolds & Prior, 2003).

From a Cartesian viewpoint, emotion is most problematic within the validity of knowledge (Code, 1991). Traditionally emotions are seen as needing to be controlled and they are not perceived as integral to the construction of knowledge. This is problematic for the informed expert patient, for as Code (1991) points out emotions such as anger or fear are often the trigger for

investigation and knowledge development. Indeed, the overt-acceptors such as M6 and F11 (6.1.2) clearly articulated the initial trigger for their knowledge development as being to ease anxiety. However, for many respondents the “baggage” was too heavy to hide and the consequences for them was to be labelled or stereotyped as non-credible.

6.4.2 Credible patients and rhetorical spaces

Although Code’s work (1991, 1995) can be criticised in defining gender biologically rather than a set of values, ways of thinking and skills that can be attributed to examples of women and men, nevertheless her work provides a useful theoretical framework. Code (1995) describes rhetorical spaces as the societal legitimization of speakers and interpreters in terms of credibility and trust. Apart from overt-challengers, most expert patients were viewed by the medical practitioners as credible, whereas the findings suggested that nurses (apart from the nurse specialists) were likely to only deem the covert-acceptors as credible. The overt-challengers were viewed by all the professionals as less credible and were frequently labelled as the heart sink patient (5.3.5). These patients were often the ones whose condition had not been diagnosed or were affected by conditions such as Chronic Fatigue Syndrome which at present has no definitive diagnostic test (Broom & Woodward, 1996). Stereotyping people as heart sink or “yellow flag” patients objectified these patients into a neat classification of problematic patient (Code, 1995), failing to respect them as individuals with their own unique narrative (Charmaz, 2002). These people were in a vicious circle for whilst they needed their condition to be medicalised to reduce stigma (Broom & Woodward, 1996), in utilising their emotional responses to underline their narrative they became untrustworthy actors in the rhetorical space. Credibility is strongly linked to the notion of morality (Asbring & Narvanen, 2002) and so these patients were likely to be labelled as manipulative, immature, hysterical (5.3.5) and quick to blame others (5.3.8). For these patients there was a lack of empathy in the professional patient encounter.

6.4.3 Living with a long term condition; needing the second person

Patients within this study generally identified the ideal professional as being kind, caring and able to deal with emotional distress with ease (5.3.7). This is congruent with the increasing acknowledgement in the literature that patients need and desire professionals that will listen to their narratives with empathy (Baker & Graham, 2004; Coulter, 2005; Lapsley & Groves, 2004). However, whilst the challenge of listening to patients by the medical profession (Kleinman, 1988) is seemingly beginning to be accepted (Tuckett *et al.*, 1985), it is argued that more than listening as a therapeutic intervention is needed (Frank, 1998). Frank suggests that listening must remain a gift rather than intervention, and until professionals are prepared to share their stories, to know and to be known, then patients will simply remain as “*the object of the professional’s privileged subjectivity...*” (p.199). During the observation it was apparent that only three professionals exhibited this sharing of stories (Taylor, 1998); the nurse specialists and consultant 02. It was also only these three who articulated this kind of communication as part of their role. Code describes this form of engagement as the second person relationship which develops “*through identification and differentiation, through listening and speaking with each other, rather than through struggles to dominate or annihilate the other...*” (1991:88).

Although these three professionals were all female it was evident that patients’ descriptions of practitioners exhibiting a second person relationship extended to some male clinicians. Classically these tended to be male GPs whom the patient had known for a number of years (Horobin & McIntosh, 1977) and thought of in terms of a friend (Code, 1991).

However, the overwhelming story was one of a lack of a second person, with participants often describing they had no credibility within the rhetorical space between patient and clinician (Code, 1995; Werner *et al.*, 2003). Whilst Kleinman’s (1980) (3.3.5) seminal work on the differing explanatory models between patient and clinician highlights why there is often a lack of connection between the two actors, it does not fully explain how the expert patient manages to traverse the popular/professional health care sectors.

6.4.4 Learning to be an expert patient

Many expert patients learnt to speak the language of the masculine, rationalistic world of health care. Both Code (1991) and Davies (1995) argue that this is compromising the real self and experiences, and so far this thesis has developed a picture of peoples' subjective experience and tacit knowledge frequently being denied in the professional-patient rhetorical space. If the notion of compromise is accepted it is unsurprising that expert patients did so, for all except overt-challengers were rewarded by the partial acknowledgment of autonomy. Consequentially it was these patients who could make decisions regarding the timing of the next appointment (5.2.3) and be more effective in pushing referrals. In relation to the medical division of labour discussed previously, it would appear that the majority of expert patients (apart from overt-challengers) had accepted many tasks in the arc of work but had also negotiated rewards (Corbin & Strauss, 1993; Strauss, 1985).

Code (1991) describes the traditional view of autonomous man as one of moral maturity, rationality and self-consciousness, all of which are congruent with the descriptors of the expert patient (5.2.3). Code goes on to paint a picture of the contemporary autonomous man (table 29). This appears to replicate the image of expert patients characterised in this study and described by professionals, particularly doctors. For example, M6 and F11 (5.2.5) had to be self-sufficient, independent and self-reliant as they lived on their own. All expert patients in the study were self-realizing, even overt-challengers were channelling their talents into researching their often un-diagnosed condition

- Self-sufficient
- Independent
- Self-reliant
- Self-realizing
- Directs efforts towards maximising personal gains
- Devises rules to protect himself from intrusion
- Awareness of rights & expectations
- Efficient

The contemporary autonomous man (Code, 1991)

Table 29

and possible treatments, and all were aware of their rights. In addition, by actively self-managing their condition they were to some extent protecting themselves from the intrusion of the medical gaze (Foucault, 1976), although it can be argued this was simply replaced by the intrusion of self-surveillance or pastoral gaze (Armstrong, 2001; Wilson, 2001). However, whilst all expert patients were attempting to have maximum gain in terms of their own health, this was rarely at the expense of others. Indeed, as the findings illustrated and as discussed in 6.1.2, there was a strong ethic of citizenship and helping others apparent in expert patients. Code's (1991) notion of autonomous man also fails to be applicable to the expert patient in another way; that of being a separated individual who appears to have no need of connectedness to another. In contrast, all expert patients' narratives told of a second person, but these took a variety of forms. Self-help groups and for some the EPP played a significant part in being the second person, whilst for others it was individual friends, spouses or colleagues. However, overt-challengers still sought and needed their narratives to be shared within the rhetorical space between doctor and patient, with their distress increasing when no one was listening (Code, 1995; Frank, 1998). Nonetheless, although the majority of expert patients had not compromised their need for a second person, nor disregarded the needs of others, their sharing of stories had been reformulated as outside of the medical encounter. Hence, what the majority of expert patients had learned over time through experience was not to expect the second person to be found in the rhetorical space between doctor and patient. Apart from overt-challengers, expert patients had learned to manage their feelings and follow the subtle "feeling rules" set by medicine (Hochschild, 1983). However, the effort of managing this was not without cost.

6.4.5 The emotional labour of being an Expert Patient

Many expert patients appear to relieve some of the blame and marginalisation experienced by people with chronic illness (Anderson, 2005; Frank, 1990) by exhibiting behaviours that are approved by the medical establishment.

However, the acting of this behaviour takes a significant amount of effort (5.2.3), which can be explored further by applying Turner's (1984) four tasks of the body (table 30).

I have argued that medical dominance was perpetuated, albeit in a reformulated version, by the majority of expert patients. Expert patients imposed self-discipline and embodied regulation ranging from self-surveillance of diet and exercise, to body responses, for example, to homeopathy. Throughout the typology (6.1.2) individuals all restrained themselves from undertaking practices, such as alcohol consumption, that they had enjoyed before learning to be an expert patient. Finally, and as previously discussed, the EPP has been developed as a commodity specifically designed to harness and develop the skills of being an expert patient (Department of Health, 2001a).

Tasks of the body	The Expert Patient body
Reproduction/patriarchy	The expert patient sustains a reformulated version of medical dominance
Regulation/panopticism	The expert patient extensively practices self-surveillance
Restraint/asceticism	The expert patient undertakes self-care practices including self-denial of pleasure from the pre-illness life
Representation/commodification	The EPP attempts to commodify and replicate the expert patient

Four tasks of the body (Turner, 1984)

Table 30

The effort that maintaining these four bodies took can be seen in relation to the extent of emotional labour undertaken by expert patients (Smith, 1992b). As discussed in 6.2.5, emotional labour is described as the management of feeling to create a publicly observable visage (Hochschild, 1983), which may well be commodified in occupations such as nursing (Frank, 1990; James, 1992).

Whilst there has been a growing body of work on emotional labour in nursing (Dingwall & Allen, 2001; Ersser, 1998; James, 1992; James, 1993; Phillips, 1996; Smith, 1992b; Smith & Gray, 2001; Smith & Lorentzon, 2005) and a recognition of patient as health worker (Strauss *et al.*, 1984), there has been comparatively little recognition of the emotional labour undertaken by

patients. Apart from overt-challengers, many expert patients had learned the skills of empathetic responses and appropriate non-verbal communication often to a level where the emotional baggage of living with a chronic disease (Frank, 1990) was disguised from the professional. Hochschild (1983) and Frank (1990) suggest that the real problem with emotional work is whether an individual's real emotions become lost to themselves. Certainly, a significant number of expert patients demonstrated such stoicism that this could have been the case. Numerous respondents within the study were not only enduring the consequences of chronic illnesses such as PD or MS, but many were concurrently dealing with events such as marital break-up. However, they would rarely bring these issues into their encounters with health professionals preferring to use other support mechanisms such as friends.

Nevertheless, whilst the effort of being an expert patient was great, so too were the consequences of not being seen as an expert patient. For some people the emotional work had become too great to bear. For them their life with the condition had become nightmarish (5.5.2) and they could no longer maintain or had never managed to develop a façade of stoicism. Whilst some respondents told how this had led to a passive acceptance of referrals to, for example, counselling, others developed the fighting spirit characteristic of overt-challengers. However, as discussed previously the consequences for this latter group was not to be respected as expert patients. These were the patients identified as "heart sink" or "yellow flag" whose stories were given less credence by health professionals. The former group who could be termed passive-acceptors of care, tended to be made up of those already marginalised through their ethnicity, gender or social class, reflecting Hochschild's (1983) observation that the lower the status of an individual then the more discreditable displays of emotion are perceived. The findings suggested that some of the professionals found it difficult to deal with people from black and minority ethnic groups, particularly if they could not speak English well. The inability of people being able to describe their symptoms in a clear and succinct manner appeared to lead some professionals into questioning the credibility of the patient story (Ali *et al.*, 2004). This was equally applicable to the response of GPs to "over-emotional females"; again the inability to relate a clear and concise history further marginalised this group of patients. Whilst

respondents in the study were predominantly white, middle class reflecting the study setting, there were a number of expert patients in manual occupations. Although inherently linked, it appeared more the level of health literacy (Gazmararian *et al.*, 2003) than social class that related to acknowledgement as an expert patient. Nonetheless, it was interesting to note that a few participants in the observation of clinics did have mild learning difficulties and yet still demonstrated many of the features in the typology (6.1.2). Whilst the observation data could not provide evidence for this, there may be a link to upbringing with Hochschild (1983) drawing on Bernstein (1974) suggests that those from a “personal family control system” will have experienced a focus on feelings rather than clear, formal rules of a “positional family control system”. Individuals brought up in the former are more likely to have been encouraged to manage their feelings. Nevertheless, the stereotyping of these patients with learning difficulties as vulnerable appeared to give permission for the development of a second person relationship (Code, 1991) and these were often comparatively enabling professional/patient encounters. The consequences for the individual of constantly balancing the outer presentation of self as expert patient and the inner self experience of living with chronic disease (5.6) were often feelings of frustration and despondency. As illustrated in figure 17 (5.6.7), visible emotional responses often led to the label of being neurotic and a poor self-manager and did not increase the chances of accessing the desired services. Unless the individual disguised the emotion within the professional encounter and developed expert patient characteristics, a vicious circle was fuelled of being perceived as a non-expert patient with consequential disempowerment and poor services. I have argued so far that many expert patients managed their emotions as reformulated by the medical paradigm. Within the critical realist framework the triggers for this reformulation will be explored.

6.5 Triggers for the reformulation of the Expert Patient.

The storyline of the findings through a critical realist interpretation has already been presented in the last chapter. This section will explore this in greater depth by discussing how both agency and structure is shaped by the dominating paradigm of biomedicine. So far I have linked this paradigm to

notions of power, the division of labour, and rhetorical spaces. I will now draw the themes together in order to demonstrate how this has shaped the expert patient.

6.5.1 Trigger 1: Organizational paradigms as structure

The NHS is fed by two rivers of rational discourse; biomedicine (Lupton, 2003) and bureaucracy (Davies, 1995). Whilst these discourses have similarities because of the underpinning rationality there are also some competing nuances. As explored previously in this chapter, medicine as shaped by biomedicine has formed itself into a virtually impregnable force as a profession (Freidson, 1970). The issues this brings both for patients and other health care professionals has been discussed, but it should also be acknowledged that the notion of medical imperialism has been critiqued (Williams, 2001). Indeed, concepts of professionalism are tied up with notions of altruism and humanism (Crowe, 2000). This is illustrated by nostalgic media portrayals of the caring NHS such as *"The Royal"* (ITV 2006), or the recent example of a doctor being elected to parliament on the single issue of local hospital closures (Greener, 2004). However, from the patient and professionals' perspective in this study it was clear that the discourse of bureaucracy dominated the image of the statutory services. Bureaucratic systems of managing care framed the professionals' working practices. Nurses frequently spoke of working to protocols, clinical guidelines and standardized care pathways (Colyer, 2004). The doctors were also affected by this discourse, for example Consultant 01 identified his focus on HbA1c measurements as being a standard used to measure the performance of his department. The drive for all professionals to be productive, efficient, mechanistic and demonstrate measurable outcomes was often incongruent with a philosophy of caring (Crowe, 2000; Dingwall & Allen, 2001). Indeed, this discourse appears to further amplify the lack of value placed on the emotional aspects of care (Ceci, 2004; Smith, 1992b) and there were a number of narratives from patient respondents about a perceived lack of care. These stories were more likely to be related to instances in long-term care scenarios, whereas the majority of patients spoke positively about their experiences of

acute services (5.4.6), possibly reflecting the historical over-emphasis on acute care in the NHS (Lapsley & Groves, 2004).

This continuing picture of services dominated by a standardized, bureaucratic discourse goes against the current rhetoric of policy. As discussed previously, current policy is aimed at increasing patient choice, participation and public involvement, and a key tool used for this is decentralization (Peckham *et al.*, 2005). This rhetoric would suggest that patients should be experiencing services more tailored to their individual needs and yet this was often not the case. This may be explained by a parallel agenda of ever increasing performance targets, centralised regulatory powers and NSFs; thus far from decentralization there is continuing centralization that is not congruent with individual patient care (Peckham *et al.*, 2005). For example, NSFs have been criticised as increasing the marginalisation of people affected by conditions not specifically identified within them (Baggott, 2004). The problem of standardization is further compounded for people with long-term conditions by a lack of integration of primary and secondary care (Mayor, 2004). Many respondents in the study cited this as a problem not only between primary and secondary NHS services but also between social care and health services. However, many expert patients appeared to have adapted to the bureaucratic discourse. For example, respondents within the Parkinson's Disease focus group spoke of funding their own welfare officer via their contributions to the Parkinson's Disease Society. The welfare officer was used by the members to negotiate the standardised care on offer into a more individualised service tailored to patient's individual needs.

However, for many patient respondents in the study, the overriding bureaucratic discourse was problematic. In addition, despite the policy rhetoric of patient centredness and patient empowerment (particularly as voiced in the EPP policy), it appears that medical power has been only marginally affected. I will now explore this parallel discourse of biomedicine and build a case that as an agency (Bhaskar, 1986), biomedicine has also shaped the expert patient.

6.5.2 Trigger 2: Health care professionals as agency

The way doctors approach the patient encounter is shaped by their training and socialization. The medical priorities in terms of effectiveness are to rapidly

collect facts in a positivist, scientific fashion and traditionally little time in medical training was devoted to interpersonal communication (Lupton, 2003). This was apparent in the respondents with consultant 01 describing medical training as focusing on concrete decision making (5.3.8).

Physiotherapists are also trained in rigorous, reductionist clinical diagnosis (Jones, 1991), and the findings of this study suggested that developing an interpersonal relationship with the patient was not high on their priorities. However, it should be noted that the physiotherapists within the study were all NHS employees, and whilst many patient respondents found interaction with physiotherapists problematic, this was often not the case with physiotherapists in private practice. Indeed, it was these practitioners that were often identified by patients as the most helpful.

From a role preparation perspective, there is comparatively greater emphasis on interpersonal communication within nurse training (Nursing and Midwifery Council, 2004b). Nursing theorists stress the importance of holistic practice (Aggleton & Chalmers, 2000), and humanistic caring approaches are seen as forming the core value of nursing (Kitson, 2002; Taylor, 1998). However, the findings suggested that the majority of nurses within the study did not articulate this aspect as being central to their work despite being one of the most valued attributes of a professional in the patients' opinions (Coulter, 2005; Smith, 1992b). It would appear that the agency of medicine was not only in a reciprocal shaping process with the structure of the NHS and wider society, but was also extending to the other agency players in this study. The interactions of the medical profession was not only shaping their own professional identity (Apker & Eggly, 2004) but also was strongly influencing the identity of nurses and physiotherapists (Salvage, 2002).

Nonetheless, as with the analysis of the structure in the previous section, medicine is not the only discourse shaping the agents and influencing the lack of emphasis on the psychosocial needs of patients (Graugaard *et al.*, 2005). Taking the didactic relationship between structure and agency (4.2.7), it is unsurprising that the discourse of bureaucracy is influencing professional actions and identities. The tensions between managerialism and autonomous professional practice have pervaded the patient-professional relationship (Maseide, 1991), with this study suggesting that even when practitioners

wanted to tailor services to meet the needs of individual patients they were unable to do so because of “*bureaucracy*” (5.4.5). Cost rationing was also frequently cited as a problem for all professionals (5.3.8), however there was some evidence that out of all the professions in this study, doctors had learned to “play the bureaucracy game” (Germov, 2005). Evidence based medicine (EBM) was a card consultant 01 aptly played in this game. His consultation was in direct contrast to consultant 02, and as described in 5.6.2 was framed almost exclusively by the HbA1c reading. Clinical data was entered into the computer contemporaneously by consultant 01 during the consultation, thus providing the evidence for departmental audit. EBM was the rationale presented to patients for the need to keep their HbA1c in a strictly confined range with the blame being laid at their feet if they were out of range (Pill *et al.*, 1999). Thus the effect on many expert patients was to respond by focusing on these readings and using technical language that placed such measurements at the fore of the consultation.

Consultant 02 hand wrote notes after the consultation and spent almost as much of the consultation on psychosocial aspects. However, it must be acknowledged that it may be the nature of dermatology with comparatively little biochemical markers and a reasonably well recognised need for psychological support that influenced the different approach. Nevertheless, EBM is seen to be a counterweight to bureaucracy, for if professionals can justify their practice as the highest standard it significantly strengthens the professional group’s armoury against rationing (Armstrong, 2002).

It was the reactions to the scenarios that proved most interesting from a professional-EBM/evidence based practice perspective. The GPs were presented the asthma and Parkinson’s disease scenarios (appendices 4b&d), consultant 01 the diabetes scenario (appendix 4c) and consultant 02 the eczema scenario (appendix 15a). Interestingly all the doctors stated they had no concerns regarding the scenarios, with comments such as it is unlikely to do any harm or in the case of the Parkinson’s disease scenario that medicine has little to offer. Thus the doctors were demonstrating a patient centred rather than EBM approach. Armstrong (2002) argues that whilst EBM strengthens the profession as a group, it weakens professionals as individuals. He goes on to suggest that patient centred medicine whilst acknowledging the patient as

central to the clinical encounter, also helps to maintain individual clinical autonomy and control. It was apparent from the findings that all the doctors used their clinical autonomy to sanction patient self-management. However, sanctioning as an activity requires an associated power (Goldie, 1977) and is more likely to occur within the division of labour when the sanctioner does not feel threatened by the transfer of work (Ovretveit, 1985).

Physiotherapists had a little more concern about the Parkinson's disease scenario because they knew little about Chinese medicine (although neither did the GPs). However, they had no anxieties over the asthma scenario. In contrast nurses had concerns about all the scenarios presented to them; wound healing (practice nurses)(appendix 15b), diabetes (diabetes nursing focus group and nurse specialists), anticoagulation (anticoagulation nurse focus group)(appendix 4a) and asthma (respiratory nurse focus group). All their concerns focused on the self-management strategy not being seen as evidence based and therefore fraught with potential legal difficulties. However, and as discussed in 6.2.6 it appeared more the case that the nurses lacked the clinical autonomy to feel able to sanction the self-management strategy. If Armstrong's (2002) argument is applied to nursing it may be that the current emphasis on evidence based practice is more to do with strengthening the professional group rather than individual practitioners. Certainly it was apparent that apart from to some extent the nurse specialists, nurses in this study did not feel able to use professional judgement at an individual patient level. The effect on many patients in this study was that narratives describing their perspective about chronic illness were not recognised (Koch *et al.*, 2004) nor engaged with (Graugaard *et al.*, 2005) either by professionals or the health care system. However, some patients had managed to navigate themselves through these turbulent waters of structure and agency, and it is to these expert patients that the chapter now turns.

6.5.3 The Expert Patient as navigator

Common to all expert patients in the typology (6.1.2) was the ability to navigate within a structure and agency dominated by medical and bureaucratic discourses. How they differed was their mode of travel; for overt-acceptors the route was relatively smooth whereas overt-challengers appeared stuck with a

bucking horse for their journey. In addition, all expert patients used signposts to help them find their way. Of these signposts it appeared that the voluntary sector provided the clearest, particularly in the form of self-help groups (Mayor, 2006). These organizations played a dual role of not only helping the person to make sense of these competing discourses, but also by providing the second person (Code, 1991). For example, an issue raised by patients and carers affected by Parkinson's Disease was the inability of nursing staff to respond appropriately to the needs of affected in-patients. One of the greatest needs is to have medication at individually set times rather than waiting for the ward drug round. The local branch of the Parkinson's Disease Society had produced literature to be placed on all wards and was attempting to run an educational programme for nurses. Support groups also provided the venue for interrogating the medical discourse, both for checking the individual's understanding and the credibility of the discourse. Providing the second person is demonstrated by M6 (5.2.5), who as a member of the local branch had been manning a help desk at the out-patients department. His narrative of sharing his story with a newly diagnosed lady and the significant effect this had on her psychological state gives testament to the need for the second person in long-term conditions.

Similarly, CAM also provided the second person for many, particularly as the very essence of such therapies depends on the sensitivity of the patient-therapist relationship (Lupton, 2003). CAM provided a resting place away from the dominant medical and bureaucratic discourses and appeared to be used as a temporary mooring for many expert patients on their journeys. Private medical care was often utilised by expert patients when the bureaucratic discourse was seen to compromise the quality of NHS care. Patients generally accessed private care when waiting lists were too long or the NHS did not provide the standard of care desired. The sense of personal control that private medicine brings (Lupton, 2003) often added fuel for the journey.

The EPP also provided a signpost for some patients in the study. As discussed previously this was dichotomous in providing information and a venue for sharing stories and comparing notes, and reinforcing behaviours shaped by the medical paradigm. The paradox of the EPP illuminates the crux of the question

about expert patients; are they reframing the medical and bureaucratic discourses, are they being shaped by these discourses, or have they managed to balance self and the dominant discourses of structure and agency?

The patient as consumer has been seen as a key challenge to medical dominance (Lupton, 2003), and the rise of health consumer groups such as the Long Term Medical Conditions Alliance are seen as an increasingly powerful movement (Baggott, 2004). However, the findings of this study did not suggest that any of the expert patients were actually changing medical dominance or the bureaucratic discourse. Whilst overt-challengers were more likely to effect a change in service delivery (an example being able to access domiciliary NHS physiotherapy 5.2.3), this tended just to be an individual case rather than the extension of the service to all clients. In addition, the continuing perceptions of these patients as heart sink or yellow flag revealed the on-going stereotyping framed by medical discourse (Code, 1995).

A more likely case are that dominant discourses are shaping the expert patient. This is reasonably visible as expert patients were constantly rewarded for their approved self-management by respect from the doctor, and better ease of access to services. Overt-challengers often followed non-approved self-management strategies such as adopting an unusual and complex dietary regime. Whilst they lost the reward of respect and were generally disliked, their fighting spirit often resulted in gaining services such as some investigations. However, the reward of respect and a relationship with an equalised feel that expert patients apart from overt-challengers received was seen as a very potent prize. As discussed previously in this chapter, it may be the case that professionals, particularly doctors, allowed this prize for a number of reasons. First, it may be perceived as the medical professions' token in patient partnership (Pattison, 2001). Second, it has the potential of shifting the blame for ineffective management of chronic disease from doctor to patient (Broom & Whittaker, 2004), and lastly in a Foucauldian sense it can be seen as extending medical surveillance from the clinic to the patient's home life (Armstrong, 2001).

However, if the work of Foucault is used to further explore the question of who is shaping whom, the case of the expert patient being shaped by the dominant discourses does not appear that clear. As Foucault suggests

(Peerson, 1995), power is not simply a matter of one person having more than another, rather it pervades all interactions and all actors. Perhaps the respondent describing “tame patients” and “tame professionals” (5.3.7) summed the process up best. Certainly the expert patients in this study were very aware of the power of the dominant discourses, but had managed to play the game to their benefit. However, this was of cost to the expert patient themselves and also for those who failed to navigate the journey.

6.6 Conclusion

Within this thesis I have developed a typology of an expert patient, arguing that the rational, objective presentation of many expert patients is shaped by the dominant medical paradigm and despite the rhetoric of empowerment strategies such as the EPP, the shaping of the expert patient further serves the medical division of labour. In addition, the influence of both the medical and bureaucratic paradigms appears to cast the expert patient as a particular threat to the relatively powerless discipline of nursing.

In developing this argument I have not conducted an exposition on a sole theoretical framework. Rather, as informed by critical realism (Bhaskar, 1986) I have drawn on a number of theories that have provided useful concepts to illuminate the thesis.

Foucault’s work (1976) has been utilised to illustrate arguments around medical dominance and the ever-present clinical gaze. Through a Foucauldian perspective the expert patient is seen not only as subject to the clinical gaze but also by extension into self-surveillance in managing their chronic disease. However, I have also argued that there is the possibility that not only is the biomedical paradigm shaping the expert patient but in turn some expert patients are shaping the medical encounter.

The relative positions of patients, doctors and nurses in terms of power have been illuminated by Strauss *et al*’s (1984, 1985) exploration of the medical division of labour. Drawing on this construct further, I have argued that whilst patients and nurses undertake the majority of work in CDM, this labour is not rewarded by equality of rights within this arc of work (Strauss *et al.* 1984, 1985). Thus patients and nurses continue to be marginalised. I have also suggested that the EPP reinforces the medical division of labour.

Finally, I have drawn on theorists whose work focus on subjective needs and emotion work (Code, 1991; Code, 1995; Hochschild, 1983; Smith, 1992b). I have argued that for a patient to be recognized as expert by the clinician they must undertake significant emotion work. The emotional labour of an expert patient results in patient/health professional encounters that are often devoid of subjectivism, with narratives of chronic illness often not recognised or engaged with by health professionals or health care services.

In conclusion, these groups of theoretical frameworks have provided an illumination to uncover the nature of the expert patient as a concept. I have presented a substantive theory by developing a typology of the expert patient. The final chapter will now explore the implications of the thesis and suggest ways of addressing the issues that have arisen out of this study.

CHAPTER SEVEN

CONCLUSION

7.0 Summary

This thesis has been constructed from a study exploring the experience of active self-management in chronic disease. I have described a storyline that illustrates the journey of an expert patient, and have investigated the barriers and enablers on the journey. I have argued that throughout the journey there is a pervading discourse of cultural codes of gender. By utilising a critical realist perspective, I have deconstructed this discourse further revealing it as shaped by the medical division of labour.

I have posited that there is a typology of expert patients. I have argued that whilst expert patients all draw on a number of sources of expertise that can be categorised as empirical, aesthetic, ethical, experiential and tacit knowledge, expert patients can be differentiated in four ways. First, there were different responses to NHS services with some accepting perceived shortfalls in services but others challenging these gaps in services. Second, there were varied motives for knowledge seeking ranging from the need to reduce anxiety to using knowledge to actively check health professionals' treatment suggestions. Third, expert patients' communication styles in consultations differed from appearing relatively passive to openly challenging. Finally, there was diverse emotion work (Hochschild, 1983) undertaken in consultations from suppression of emotional expression to complete openness. These responses and behaviours reflect the discourse of the cultural codes of gender. In particular, the category of overt-acceptor was characterised by the masculine gender code, and was presented as the idealised expert patient from the biomedical paradigm.

As with all attempts at categorizing human behaviour and responses, the typology was not fixed but each expert patient had a number of dominating features that would map them more strongly into one area of the typology. There was also some evidence that expert patients moved within the typology over time; an area that merits further research and will be discussed later in this chapter.

I have also presented the differing professional responses to expert patients. Compared to the other health professionals, nurses regarded expert patients as a particular threat to their professional integrity. This difference was particularly marked by anxieties regarding litigious issues in self-management, with nurses very concerned about their vulnerability in patients' self-management errors. I have argued that the nurses' responses are one of the many features that suggest the medical division of labour continues to shape both service provider and user.

Drawing on a number of theoretical frameworks (Code, 1995; Foucault, 1976; Hochschild, 1983; Strauss, 1985) I have argued that the medical division of labour has transmuted an idealised expert patient into someone who removes the subjective self out of medical encounters. This not only results in significant emotion work for patients but also reinforces the marginality of caring work such as nursing with its associated focus on meeting subjective needs.

Finally, I have argued that the Expert Patients Programme as the flagship initiative in promoting active self-management is paradoxical in nature for whilst it does provide an arena for the subjective self, it simultaneously reinforces the idealised expert patient as someone who keeps the subjective invisible within medical consultations.

7.1 Implications for policy

The chapter will now turn to the policy implications for the four main areas of service provision explored in the thesis; the EPP, medicine, physiotherapy and nursing.

7.1.1 Implications for the EPP

I have argued that through the course and teaching material the EPP inherently articulates the medical division of labour by coaching participants on their role within chronic illness as defined by the medical paradigm. However, one can question whether this in itself is problematic, for the findings of this study also suggest that individuals such as overt-acceptors were rewarded for their behaviour by increased ease of access to services and overt respect from clinicians. As such the EPP is acting as a facilitator of the patient activation

approach where patients prepare for consultations, perceive they are actively involved in decision-making and act as partners in the consultation, with a systematic review suggesting that this approach will improve health outcomes and self-efficacy (Michie *et al.*, 2003). Nevertheless, many aspects of the EPP are problematic not least because it reinforces illness as part of self-identity and emphasises the requirement to be “successfully ill” (Bury, 2006). The rigid teaching materials not only underline the medically defined attributes of an expert patient such as succinctness, but as identified by many lay tutors (Kennedy, 2006) are difficult to coach from and fail to recognise the complexities of living with a long-term condition.

Proponents of the EPP would counter these criticisms by pointing out the life-changing stories where participants have voiced a sense of regaining control and autonomy (Expert Patients Programme, 2006). However, the notion of patient autonomy plays to the middle class with commentators arguing that the EPP may actually be promoting health inequalities (Bury, 2006; Daykin *et al.*, 2004) particularly as it reaches so few (Kralik *et al.*, 2004).

Although I have presented the above issues as inherently problematic within the EPP, I have also argued that the EPP has the potential to play a major part in helping people live with their chronic disease by providing the “second person” or “rhetorical space” (Code, 1995). Whilst it has been questioned whether it is appropriate for statutory health services to be providing this social network (Bower, 2006), nevertheless emotional support is high on the patient wish list (Coulter, 2005) and recently recognised by government (Department of Health, 2006d). Perhaps for the ears of commissioners a more cogent case for the provision of the “second person” is the increasing evidence that it is emotional distress and social isolation that are the main indicators of risk for frequent unplanned hospital admissions (Cole, 2006). I would suggest that it is this evidence in combination with the findings of this study and others on the merits of the EPP that may facilitate its survival as a Community Interest Company (CIC) (Lord Warner, 2005).

The implications for the EPP are therefore to focus more on this element of the programme by a number of mechanisms. First, there needs to be a move away from the rigid material so that lay tutors may more flexibly respond to the needs of the group. Second, I have argued that the ability to respond flexibly is

at present reliant on the tutor's previous work experience and personality. For all lay tutors to meet this challenge there needs to be a more robust preparation for dealing with emotions and group management (Kennedy, 2006). Third, whilst the increased local embedment a CIC will bring is likely to result in less tokenistic public involvement than a centralised top-down approach (Peckham *et al.*, 2005), nevertheless the EPP does need to be entwined with the NHS if a successful whole systems approach to self-care is to be achieved (Rogers *et al.*, 2005b). Self-care as envisaged by the philosophy of the EPP is more likely to be seen as a valued part of the NHS if the promised focus on self-care in the Quality Outcomes Framework is realised (Department of Health, 2006d). Fourth and as part of a whole systems approach, the role in the voluntary sector from where self-management programmes were first evangelised needs to be acknowledged and valued by the statutory health services. The breaking down of boundaries between the voluntary and statutory health care sectors may be the way to increase effectiveness of the EPP at community level and be central to the self-care networks for all envisaged by current policy (Department of Health, 2006d).

7.1.2 Implications for professionals; doctors & physiotherapists

I have argued that whilst there has been an increasing acknowledgement of the need to involve patients as partners in making decisions concerning their treatment, there is a pervading sense that this is simply a reformulation of the traditional doctor-patient relationships, with medicine retaining the fundamental elements of its power (Salter, 2004).

Despite the medical profession's work on adapting the medical curriculum to have an increased emphasis on communication skills, relationships with patients (General Medical Council, 2003) and a foundation based on concordance (Raynor *et al.*, 2001; Royal Pharmaceutical Society of Great Britain, 1997), there appears to be a continuing problem exemplified by an enduring adoption of the acute care model in the majority of situations (Assal, 1999). This approach assumes a rapid intervention carried out by professional expert on a relatively passive patient with the aim of cure or significant recovery. I have argued that while doctors and physiotherapists generally voiced engagement with the chronic care model, their unanimous description

of an ideal patient being one that was quick and easy to treat suggested a preference for many aspects of the acute care model. One of the resulting implications is that concordance is generally professionally rather than jointly defined with the patient. Although interviews with doctors and physiotherapist focus groups gave accounts of being at ease when patients refused treatments, the observation of clinics and interviews with physiotherapists suggested this was often not the case. There appears to be two competing reasons for this tension; firstly health professionals, particularly doctors, are deemed responsible for a number of public resources such as medicine costs. Hence if a patient refuses a certain treatment option in preference for a more expensive one concordance may be difficult to achieve in a climate of budgetary constraints (Maseide, 1991). Second, whilst the former patient behaviour may be typified by overt-challengers, other patients may feel unable to discuss the effect of the treatment on their everyday life with the doctor, passively accepting the prescription at the consultation but then not adhering to the treatment (Britten *et al.*, 2004).

Difficulties health professionals have in adopting the philosophy of concordance have been highlighted elsewhere (Raynor *et al.*, 2001; Thistlethwaite *et al.*, 2003; Wilson, 2001) but I argue that some of the measures taken to challenge clinicians assumptions regarding active patients may fail. Expert patients are increasingly being used to teach medical, physiotherapy and nursing students (Wykurz & Kelly, 2002), but the patients involved are unlikely to represent the full spectrum of expert patients. I have suggested that overt-acceptors are most likely to be involved in clinician education and therefore students are unlikely to be challenged about meeting the needs of those who at present are not facilitated to disclose their self-management strategies (Barry *et al.*, 2000). Equally, reliance on overt-acceptors is unlikely to prepare students adequately to address the needs and perceptions of service shortfalls from overt-challengers. Many respondents in this study including physiotherapists appeared to have an almost mythical notion of over-demanding patients (Greenhalgh & Gill, 1997). Utilising the skills of overt-challengers within clinical education may help professionals gain a deeper appreciation of the effects of living with medically unexplained symptoms and the consequences of previous patient experience of poor

practice. Overt-challengers may also help professionals gain an understanding of potential patient outcomes when patients perceive a lack of respect or not being valued as a person (Thorne *et al.*, 2005; Walter *et al.*, 2004).

Another strategy increasingly being used to facilitate clinicians' adoption of the chronic care approach is inter-professional education. It would appear that the medical profession is accepting to some extent the merits of inter-professional learning, albeit that any attempts to create a generic health professional are strongly resisted (Levison, 2003). I have suggested that the potential contribution of physiotherapists to chronic disease management was unrecognised by the doctors and nurses in the study. Inter-professional education both at under and post graduate level may address this issue as will the increasing numbers of multidisciplinary teams. However, although multidisciplinary working is not only seen as central in meeting the needs of people with chronic disease but also has a way of breaking the sole reliance on biomedical values (Assal, 1999), I have argued that despite the rhetoric these values continue to be given priority. In addition the teams observed as part of this study were still overtly led by a doctor and with competitiveness an enduring feature of medicine (Kassem, 2004) this leadership role is unlikely to be relinquished.

Finally, I have contended that for people with long-term conditions communication with the clinician underpinned by a trusting and sharing relationship is as important as technical competence, and vital for good health outcomes (Chisholm *et al.*, 2006). As discussed above, uncovering the reasons behind individual's "heart sink" or "yellow flag" behaviour particularly by the sharing of each others stories (Charmaz, 2002) may engender more mutual trust (Entwistle, 2004) and help prevent consultations where little is achieved for either party (Broom & Woodward, 1996).

7.1.3 Implications for professionals; nurses

This thesis raises significant implications within the context of the expanded role of the nurse within CDM, and the paradigmatic shift towards self-management as a right (Edwards *et al.*, 2004), necessity (Department of Health, 2005e), and obligation (Salter, 2004) in CDM.

Previous studies have identified the characteristics of patients perceived as problematic by British nurses (Kelly & May, 1982; Stockwell, 1984), and more recently have linked the concept with value judgements made by the nurses (Johnson & Webb, 1995) and nurses' perceptions of patient's refutation of their competence (Breeze & Repper, 1998). This thesis adds to this body of work by suggesting that many nurses appear challenged by reasonable queries regarding possible self-management strategies, and rather than being accepted as a genuine suggestion the patients described in the scenarios and within the data were viewed as non-compliant in the narrowest sense (World Health Organization, 2003). I have argued that the enduring medical division of labour fosters a paternalistic viewpoint (Raynor et al., 2001) in many nurses contrasting with professional standards, with respect both for the patient as a partner and their contribution to care as fundamental (Nursing and Midwifery Council, 2004a). I have considered how the Victorian ethic of patient as passive still appears to be a covert value within nursing (Salvage, 2002), and with the continuing reliance on medicine as a template for professionalism (Salvage, 2002) there is a focus on evidence-based practice (Kitson, 2002). This focus has not only impacted on the way nurses know their patient, moving from a relationship based on aesthetics, ethics and personal knowing to a discourse now dominated by empirical knowledge (Crowe, 2000; Speed & Luker, 2004), but is also emerging as a criticism as inappropriate for chronic illness increasingly characterised by co-morbidity (Tinetti et al., 2004) and user participation (Nolan, 2005). Examination of the competencies required in many of the current extended roles in the UK such as the Advanced Primary Nurse (Evercare) (Department of Health, 2003), reveal a clear orientation towards the biomedical model. Colyer (2004) critiques the functional description of such extended roles as lacking ontological foundation, with the value base of the profession eroded. During the interviews and focus groups, nurses rarely articulated meeting the emotional needs of patients as a key skill and yet observation of their work and data from the patients revealed this as a clear area of expertise. These new roles often bring isolation from nursing colleagues (Colledge et al., 2003) compounding the loss of nursing values (Hale, 2002) such as caring and valuing the patient perspective (Benner & Wrubel, 1989). There also appeared to be a lack of trust from the nurses

regarding patients' abilities to self-manage responsibly, directly impacting on their facilitation of patient involvement in decision-making (Entwistle, 2004). Paradoxically, it was the perceived sense that the patient did not trust the abilities of the nurse and was therefore questioning the suggested treatment (Kraetschmer et al., 2004) that resulted in the nurses' feeling challenged with a subsequent loss of self-worth (Breeze & Repper, 1998).

However, it has been revealed that the nurse specialists felt less challenged by expert patients and were consequently able to enter an appropriate therapeutic relationship with them (Wilson & Miller, 2004), and I would argue that the characteristics of these nurses should be used as a model for practice. The nurse specialists had confidence in their empirical knowledge which not only formed part of their decision making process but was also shared in an egalitarian manner with patients (Henderson, 2003). This confidence also resulted in a clear articulation of what they perceived as their strengths, and hence when patients did question treatment options there was openness and encouragement of the patient perspective, but with a co-existing continuing belief in their own abilities (Williams et al., 2005). However, there was not a sole reliance on this form of knowing with a concurrent emphasis placed on knowing the patient as a person (Morse, 1991). Indeed, it was very striking within the observation that the physician could remember all his patients' HbA1c readings but not their names, but the nurse specialists would describe the significant non-medical life stories of each patient before they came into the consulting room. As with all the professionals, the nurse specialists could describe their heart sink patient, but in contrast to the other nurses these were not the "*know-it-all*" but rather the infrequent potentially violent patient when the nurse specialists felt physically vulnerable. The nurse specialists also displayed two other key characteristics that are linked to the organisational structure within which they worked. Firstly, not only could they describe their discrete area of expertise but could also articulate the boundaries of their role which is in direct contrast to the reported problems in lack of clear advanced nursing role specifications (Bryant-Lukosius *et al.*, 2004; Nursing Times, 2004a). Although like many of the other nurses in the study they voiced feelings of being left with the "problematic" patient, they appeared to reframe their interactions with these patients based on an educational and supportive

approach as an important and valued role within the multidisciplinary team. Secondly and following on from the last point, their place within the multidisciplinary team and the way this team functioned exemplified contemporary concepts of professionalism (Davies, 1996). Davies describes new professionalism as being underpinned by reflective practice, interdependent decision making with patients and colleagues, practice that is supported, collective responsibility within a team, engagement with both the patient and colleagues, and the professional's strengths being clearly specified. Within the context of the expert patient (Coulter, 2002), it would also be appropriate to add that the patient's specific strengths and expertise should be acknowledged within the model of new professionalism. However, it should be noted that the nurse specialists worked in a team where the doctor was clearly in charge. Nevertheless, they voiced a stronger perception of autonomy than other nurses in this study who often appeared too constrained by the organizational structure to have autonomy (Daiski, 2004) and responsibility with authority (Manthey, 1992) that may have enabled them to respond more appropriately to expert patients. Although the rhetoric of enterprise (McDonald, 2004) pervades the UK National Health Service organizations, the majority of the nurses were too bound by hierarchy and protocols to be able to develop initiative, self-reliance and the ability to accept responsibility for one's own action such as enabling patients to undertake their own self-management strategies.

A great deal is expected of British nurses and indeed nurses from elsewhere (Bodenheimer et al., 2005) in meeting the challenge of CDM, not only from employers (Department of Health, 2005i) but also from patients (Hicks & Fide, 2003). As expert patients become increasingly common, professional roles need to change (Salvage, 2002) in order to respond to peoples' desires to have some meaningful control over treatment and to be treated as a valued partner in care (Breeze & Repper, 1998). Bodenheimer *et al.* (2005) describe the essence of the chronic care model as being the interaction between informed, activated patients and a prepared, proactive team. A number of authors (Campbell & McGauley, 2005; Coulter, 2002; Edwards *et al.*, 2004; Ersser, 2000; Kitson, 2002) describe the characteristics of professionals that would be part of this team with all emphasising the depth of understanding the

patient's viewpoint as key and reflecting on the professional's own response to that perspective. Whilst reflective practice and an emphasis on the patient perspective are espoused within British basic nurse education (Nursing and Midwifery Council, 2004b), there still appears to be room for improvement. In particular, although attitudes may be affected by paper exercises and pedagogic approaches, skills training, working with role models (Peden-McAlpine *et al.*, 2005; Thistlethwaite *et al.*, 2003) in a relationship of critical companionship (Titchen & Ersser, 2001) is essential. However the latter may be problematic in nursing if students are placed with senior nurses who do not display appropriate responses to expert patients. Whilst basic education is essential for the development of appropriate values, ethics and identity of a professional group (Apker & Eggly, 2004; Assal, 1999; Hale, 2002), continuing professional development is also of key importance (Gilbert, 2005). As discussed in the previous section, both basic and post-basic nurse education would benefit from utilising the skills of a range of expert patients including overt-challengers to confront assumptions (Coles, 1995; Wykurz & Kelly, 2002), and may benefit from adopting approaches from consumer orientated service industries (Nursing Times, 2004b).

However, educational development on its own will not be sufficient and nursing employers also need to address issues within organizations that impact on nurses' responses to expert patients. Temptation to routinize care is very high when there are unrealistic work loads and time pressure (Ersser *et al.*, 2005; Woodward, 1998) whereas the nurse specialists were notable in working within clinics where there was sufficient time allowed to explore the patient perspective. Whilst the development of multidisciplinary teams is linked to the rhetoric of nursing autonomy, the reality is all too often that they are medically dominated (Cott, 1997). Often nurses have little say in the planning and management of new posts (Dowling *et al.*, 1996), with substitution for doctors the main driving force rather than innovation in care (Salvage, 2002) and many nurses feeling forced to accept identities that meet organizational goals but not their own (McDonald, 2004). In order to respond appropriately to expert patients, nurses need to work in an organizational environment where professionals and patients learn from each other and where ways of working

are not decided by one group on behalf of another, but where activities are undertaken together (Kitson, 2002).

7.2 Future research

The findings in this thesis indicate a number of areas for future research. These focus on five main areas; the typology of the expert patient, professional education, litigation in self-management, nurses working in CDM and the EPP.

7.2.1 Typology of the expert patient.

I have presented the typology of the expert patient as the substantive theory in this grounded theory study. The findings indicated that expert patients travelled a journey and part of this journey may traverse the quadrants of the typology. Further in-depth research is merited in retrospectively tracking how people develop the characteristics of each quadrant and what triggers influence expert patients to change dominant behaviours¹.

In order to test the typology further and to enable the development of a potential formal theory (Strauss & Corbin, 1990), further research should be considered in a non-health care setting. This setting would need similar characteristics of an increasingly activated and informed user attempting to navigate well-established and relatively powerful institutions. I would suggest that one possible setting is parents and state schools and a qualitative study exploring whether the typology of overt and covert-acceptors and overt and covert-challengers is applicable to active and informed parents would be of theoretical relevance. If the typology was found to be applicable it may be of practical use in developing partnership approaches between schools and parents.

7.2.2 Professional education

I have argued that there needs to be a move away from solely utilising overt-acceptors as expert patients invited to teach on professional education courses.

¹ Through drawing on the study findings I have been awarded a grant by the British Skin Foundation to explore the development of patient expertise in Atypical Mole Syndrome. The results of this study may further illuminate the expert patient journey.

Research should be considered that explores how to recruit and support a range of expert patient contribution to professional education. Possible links to Patient Advocacy and Liaison Services (PALS) could be explored and evaluated as to whether overt-challengers who may access this service would find it a positive experience to share their knowledge with professionals, and whether this would be an effective mechanism to challenge professionals' assumptions regarding these types of expert patients.

7.2.3 Litigation in self-management

This thesis has highlighted that despite an increasing move towards active self-management in chronic disease, the UK law continues to be based on the notion of passive patient. Further research and clarification of the litigious issues in active self-management would be beneficial and may be particularly helpful in reducing the barriers imposed by professionals on patients who wish to self-manage.

7.2.4 Nurses working in chronic disease management

I have argued that despite an expanding role in CDM many nurses have particular anxieties working with active expert patients. This thesis has critiqued the focus on functional aspects of contemporary expanded nursing roles and I have argued that this has often led to a loss of attention on the central core of nursing in supporting the psychosocial needs of patients. Further research is required to evaluate the discrete strengths and skills nurses bring to CDM and the impact they have on patient outcomes, and to explore the contextual features that enable nurses to respond appropriately to the needs of expert patients².

7.2.5 Expert Patients Programme

I have developed an argument in this thesis that there is a need for the EPP to move away from the rigid delivery to one that is able to flexibly respond to the needs of differing individuals and groups. There is currently a move towards modifying the EPP and other self-management programmes in order to meet

² Following a successful bid for Service, Delivery and Organization research monies I am currently part of a research team undertaking a national evaluation of the nursing contribution to CDM.

the needs of groups with special needs such as ethnic minority groups³, those with learning difficulties⁴ and serious mental health problems with coexisting physical long-term conditions (Department of Health, 2006a), with a corresponding need for rigorous evaluations of these initiatives.

In addition it has been highlighted that evaluations of the standardised EPP format do not follow-up participants over a length of time and a longitudinal study of the effect and impact on, for example, health consumer groups (Mayor, 2006) would illuminate the extent to which claims of empowerment by the EPP can be justified.

7.3 Conclusion; a personal viewpoint

As described in chapter four, this doctoral study was triggered by a trio of experiences. First, as a nurse with a district nursing background I had some idea of the burden chronic illness brings to the individual patient and their family and yet felt I was probably only seeing the tip of the iceberg of this burden. Second, as an academic I had already carried out some small scale research exploring nurses' work with people with long-term conditions (Wilson, 2000) which had left me with a number of areas I still wished to explore. Finally, as someone with a long-term condition who has had attempts at self-management rebuffed by professionals I had a personal interest in exploring the reasons for this. It is only now towards the end of this work that I am able to reflect on how the typology of the expert patient, which I would posit is the unique contribution to knowledge that this thesis offers, relates to me. In over a decade I have managed my condition and can identify turning points when I gradually transformed from a covert-acceptor to overt-acceptor. Whilst I receive the "rewards" of respect and accessibility to services, I now reflect on whether this behaviour has only served to contribute to the invisibility of the needs of so many people living with long-term conditions.

³ I am currently part of a research team bidding for funds from Diabetes UK to develop and evaluate an intervention of peer education for South Asian groups affected by diabetes.

⁴ I have been awarded a grant from Valuing People (Department of Health) to evaluate a pilot EPP modified for people with moderate learning difficulties.

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Quality requirements of the NSF for long term conditions

Quality Requirement 1	A person-centred service <ul style="list-style-type: none"> • Integrated assessment and care planning • Information, advice, education and support • Meeting the special needs of people with rapidly progressing conditions
Quality Requirement 2	Early recognition, prompt diagnosis and treatment <ul style="list-style-type: none"> • Recognition and diagnosis • Information at diagnosis • Treatment • Meeting the special needs of people with rapidly progressing conditions
Quality Requirement 3	Emergency and acute management <ul style="list-style-type: none"> • Initial early resuscitation • Early treatment in specialist centres (for example Head Injury Units) • Early assessment by multidisciplinary rehabilitation teams • Information
Quality Requirement 4	Early and specialist rehabilitation <ul style="list-style-type: none"> • Specialist inpatient neuro-rehabilitation • Meeting the special needs of people with rapidly progressing conditions
Quality Requirement 5	Community rehabilitation and support <ul style="list-style-type: none"> • Appropriate information, practical advice, support and skills training for the patient and carers • Access to family or sexual counselling if needed • Co-ordination of health and social care resources • Provision of appropriate social support • Enabling interventions that focus on wider social participation.
Quality Requirement 6	Vocational rehabilitation <ul style="list-style-type: none"> • Basic vocational assessment • Informed guidance • Specialist vocational rehabilitation
Quality Requirement 7	Providing equipment and accommodation <ul style="list-style-type: none"> • Equipment to help with daily activities of living • Specialist, custom-built equipment for those with complex needs • Equipment to prevent deterioration • Providing accommodation • Information • Meeting the special needs of people with rapidly progressing conditions
Quality Requirement 8	Providing personal care and support <ul style="list-style-type: none"> • Choice and supported living • Improving access to support in the community • Improving access to care • Information • Meeting the special needs of people with rapidly progressing conditions
Quality Requirement 9	Palliative care <ul style="list-style-type: none"> • Adapting NICE guidance for supportive and palliative care for adults with cancer to the needs of people in the advanced or final stages of certain long-term neurological conditions

Quality requirements of the NSF for long term conditions

	<ul style="list-style-type: none"> • Information • Meeting the special needs of people with rapidly progressing conditions
Quality Requirement 10	<p>Supporting family and carers</p> <ul style="list-style-type: none"> • Integrated assessment of carers' health, social care and other needs • Designated contact person • Giving carers choice • Involving carers in planning and implementing (with appropriate training) care plans • Providing support and advice on relationships • Information • Flexible and responsive respite • Culturally responsive services • Carer awareness training for all professionals • Meeting the special needs of people with rapidly progressing conditions
Quality Requirement 11	<p>Caring for people with neurological conditions in hospital or other health and social care settings</p> <ul style="list-style-type: none"> • Recognising the person's and their carer's understanding and experience of own needs and consulting them on managing their condition • Making neurological care plan available in case of planned admissions • Clear protocols for liaison with specialist services in case of emergency admissions • Getting advice about meeting the specific needs of people from specialist staff • Information • Meeting the special needs of people with rapidly progressing conditions

Expert Patients Programme content**Expert Patients Programme****2½ hours per week****Week 1**Action planning,
relaxation, better breathing**Week 2**

Action planning, anger, fear & frustration, fitness & exercise

Week 3

Action planning, relaxation, fitness & exercise, fatigue

Week 4

Action planning, relaxation, nutrition, living wills, communication

Week 5Action planning, relaxation, medications, making treatment decisions,
depression**Week 6**Action planning, relaxation, informing the health care team, working
with your health care team, future plans

A study on the Expert Patient

STUDENT INFORMATION SHEET

What's it all about?

A University lecturer has agreed to present a session to your group on the Expert Patient. She is currently undertaking a PhD study on this topic and would like to audio-tape the discussion element of the lecture so that she can include your valuable comments as part of the data.

Background to the study

Pilot Expert Patient Programmes are now running throughout the country and will be implemented in all NHS Trusts between 2004 and 2007. This study is a qualitative exploration of whether the Expert Patient Programme is a more effective approach to patient involvement and empowerment, and as part of this will describe professionals' experiences of dealing with patients who have long-term conditions.

What will it involve?

Your participation in the study will involve nothing more than your usual participation in a lecture. The lecturer will present the session as normal but will audio-tape the feedback from group work.

Will it be confidential?

Only the researcher will have access to the audio-tape and it will be destroyed at the end of the study. The lecturer will not record any of your names or employing Trust, and all publications will be anonymised.

Who has reviewed the study?

This part of the study has been reviewed by the University of Hertfordshire's Ethics Committee.

Do I have to take part?

No. It is up to you whether the discussion will be used as part of the research. If you decide you don't want it to be included in the research the session will go ahead as a normal lecture. You can also change your mind at any time about participating in the research.

Who can I contact for further information?

The lecturer/researcher will be happy to discuss any queries you have. Please contact Tricia Wilson on 01707 286391. She is based in Room 2F267.

Nurse Focus Groups Scenarios**APPENDIX 4a**

Claire is a 42 year old graduate who has a middle management post with a large company. She was diagnosed with anti-phospholipid syndrome 10 years ago, and was started on long-term warfarin therapy following the birth of her second child.

Claire has heard about the possibility of self-managed anticoagulation and is keen to undertake this. Her reasons are that it would save visits to the clinic which often impinge on her work, and would allow her more flexibility in monitoring her INR when she has lifestyle changes which she knows impact on her INR, such as changes in diet when away on business or on holiday. Claire tells you that she wants to take control of the warfarin, rather than it feeling that the warfarin is in charge of her life.

APPENDIX 4b

John Smith is a 40 year old man who's had asthma since childhood, and has a self-management plan to control his asthma. He is knowledgeable regarding the use, action and side effects of both his ventolin and becotide inhalers and monitors his peak flow regularly. Recently he has used the Buteko technique to control his breathing. He doesn't wish to continue with his steroids or ventolin inhalers as his peak flows have remained stable for the past 6 months without using them whilst practising buteko. However, he is prepared to take the inhalers if he gets a cold.

APPENDIX 4c

Simon is 32, a merchant banker and has diabetes Type 1. He has a history of hypoglycaemic attacks although in recent years these have reduced. His lifestyle is becoming more active since marrying a few years ago. He and his wife want to go on a cross-country skiing holiday together and also have plans to train for the London marathon. However, both worry about Simon having a hypo. Simon has heard of a non-invasive, continuous glucose monitoring system based on impedance spectroscopy. He is keen to try this method in order to monitor his blood glucose during his planned activities.

APPENDIX 4d

Eric is 68 and has had Parkinson's Disease for several years. As time has gone on his medication has become less effective and he is increasingly troubled by side effects and wants to try a new approach. He discusses with you the possibility of trying Chinese medicine (herbal medication and acupuncture) as an alternative to his current treatment.



A study on the Expert Patient

PHYSIOTHERAPIST INFORMATION SHEET

What's it all about?

A University lecturer has agreed to present a session to your group on the Expert Patient. She is currently undertaking a study on this topic and would like to audio-tape the discussion element of the lecture so that she can include your valuable comments as part of the data.

Background to the study

Pilot Expert Patient Programmes are now running throughout the country and will be implemented in all NHS Trusts between 2004 and 2007. This study is a qualitative exploration of whether the Expert Patient Programme is a more effective approach to patient involvement and empowerment, and as part of this will describe professionals' experiences of dealing with patients who have long-term conditions.

What will it involve?

Your participation in the study will involve nothing more than your usual participation in an in-service session. The lecturer will present the session as normal but will audio-tape the feedback from group work.

Will it be confidential?

Only the researcher will have access to the audio-tape and it will be destroyed at the end of the study. The lecturer will not record any of your names or employing Trust, and all publications will be anonymised.

Who has reviewed the study?

Hertfordshire Local Research Ethics Committee has reviewed the study.

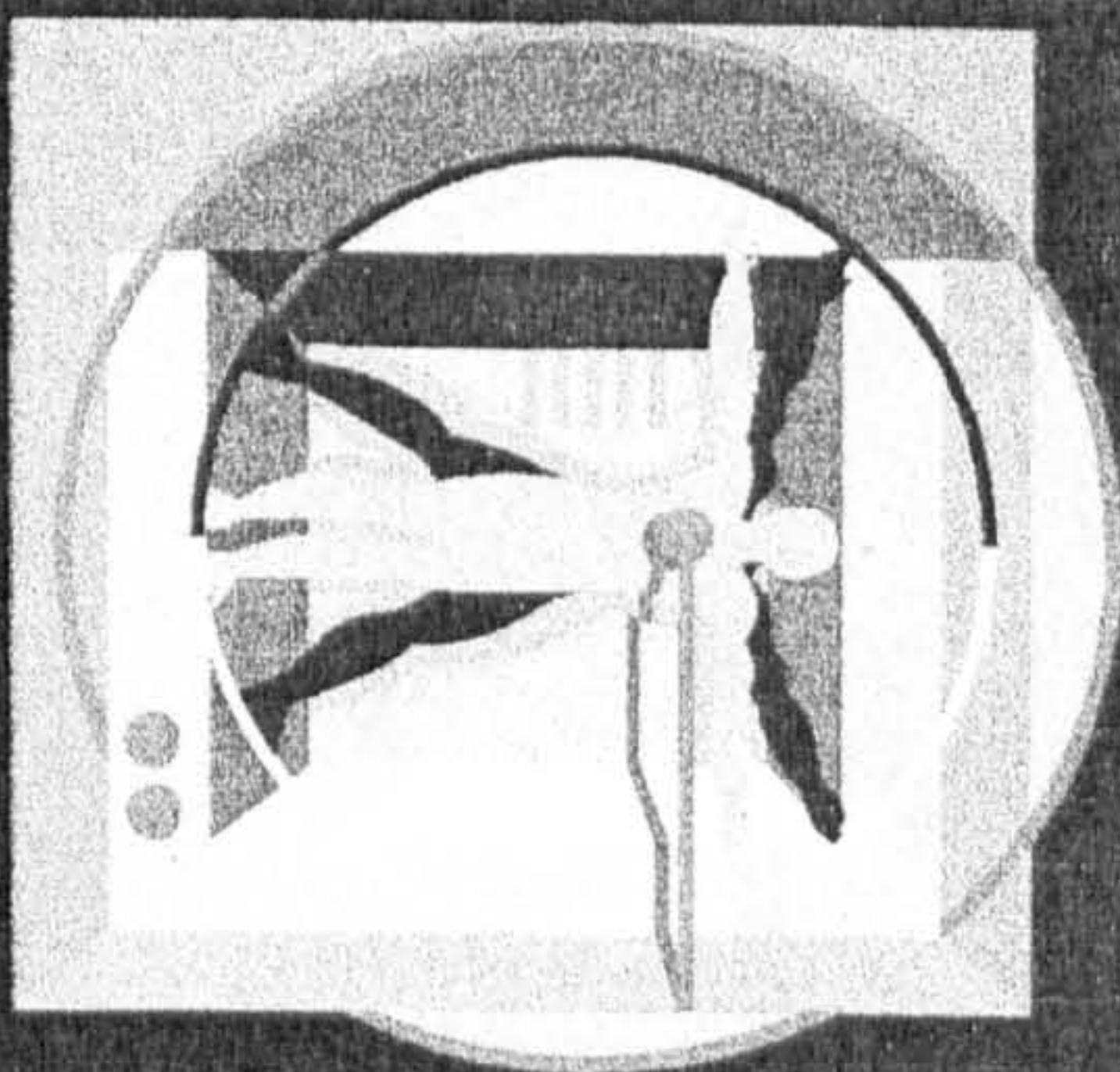
Do I have to take part?

No. It is up to you whether the discussion will be used as part of the research. If you decide you don't want it to be included in the research the session will go ahead as a normal session. You can also change your mind at any time about participating in the research.

Who can I contact for further information?

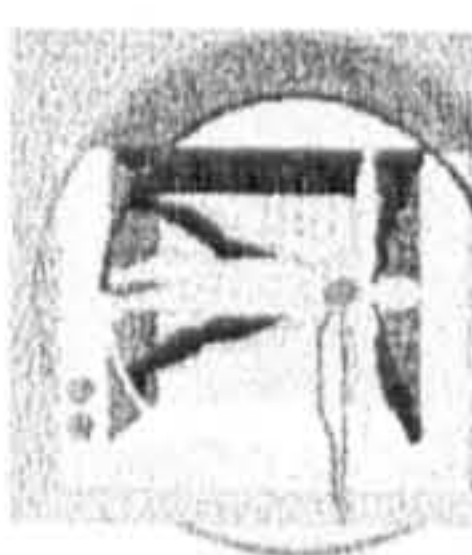
The lecturer/researcher will be happy to discuss any queries you have. Please contact Tricia Wilson on 01707 286391.

People & long-term conditions



Invitation to attend a focus group

Researchers at the University of Hertfordshire are doing a study looking at people's experience of having a long-term condition.



What is it all about?

Researchers at the University of Hertfordshire are doing a study looking at the experience of having a long-term condition. We are especially interested in the knowledge people build up over time about their illness & how doctors and nurses help people to



Why are we writing to you?

Your support group has agreed to give this invitation to members. Because the invitation was given out by the support group, your name & address

What is a focus group?

The group will consist of 6-8 people who have agreed to take part in the study. Within the group we will talk about things like how much you feel you know about your condition, where you have learnt about it, and how you feel that doctors & nurses take your



Will it be confidential?

The discussion will be led by a researcher and will be completely confidential, which means that no-one outside of the group will find out what you or anyone else has said. The discussion will be tape-recorded, but the tapes will only be available to the researchers working on the project, and will be destroyed once the study



Where & when?

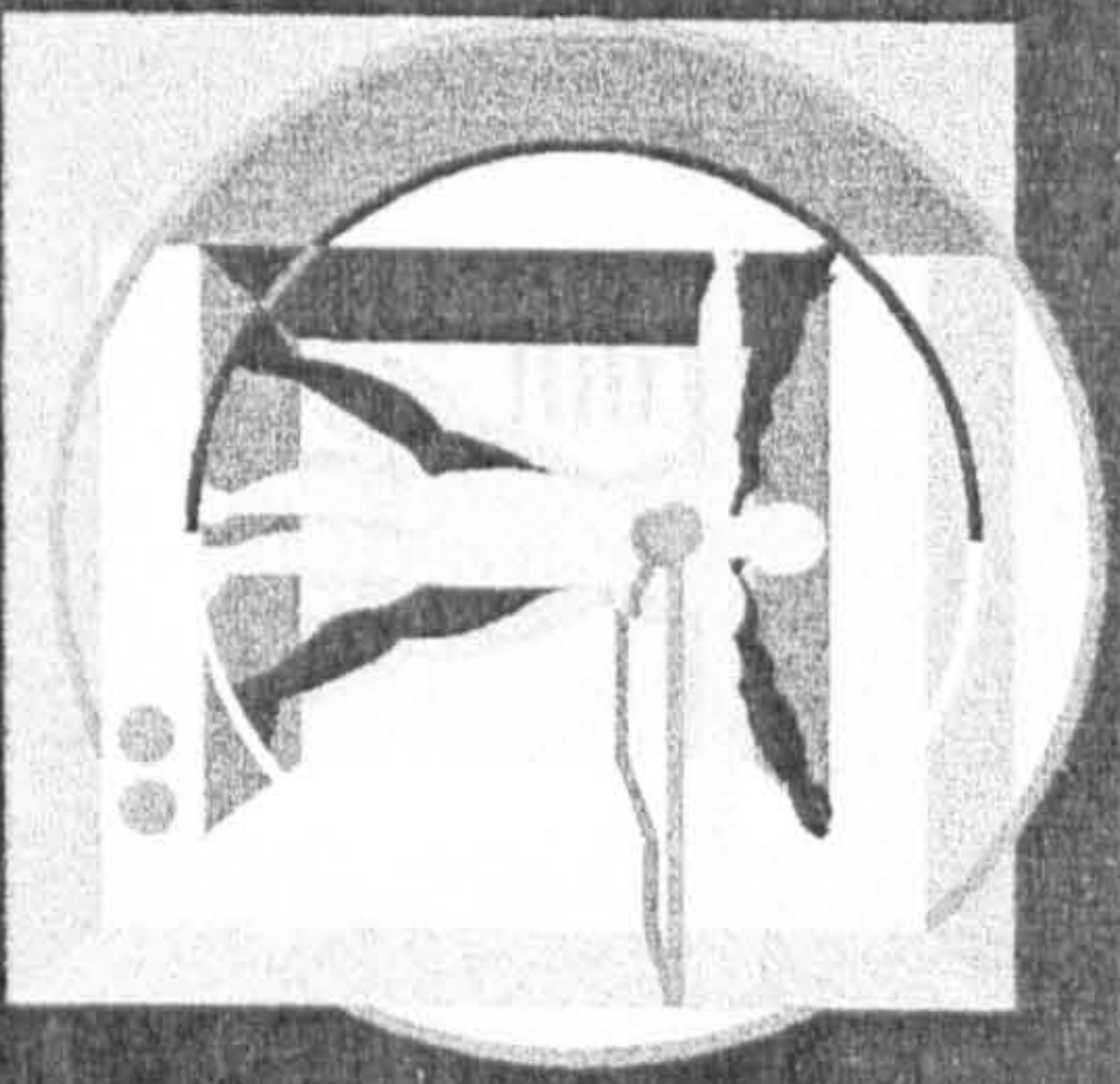
Your support group has kindly offered to provide a mutually convenient venue. It will be arranged for a time that suits those who want to take part

What next?
If you do want to help us by taking part then let your support group know as they have kindly agreed to arrange the venue.

We want to hear both from those who feel they have a lot of knowledge about their condition and those who

don't feel this

People & long-term conditions



Invitation to attend a focus group

Researchers at the University of Hertfordshire are doing a study looking at people's experience of having a long-term condition.
Can you help us?



What is it all about?

Researchers at the University of Hertfordshire are doing a study looking at the experience of having a long-term condition. We are especially interested in the knowledge people build up over time about their illness & how doctors and nurses help people to get this knowledge.



Why are we writing to you?

Your support group has agreed to give this invitation to members. Because the invitation was given out by the support group, your name & address has not been handed to any of the researchers.

What is a focus group?

The group will consist of 6-8 people who have agreed to take part in the study. Within the group we will talk about things like how much you feel you know about your condition, where you have learnt about it, and how you feel that doctors & nurses take your knowledge into account.



Will it be confidential?

The discussion will be led by a researcher and will be completely confidential, which means that no-one outside of the group will find out what you or anyone else has said. The discussion will be tape-recorded, but the tapes will only be available to the researchers working on the project, and will be destroyed once the study has finished.



Where & when?

The focus group will take place in a mutually convenient venue. It will be arranged for a time that suits those who want to take part and will last 1 - 1.5 hours.

What next?

If you do want to help us by taking part then please fill in the response slip with this leaflet & return it to us in the envelope provided. A researcher will then contact you

We want to hear both from those who feel they have a lot of knowledge about their condition and those who don't feel this



Diabetes Focus Group Agreement Form

APPENDIX 8

AL10 9AB
UK

Switchboard 01707 284000
Minicom 01707 284000
Fax 01707 284115
www.herts.ac.uk

PEOPLE & LONG-TERM CONDITIONS

Yes, I would like to take part in a focus group on people and long-term conditions!

Name.....

Telephone number.....

Age.....

These times would suit me best:

	morning	afternoon	evening
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			



Patient Focus Group Trigger Questions

Patient focus groups

Introduce myself, brief & general outline of the study

Ground rules, eg. Confidentiality, tape recording – 1 person to speak at a time, agree finish time

Introduce themselves and their stories - tell me a little about yourself and your condition such as are you married, do you work, what condition do you have and when did you find out?

General experiences & impressions of the health services?

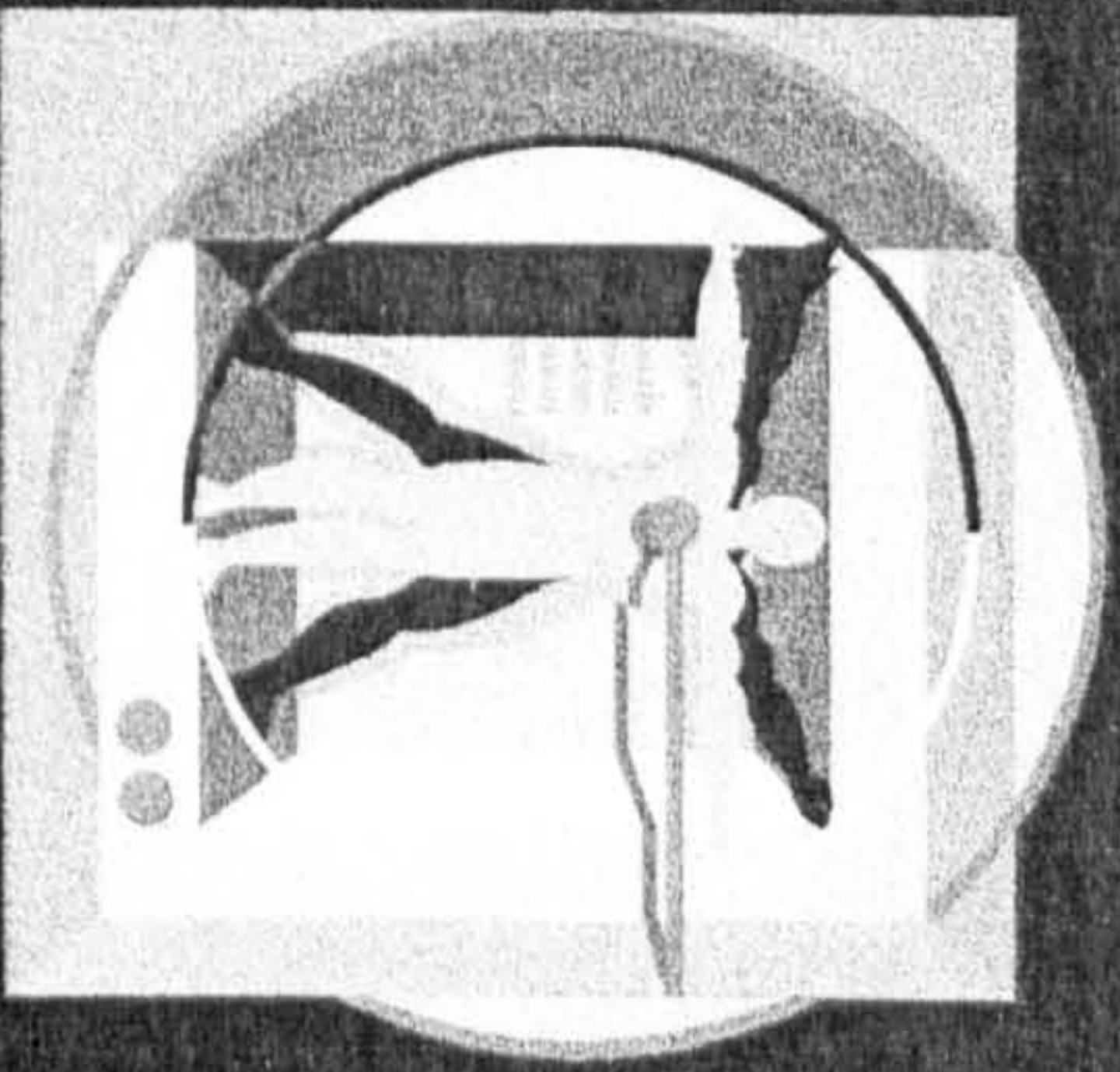
Which health care professionals have they dealt with? Who has been most helpful, and what areas have they experienced problems?

Where have they learned about their condition?
Friends, family, other patients, internet, libraries (books or medline), media, health education leaflets, support groups?

What do they think are the most important issues we have talked about today?

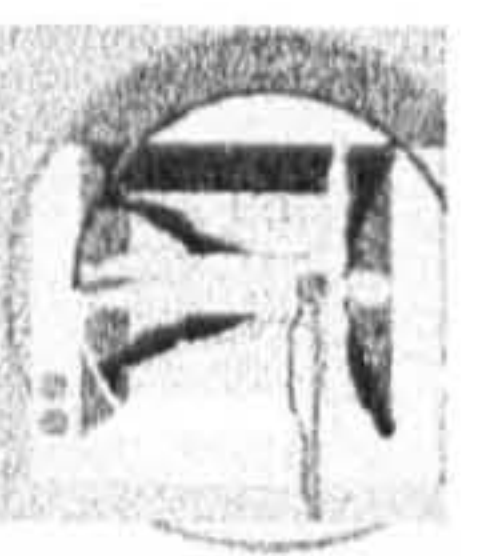
Thanks and closure. Arrangements for feedback.

People & long-term conditions



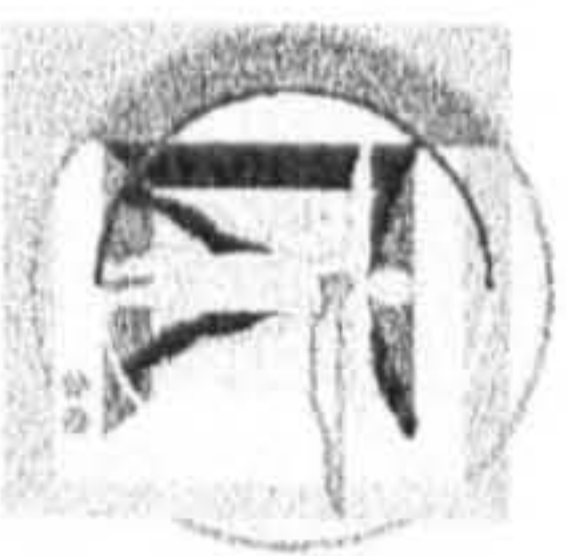
Invitation to be interviewed

Researchers at the University of Hertfordshire are doing a study looking at people's experience of having a long-term condition.
Can you help us?



What is it all about?

Researchers at the University of Hertfordshire are doing a study looking at the experience of having a long-term condition. We are especially interested in the knowledge people build up over time about their illness & how doctors and nurses help people to get this knowledge.

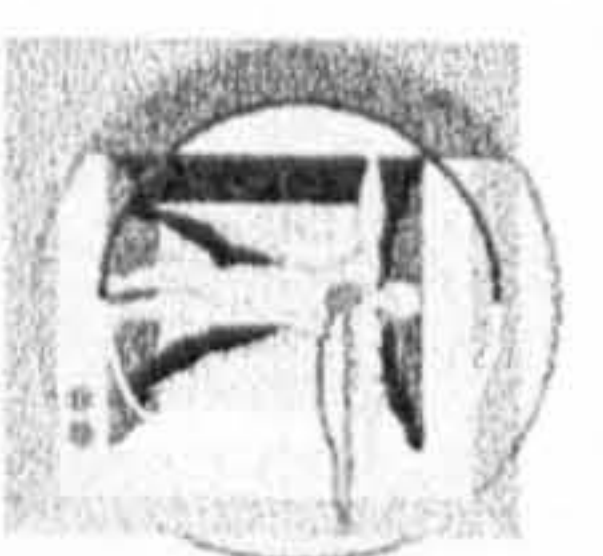


Why are we writing to you?

Your Primary Care Trust has agreed to send this invitation to all people over 18 who have attended or are on the waiting list for an Expert Patient Programme. Because the invitation was sent by your Primary Care Trust, your name & address has not been handed to any of the researchers. It is only if you decide to take part in this study that we at the university will need your contact details.

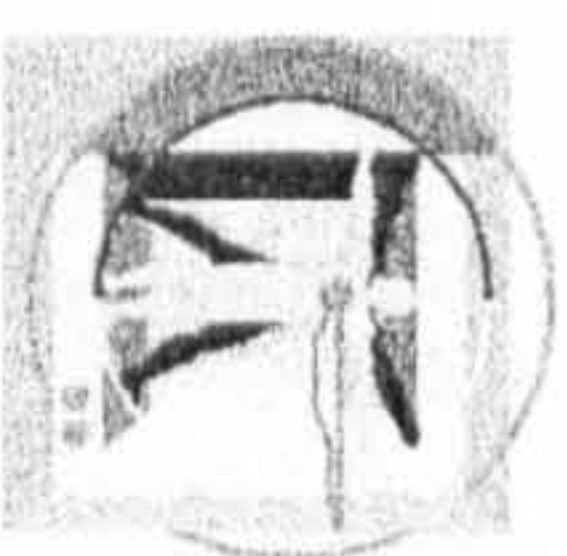
What will the interview be like?

A researcher will talk to you in private about things such as how much you feel you know about your condition, where you have learnt about it, and how you feel that doctors & nurses take your knowledge into account.



Will it be confidential?

The interview will be completely confidential, which means that no-one apart from the researcher will find out what you have said. The interview will be tape-recorded, but the tapes will only be available to the researchers working on the project, and will be destroyed once the study has finished.



Where & when?

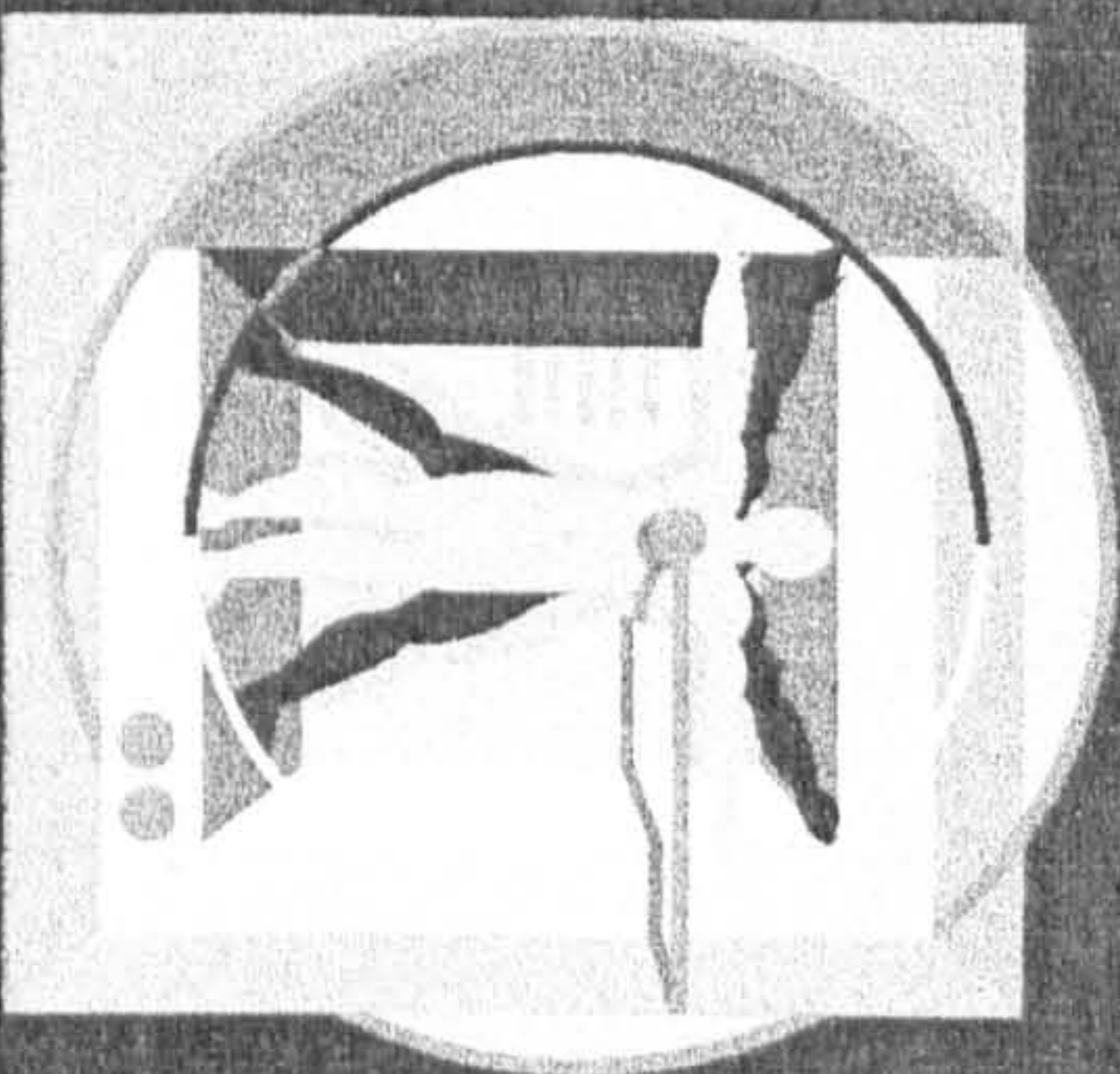
The interview will happen at a time and place that is most convenient for you such as your home. It will last 1-1.5 hours.

What next?

If you do want to help us by taking part then please fill in the response slip with this leaflet and return it to us in the envelope provided. A researcher will then contact you.

We want to hear both from those who feel they have a lot of knowledge about their condition and those who don't feel this

People & Long-term conditions



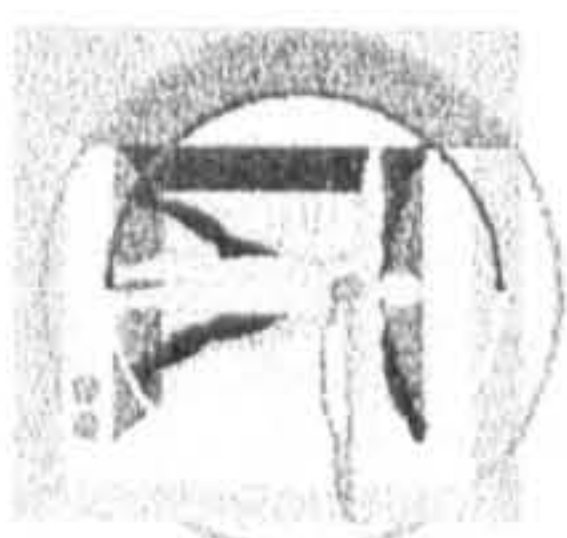
Invitation to be interviewed

Researchers at the University of Hertfordshire are doing a study looking at people's experience of having a long-term condition.
Can you help us?



What is it all about?

Researchers at the University of Hertfordshire are doing a study looking at the experience of having a long-term condition. We are especially interested in the knowledge people build up over time about their illness & how doctors and nurses help people to get this knowledge.



Why are we writing to you?

Your support group has agreed to hand out this leaflet to members. Because the invitation was given out by the support group, your name & address has not been handed to any of the researchers. It is only if you decide to take part in this study that we at the university will need your contact details.

What will the interview be like?

A researcher will talk to you in private about things such as how much you feel you know about your condition, where you have learnt about it, and how you feel that doctors & nurses take your knowledge into account.



Will it be confidential?

The interview will be completely confidential, which means that no-one apart from the researcher will find out what you have said. The interview will be tape-recorded, but the tapes will only be available to the researchers working on the project, and will be destroyed once the study has finished.



Where & when?

The interview will happen at a time and place that is most convenient for you such as your home. It will last 1-1.5 hours.

What next?

If you do want to help us by taking part then please fill in the response slip with this leaflet and return it to us in the envelope provided. A researcher will then contact you.

We want to hear both from those who feel they have a lot of knowledge about their condition and those who don't feel this



PEOPLE & LONG-TERM CONDITIONS

Yes, I agree to be interviewed for the study and would like a researcher to contact me to agree a time and place for the interview.

Name.....

Telephone number.....

Age.....

I understand that I can change my mind about being interviewed at any time.

Signed.....



INVESTOR IN PEOPLE





A study on the Expert Patient

Expert Patient Programme Tutor Information Sheet

Researchers at the University of Hertfordshire are undertaking a study evaluating the impact of the Expert Patient Programme on patients with long-term conditions and health care professionals. As an Expert Patient Trainer it is hoped that you could help with the study by agreeing to be interviewed.

Background to the study

Pilot Expert Patient Programmes are now running throughout the country and will be implemented in all NHS Trusts between 2004 and 2007. This study will explore whether the Expert Patient Programme is a more effective approach to patient involvement and empowerment than other existing approaches.

What will be involved?

It is entirely optional whether you take part but if you do agree a researcher will arrange a convenient time and location to interview you. The interview will take 45 – 60 minutes and will focus on your experience as both a patient and a trainer. The researchers are particularly interested in how people build up knowledge about their condition and the part health care professionals play in this. Lunch or other appropriate refreshments will be provided.

What are the benefits of taking part?

The researchers will present the findings at the end of the study and it is hoped that this will help people develop their role further. The study is collaborative with local PCT's and the findings will be used to facilitate implementation of Expert Patient Programmes.

Will it be confidential?

The interview will be audio-taped but only the researcher will have access to the tapes and they will be destroyed at the end of the study. All information collected about you will be kept strictly confidential, and your name will not be on any of the researchers' notes. All publications will be anonymised.

Who has reviewed the study?

Your Health Authority Ethics Committee has reviewed the study.

Who can I contact for further information?

The researchers will be happy to discuss any queries you have. Please contact Tricia Wilson on 01707 286391





A study on the Expert Patient

**MEDICAL PRACTITIONER, NURSE & PHYSIOTHERAPIST
INFORMATION SHEET**

Researchers at the University of Hertfordshire are undertaking a study evaluating the impact of the Expert Patient Programme on patients with long-term conditions & health care professionals. As a clinician & practitioner with a significant involvement with patients who have a chronic condition, the researchers hope that you could help with the study by agreeing to be interviewed.

Background to the study

Pilot Expert Patient Programmes are now running throughout the country and will be implemented in all NHS Trusts between 2004 and 2007. This study is a qualitative exploration of whether the Expert Patient Programme is a more effective approach to patient involvement and empowerment, and as part of this will describe professionals' experiences of dealing with patients who have long-term conditions.

What will be involved?

It is entirely optional whether you take part but if you do agree a researcher will arrange a convenient time and location to interview you. The interview will take 30-45 minutes and will focus on your experience of patients with long-term conditions.

What are the benefits of taking part?

The study is collaborative with local PCTs and the findings will be used to facilitate implementation of Expert Patient Programmes, and to help an understanding of how patients manage their long-term conditions and how practitioners can support this. The findings will be presented to participants at the end of the study.

Who has reviewed the study?

Hertfordshire Local Research Ethics Committee and the University of Hertfordshire Research Degrees Committee have reviewed the study.

Who can I contact for further information?

The researchers will be happy to discuss any queries you have. Please contact Tricia Wilson on 01707 286391.

Interview guide - patients

Patient interviews

Tell me a little about yourself and your condition such as are you married, do you work, what condition do you have and when did you find out?

What has been your general impression of the health services?

Which health care professionals do you deal with? Who has been most helpful, and what areas have you experienced problems?

Where have you learned about your condition?

Friends, family, other patients, internet, libraries (books or medline), media, health education leaflets, support groups?

Are there particular “tricks” you have learned that help you manage your condition? How comfortable are you at discussing these with your doctor, nurse etc.

In your mind, what is the most important thing we have talked about today?

Interview guide – health professionals

Consultant interview

Tell me a bit about what motivated you to specialise in

What sort of relationship with patients do you look for?

During your time as a consultant do you feel there has been any change in the way patients' interact with you?

Every doctor has a view of a heartsink patient – what's yours?

How do you feel about patients use of the internet to access medical information?

How would you characterise an ideal patient from your perspective?

How would you define an Expert Patient?

In what ways do you feel male and female patients approach differently?

SCENARIOS A & B

Initial thoughts

Major issues

Major concerns with self-management

The study has indicated that other professionals have concerns with:

Litigation and accountability particularly in self-management of medication

Time resource

The knowledge base of the patient

Whether one can trust patients to do as they say they will

Which concern do you most agree with and why?

Do you disagree with any of these concerns and why?

And finally:

Do you find that the nurses you work with have particular concerns about patients that you don't share?

Interview guide – health professionals

GP interview prompt

Tell me a bit about what motivated you to become a GP

What sort of relationship with patients were you looking for?

How long have you been in medical practice?

During this time do you feel there has been any change in the way patients' interact with you?

Every GP has a view of a heartsink patient – what's yours?

How do you feel about patients use of the internet to access medical information?

How would you characterise an ideal patient from a doctor's perspective?

How would you define an Expert Patient? Have you ever dealt with any and if so can you describe them?

SCENARIO A and B

Initial thoughts

Major issues

Major concerns with self-management

The study has indicated that other professionals have concerns with:

Litigation and accountability particularly in self-management of medication

Time resource

The knowledge base of the patient

Whether one can trust patients to do as they say they will

Which concern do you most agree with and why?

Do you disagree with any of these concerns and why?

And finally:

Is there any way in which health services could be better organised to help patients self-manage their health needs?

Interview guide – health professionals

DSN interview

Tell me a bit about what motivated you to become a DSN

What sort of relationship with patients do you look for?

How long have you been in nursing and diabetic nursing?

During this time do you feel there has been any change in the way patients' interact with you?

Every nurse has a view of a heartsink patient – what's yours?

How do you feel about patients use of the internet to access medical information?

How would you characterise an ideal patient from a nurse's perspective?

How would you define an Expert Patient? Have you ever dealt with any and if so can you describe them?

How do you think patients' use their consultation with you differently than with the doctor?

SCENARIO

Initial thoughts

Major issues

Major concerns with self-management

The study has indicated that other professionals have concerns with:

Litigation and accountability particularly in self-management of medication

Time resource

The knowledge base of the patient

Whether one can trust patients to do as they say they will

Which concern do you most agree with and why?

Do you disagree with any of these concerns and why?

And finally:

Is there any way in which health services could be better organised to help patients self-manage their health needs?

Interview guide – health professionals

PN interview

Tell me a bit about what motivated you to become a PN

What sort of relationship with patients do you look for?

How long have you been in nursing and practice nursing?

During this time do you feel there has been any change in the way patients' interact with you?

Every PN has a view of a heartsink patient – what's yours?

How do you feel about patients use of the internet to access medical information?

How would you characterise an ideal patient from a nurse's perspective?

How would you define an Expert Patient? Have you ever dealt with any and if so can you describe them?

SCENARIO A and B

Initial thoughts

Major issues

Major concerns with self-management

The study has indicated that other professionals have concerns with:

Litigation and accountability particularly in self-management of medication

Time resource

The knowledge base of the patient

Whether one can trust patients to do as they say they will

Which concern do you most agree with and why?

Do you disagree with any of these concerns and why?

And finally:

Is there any way in which health services could be better organised to help patients self-manage their health needs?

Interview guide – health professionals

Physiotherapist interview

Tell me a bit about what motivated you to become a Physio

What sort of relationship with patients/clients do you look for?

How long have you been in physiotherapy and do you have a particular speciality?

During this time do you feel there has been any change in the way patients' interact with you?

Every Physio has a view of a problematic or heartsink patient – what's yours?

How do you feel about patients use of the internet to access medical information?

How would you characterise an ideal patient from a physio's perspective?

How would you define an Expert Patient? Have you ever dealt with any and if so can you describe them?

SCENARIO A and B

Initial thoughts

Major issues

Major concerns with self-management

The study has indicated that other professionals have concerns with:

Litigation and accountability particularly in self-management of medication

Time resource

The knowledge base of the patient

Whether one can trust patients to do as they say they will

Which concern do you most agree with and why?

Do you disagree with any of these concerns and why?

And finally:

Is there any way in which health services could be better organised to help patients self-manage their health needs?

Dermatology Scenarios

Dermatology scenarios

15a

Lisa is a 32 year old first time mother who had severe eczema in the past. Her 2 year old child is being prescribed conventional treatments for eczema that are having a limited effect. Lisa wishes to use alternative remedies on the child as they had a dramatic impact on her own skin condition. She still wishes the child to be monitored by the eczema clinic.

15b

Peggy, a 70 year old retired teacher with a venous ulcer has decided that she would like honey to be applied to the wound surface, but is happy for pressure bandaging to be applied over this.



INFORMATION SHEET

Expert Patient Programme

Researchers at the University of Hertfordshire are doing a study looking at people's experience of having a long-term condition and would like to see how this group runs.

What is it all about?

Researchers at the University of Hertfordshire are doing a study looking at the experience of having a long-term condition. They are especially interested in the knowledge people build up over time about their illness and how they are helped to get this knowledge.

Why are they interested in this group?

The Expert Patient Programme is being run nationally to help people with long-term conditions feel more comfortable about dealing with both their illness and the doctors, nurses and other health care staff they come into contact with. They have been provided the name of the contact person of this programme but your names and addresses have not been given to the researchers.

What will it mean?

A researcher will attend the group with you and take part in any activities. The researcher is interested in how an Expert Patient group is different from other types of groups that help people manage their condition.

Will it be confidential?

The researcher will not have access to any of your names or addresses. Only the researcher will have access to notes they make about the programme and these will be destroyed at the end of the study.

Who can I contact if I need more information?

The researchers will be happy to discuss any queries you have. Please contact Tricia Wilson on 01707 286391

Critical reflection framework

FRAMEWORK FOR CRITICAL FRAMEWORK

Describe the events in as much detail as possible

How did it feel?

What are the particular moments you noticed?

What insights did you gain?

Is there anything you particularly need to watch for next time?

(Based on Boud and Walker 1990)

INFORMATION SHEET
People with long-term conditions

Researchers at the University of Hertfordshire are doing a study looking at people's experience of having a long-term condition and would like to see how this clinic runs.

What is it all about?

Researchers at the University of Hertfordshire are doing a study looking at the experience of having a long-term condition. They are especially interested in the knowledge people build up over time about their illness and how they are helped to get this knowledge.

Why are they interested in this clinic?

People with long-term conditions often attend clinics such as this one, and it may be an important place for people to learn about their condition.

What will it mean?

A researcher will spend time in the clinic and is interested in the way the clinic provides you with information, both in the waiting area and in the doctors or nurses room. The researcher may like to be present when you see your doctor or nurse but will ask your permission first. If you do not wish the researcher to be present please feel free to say so – this will not affect your care in any way.

Will it be confidential?

The researcher will not have access to any of your names, addresses or medical files. Only the researcher will have access to notes they make about the clinic and these will be destroyed at the end of the study.

Who can I contact if I need more information?

The researchers will be happy to discuss any queries you have. Please contact Tricia Wilson on 01707 286391



PEOPLE & LONG-TERM CONDITIONS

Yes, I agree for the researcher to be present during my consultation and understand that I can change my mind about this at any time without affecting my care

Signature.....

Name (please print).....

Age.....





INFORMATION SHEET *Back Fitness Course*

Researchers at the University of Hertfordshire are doing a study looking at people's experience of having a long-term condition and would like to see how this group runs.

What is it all about?

Researchers at the University of Hertfordshire are doing a study looking at the experience of having a long-term condition. They are especially interested in the knowledge people build up over time about their illness and how they are helped to get this knowledge.

Why are they interested in this group?

Groups that are led by a nurse or other health care professionals are an important way to help people with long-term conditions feel more comfortable about dealing with their illness and its impact on their lives. The researchers have been provided with the leader's name of this programme but your names and addresses have not been given to the researchers.

What will it mean?

A researcher will attend the group with you and will watch how it runs. The researcher is interested in how group helps people manage their condition.

Will it be confidential?

The researcher will not have access to any of your names or addresses. Only the researcher will have access to notes they make about the programme and these will be destroyed at the end of the study.

Who can I contact if I need more information?

The researchers will be happy to discuss any queries you have. Please contact Tricia Wilson on 01707 286391

Clinic Observation Schedule

Observation framework

- Length of contact
- Informant
- Focus of interaction
- Balance of interaction
- Patient message
- Consultant message
- Outcomes
- Feel of contact
- New hypotheses
- Memo for future observation

Report for health professionals

**Patient Empowerment in Primary Care: an
evaluation of the Expert Patient**

*A summary of findings compiled for the doctors, nurses &
physiotherapists who participated in the study*

January 2005

**Patricia Wilson
Professor Sally Kendall
Dr Fiona Brooks**

**CRIPACC
Faculty of Health and Human Sciences
University of Hertfordshire**

Report for health professionals

Who this summary is for

This summary has been prepared for all the nurses, doctors, physiotherapists and other rehabilitation practitioners who participated in the study which focused on the Expert Patient. Your contribution sometime during the past 2 years will have been via a focus group, interview or allowing a researcher to observe the clinic you ran. We would like to thank you again for your help with the study and hope you will find this summary interesting. A fuller report which has been prepared for Primary Care Trusts can be found at:

<http://perseus.herts.ac.uk/uhinfo/index.cfm?DBE6BC6A-0498-E5D6-6976-4A274729A00F>

If you have any comments or questions about the summary please contact Tricia Wilson: p.m.wilson@herts.ac.uk

01707 286391

What was the study about?

The study was a response to both the implementation of pilot Department of Health Expert Patient Programmes (Department of Health, 2001) (EPP) within primary care and the increasingly common phenomenon of active and informed patients, termed throughout this report as expert patients. We were interested in finding out what helps or hinders patient expertise in self-management of long term conditions, and particularly wanted to explore the differences between lay and professional led self-management courses, and how health professionals responded to expert patients.

Who was involved in the study?

More than 100 health professionals were involved. These included nurses undertaking post registration courses in the care and management of a long term condition, practice nurses, diabetes nurse specialists, general practitioners, consultant physicians, physiotherapists and other rehabilitation practitioners. Nurses and therapists contributed to both interviews and focus groups, and practice and specialist nurse clinics were observed. All doctors were interviewed and the consultant physician clinics were observed.

In addition more than 100 adults with a physical long term condition were interviewed, participated in a focus group or agreed to have their clinic

Report for health professionals

consultation observed. A lay led Expert Patient course (also known as Living Well course) and a professional led self-management course (Back Fitness) were observed. The study took place in 6 Hertfordshire Primary Care Trusts and 1 Acute Trust.

How were the findings reached?

We transcribed all the interviews and focus group discussion and analysed them along with the notes that were taken during the observation. This was a qualitative research study as we were interested in seeing whether any recurring themes about peoples' experiences and thoughts emerged. Consequently what we report here are the major themes which may not necessarily reflect your experiences but we have attempted to indicate which themes were most common and also give examples of any opposite cases. In order to improve the validity we have presented the major findings to a selection of professional and patient groups to ensure that we were interpreting the data appropriately. Data has and will continue to be anonymised at all times.

Findings

1. Expert Patient (Living Well) Programme

The EPP is a 6 week self-management course for people with long term conditions and is now running in all PCTs. It is seen by the Department of Health as the cornerstone of their Chronic Disease Management policy. The key characteristic is that it is facilitated by a lay person who has long term condition and has received training as an EPP lay tutor, and is generic rather than condition specific. Data from the observation of the course and interviews with participants suggest that the key strengths are:

- credibility for participants as it is led by a lay person who has a long-term condition;
- it can reduce feelings of isolation firstly by validating the emotional issues chronic illness may bring, meeting with people who understand the consequences of chronic illness, and lastly

Report for health professionals

some participants reported it had improved their social life by introducing them to new people;

- learning from each other strategies that are useful in self-management (examples are changes to diet, or joining Support Groups) or what services are available in their PCT (an example is “Prescription for Fitness”);
- establishing self-care practices such as appropriate levels of exercise as a habit;
- suggesting and validating communication strategies in the patient-professional relationship such as preparing a checklist of queries before a consultation.

However, the strength of the EPP appears to be dependent on four factors. Firstly, the attributes of the lay tutors are very important; charisma, being non-judgemental and inclusive was cited as key characteristics of an effective tutor. Secondly, participants who found the EPP most helpful were at a certain stage of their condition; neither newly diagnosed nor established self-managers. It was also imperative that they had actively chosen to attend to the EPP rather than being persuaded by a professional and felt well enough to attend. Thirdly, the success of an individual EPP is dependent on how the group bonds, if group cohesion is weak it will negate the facilitation skills of the tutor. Lastly, positive feelings about an EPP can rapidly diminish if discussed with an ambivalent professional.

2. Comparison of EPP & professional led course

There are many condition specific courses run by health professionals aimed at improving patients’ self-management skills. We were interested in comparing these courses with the EPP and observed a Back Fitness course (BFC) which was based in a Sports Centre and facilitated by a PCT employed psychologist. The course was designed for people with chronic back pain who had been assessed and referred to the course by a doctor or physiotherapist. Although course content covered similar areas, the depth was noticeably greater in the BFC, as were the facilitation skills of the psychologist. However, there appeared less engagement by

Report for health professionals

the BFC participants with both the material and group support. The data suggests that the credibility of lay tutors appears to outweigh the benefits of facilitation skills, for whilst the professional was acknowledged as very knowledgeable the BFC participants queried whether the facilitator knew what it was actually like to live with back pain. Commitment also appeared higher with EPP participants as they had chosen to attend the course rather than being referred by a professional. Although not within the scope of this study it would be worthwhile to carry out a longer term evaluation of the differences in outcomes between the two approaches to self-management training.

3. Characteristics of the expert patient

The Department of Health describe an expert patient as someone that will self-diagnose, offer suggestions about treatment and seek help appropriately (Jones, 2003). Using that description as a baseline we wanted to find out more about their characteristics and from the significant number of expert patients in the study were able to discern shared characteristics:

- **View of health:** Despite varying degrees of disease severity, expert patients tend not to think of themselves as unwell, rather they term their situation as living with a condition and getting on with life.
- **Self-presentation:** Perceived it as very important to exhibit an appearance of cheerfulness or stoicism. In practical terms this often meant they felt it necessary to hide feelings of anxiety or “feeling low” when dealing with some professionals.
- **Inner resourcefulness:** Often recounted years of persistence in getting investigations done or referrals to specialist centres, often identified themselves as having a fighting spirit.
- **Intelligent:** Generally described themselves as intelligent.
- **Self-educating:** Invested time, money & energy in obtaining books, attending conferences or courses about their condition.
- **Sense of responsibility:** often saw it as a duty to put something back into society as they had received so much from the health care system. This usually took the form of active involvement in support

Report for health professionals

groups or teaching health professionals. There was a great willingness to provide active lay contributions within statutory health services.

- **Logical and well-organised:** spent much time in preparing for consultations, often kept detailed files and records about treatments.
- **Knew the system:** described the importance of knowing the consultant's secretary or GP Surgery staff, could circumvent barriers other patients often come up against.
- **Risk assessment skills:** Could give well-informed and balanced reasons for adapting their treatment strategies between consultations.
- **Relationship with professionals:** saw it as vital to develop a rapport with professionals, displayed good communication skills and identified it as crucial not to appear to be a "challenging" patient.

"...if you've got a long-term situation, well it's to your own advantage to create a rapport...you think of them as your friends rather than your foes."

Patient M6

4. Expert patients' views on professionals

Expert patients' strongest views were about doctors, either describing the relationship they had with them as particularly helpful or very unhelpful. Views about other professionals were less polarised with a variety of experiences described. The practical nature of help from both nurses and therapists was frequently cited, with emotional support seen as a key strength of nurses. A summary of expert patients' perceptions of good and bad characteristics of a professional is shown below.

Positive characteristics	Negative characteristics
<ul style="list-style-type: none"> • Makes you feel good in yourself • Encourages you to try things out • Removes barriers • Helps you reach your goals • Knows your feelings & experiences 	<ul style="list-style-type: none"> • Lacks time for you • Brutally frank • Just deals with one problem at a time, not holistic • Does not know you • Lack of continuity • Inhibits emotional release • Makes you feel neurotic

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<ul style="list-style-type: none"> • Open to requests • Open to complimentary therapy • Gives you choices • Asks your opinion • Honest but kind advice • Good listener • Gives information • Accessible • Helps you keep things in proportion • Helps you to take responsibility for own health • Chases things up • Keeps in touch with you when things are bad • Caring • Sees you as a partner in care 	<ul style="list-style-type: none"> • Dishonest • Poor communicator • Lacks clinical competence • Inflexible • Treats you with a lack of respect • Lack of interest • Does not suggest a plan
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5. Suggestions from expert patients

Many of the patients had suggestions regarding service delivery improvement:

- **Patient centred approaches:** The most recurring theme was the need for individualised approaches by professionals, promoting patient involvement throughout the care pathway, being non-judgemental and open to patient suggestions such as complimentary or alternative medicines, and enabling the feeling that the patient, not the professional is in charge of the condition. For many patients the worst experiences were described as being admitted to a General Hospital and having to cope with staff who had limited knowledge of their condition and being refused permission to continue their normal self-care practices.

The greatest thing we fear is going into hospital because they are going to take all the drugs away...

Parkinson's disease focus group

- **Professionals' responses:** Another issue for many patients were perceived inappropriate responses to the patient's expression of emotional distress. Many cited nurse specialists as providing a good example of appropriate responses; easily accessible, takes time to listen and offers practical advice where appropriate.

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- **Support groups:** The majority of interviewees saw voluntary organizations as the most effective source of support, particularly emotional, but would like to see greater knowledge & dissemination of information by professionals about the groups and closer links with statutory services.
- **Nutritional advice:** Several interviewees (not exclusively those living with diabetes) felt that health services were poor in delivering nutritional advice in long-term conditions and felt this should be improved.
- **Other advice:** It was suggested by some interviewees that written information should be provided about the different services available and how to access them, and also clearer advice on financial issues in long-term conditions.
- **Public involvement:** whilst there was a willingness to become involved in statutory organizations two barriers were identified. Firstly, jargon used at, for example PCT open meetings was perceived by some as a problem, and secondly there was a perception by some interviewees that patients were “hand picked” for patient forums.

6. Professionals' responses to expert patients

A number of major themes emerged from the data;

- **Time resource:** all the professionals described expert patients as taking more time in consultations. However, both the doctors and physiotherapists described this as an initial investment that would save time in the long-term. In contrast many nurses saw the time resource issues as an on-going burden, apart from the nurse specialist interviewees who described part of their role as giving more time to the patient. Patients frequently described nurses as having more time for them and paradoxically it may be that patients use this perception of time to ask more questions of the nurses hence contributing to the nurses' perception of an on-going burden. Whilst the period of observation in the clinics did not suggest any differences between patient behaviour with the nurse or doctor, the nurse-led clinics

Report for health professionals

appeared far less rushed for the patient, with nurses actively facilitating opportunities for patient discussion. Although physiotherapists did not see time as an ongoing issue it should be noted that the majority of these professionals in the study worked with patients for a set period of time and described keeping strictly to timed appointments.

you've got a big clinic & they'd want to know this, that, & this & that, & you'd give them that answer but it's not good enough & you have to give them that answer & that answer so I would have thought it would be somebody who would take longer

Nurse Focus Group

- **Physical measurement:** all professionals utilised a physical measurement to judge patients' levels of expertise, for example HbA1c readings were described and observed as forming the basis of consultations with people living with diabetes. Many of the patient interviewees were well aware of this reliance but it often contrasted with their key issue and the need for an individualised, patient centred consultation.
- **Litigation:** whilst doctors and physiotherapists were comfortable with their liability in the self-managing expert patient, the vast majority of nurses had particular concerns in this area. The concerns appear to stem from the perception that even in cases where the patient is competent, fully informed and has chosen to self-manage, errors made by the patient will be blamed on the nurse involved. The majority of nurses described their working practices as adhering strictly to protocols and sometimes felt unable to "allow" patients to self-manage aspects of their condition as the nurse themselves perceived they did not have permission for this from either the organization within which they worked or from the doctor with whom they worked. The few examples of nurses within the study who were more comfortable with liability worked autonomously in Multi Disciplinary teams where there was a shared understanding and history of informed patients self-managing their long-term condition.

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“As long as you’re clear, and you document it, at the end of the day it’s their choice, they have the right...We are not responsible for what the patient chooses to do” Physiotherapist Focus Group

“...we’ll get blamed for their self-management” Nurse Focus Group

- **Perception of the expert patient as challenging:** Physiotherapists and doctors did not feel that expert patients triggered any feelings of threat to them and this appeared to be linked to these professionals ease with their role definition and area of particular expertise. However, a significant number of nurses did describe active and informed patients as particularly challenging who caused feelings of unease with the nurses’ own knowledge. This appeared to be a particular issue for the more recently qualified nurses who were still developing experiential knowledge and a recently qualified physiotherapist described her anxiety when dealing with particularly informed patients. Interestingly, a significant number of expert patients would actively ensure they did not appear challenging and would do their best to put the professional at ease. Contrasting examples of nurses were those who described feelings of confidence with their expertise, and could clearly articulate a role that was distinct and autonomous from others.

“My years of experience count for nothing, they think they know better & it just counts for nothing ...

It’s interpreted by myself as a lack of respect because sometimes people don’t go about it in a nice way & that immediately gets your defenses up...”

Nurse Focus Group

- **Responses to emotional needs of patients:** Many patients described the negative emotional consequences of living with a long-term condition, but as stated earlier actively suppressed these in consultations. For patients who did discuss their feelings with medical practitioners there were frequent descriptions of what they perceived as inappropriate responses. Examples of these were being referred for

Report for health professionals

counselling or prescriptions for anti-depressants, whereas the patients stated all they really wanted was to be listened to just for that one consultation and for their feelings to be acknowledged. The data from the patients was reinforced by the GPs in the study who often described the most challenging patient to be the over-emotional and tearful one. In contrast nurses were clearly comfortable in dealing with the emotional consequences of the condition and were often identified by patients as being the most responsive to this need. Some patients also cited physiotherapists as providing appropriate responses, particularly if the physiotherapist was outside of the normal time limited provision provided within the National Health Service.

What has happened to the study results?

A number of recommendations arising from the results have been presented to the PCTs involved. They cover issues surrounding the delivery of the EPP, initial and in-service professional education, service delivery and developing enabling organizations – further details can be found in the PCT report. To explore the more complex issues there is on-going analysis of the data, which will form the basis for national and international dissemination.

References

- Department of Health (2001) *The expert patient - a new approach to chronic disease management for the 21st Century*. Stationary Office, London.
- Jones N. (2003): How are expert patients different? *EPP Update* 8 1, 3.

Report for patients

People and long-term conditions: being an expert patient

A summary of findings compiled for the people living with a long-term condition who participated in a research study

January 2005

**Patricia Wilson
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Dr Fiona Brooks**

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Report for patients

Who this summary is for

You may remember that sometime in the last two years you agreed to be interviewed or participated in a focus group as part of a study that researchers from the University of Hertfordshire were running. As promised at the time we now have pleasure in sending you a copy of the findings from the study which we hope you will find interesting. We would also like to take this opportunity to thank you again for your participation which was invaluable to the study.

If you have any comments or questions about the summary please contact Tricia Wilson: p.m.wilson@herts.ac.uk

01707 286391

What was the study about?

The study was carried out when pilot Department of Health Expert Patient Programmes (Department of Health, 2001) were being run and also when it was becoming recognised that people with long-term conditions are often active and informed. Throughout this report we call these people expert patients. We were interested in finding out what helps or hinders patient expertise in self-management of long term conditions, and particularly wanted to explore the differences between lay¹ and professional led self-management courses, and how health professionals respond to expert patients.

Who was involved in the study?

More than 100 adults with a physical long term condition were interviewed, participated in a focus group or agreed to have their clinic consultation observed. A lay led Expert Patient course (also known as Living Well course) and a professional led self-management course (Back Fitness) were observed, and some of the people we interviewed had attended an Expert Patient Programme. In addition more than 100 health professionals were involved. These included nurses undertaking post registration courses in the care and management of a long term condition, practice nurses, diabetes nurse specialists, general practitioners, consultant physicians, physiotherapists and other

¹ "Lay" within this study indicates that the course was led by someone who had a long-term condition but did not have a health professional qualification. They will have received some basic training in how to run the course.

Report for patients

rehabilitation practitioners. Nurses and therapists contributed to both interviews and focus groups, and practice and specialist nurse clinics were observed. All doctors were interviewed and the consultant physician clinics were observed. The study took place in 6 Hertfordshire Primary Care Trusts and 1 Hertfordshire General Hospital.

How did we reach our findings?

We transcribed all the interviews and focus group discussion and analysed them along with the notes that were taken during the observation, looking for recurring themes. We are reporting the major themes which may not necessarily reflect your experiences but we have attempted to indicate which themes were most common and also give examples of any opposite cases. To make the findings as trustworthy as possible we have presented the major findings to a selection of professional and patient groups to ensure that we were interpreting the data appropriately. Data has and will continue to be anonymised at all times.

Findings

1. Expert Patient Programme

The Expert Patient Programme (in some areas called the Living Well Course) is a 6 week self-management course for people with any long term condition and is now running throughout Hertfordshire². It is seen by the Department of Health as the cornerstone of their Chronic Disease Management policy. The key characteristic is that it is led by a lay person who has long term condition and has received training as a lay tutor. Data from the observation of the course and interviews with participants suggest that the key strengths are:

- credibility for participants as it is led by a lay person who has a long-term condition;
- it can reduce feelings of isolation firstly by helping the emotional issues a long-term condition may bring, meeting with people who understand what it is like to have a long-term condition, and

² For further information about your local Expert Patient Programme, please contact your Primary Care Trust

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lastly some participants reported it had improved their social life by introducing them to new people;

- learning from each other strategies that are useful in self-management (examples are changes to diet, or joining Support Groups) or what services are available in their Primary Care Trust such as fitness programmes;
- helping to establish healthy living as a habit;
- suggesting ways of getting most out of a visit to the doctor such as preparing a checklist of queries before an appointment.

However, the strength of the Expert Patient Programme appears to be dependent on four factors. Firstly, the attributes of the lay tutors are very important; charisma, being non-judgemental and inclusive was cited as key characteristics of an effective tutor. Secondly, participants who found the Expert Patient Programme most helpful were at a certain stage of their condition; neither newly diagnosed nor very confident in living with the condition. It was also very important that they had actively chosen to attend an Expert Patient Programme rather than being persuaded by a professional and felt well enough to attend. Thirdly, the success of an individual Expert Patient Programme is dependent on how well the group gets on together. Lastly, positive feelings about an Expert Patient Programme can rapidly diminish if discussed with a professional not interested in hearing about it.

2. Comparison of Expert Patient Programme & professional led course

There are many courses run by health professionals aimed at improving peoples' self-management skills in particular conditions, for example diabetes. We were interested in comparing these courses with the Expert Patient Programme and observed a Back Fitness course which was based in a Sports Centre and led by a psychologist. The course was designed for people with long-term back pain who had been assessed and referred to the course by a doctor or physiotherapist. Although course content covered similar areas, the psychologist was more experienced in running group discussions. Even so, the Back Fitness participants appeared to find the course material and group support less helpful when compared

Report for patients

to the Expert Patient Programme participants. It seems that the credibility of lay tutors appears to outweigh the benefits of having a highly trained professional leading the group, for whilst the professional was acknowledged as very knowledgeable, it was obviously very important to feel that the leader actually knew what it was like to live with a long term condition. Commitment also appeared higher with the Expert Patient Programme participants as they had chosen to attend the course rather than being referred by a professional.

3. Who are expert patients?

The Department of Health has described an expert patient as someone who may self-diagnose, offer suggestions about treatment and seek help appropriately (Jones, 2003). However it seemed to us that there was likely to be more to being an expert patient and it was apparent during the focus groups and interviews that many of you were expert in living with your condition. By looking carefully at what you were saying about your experiences it was possible to identify some common characteristics;

- **View of health:** Despite the variety of long term conditions and their impact on life, expert patients tended not to think of themselves as unwell, describing their situation as living with a condition and getting on with life.
- **Self-presentation:** Many perceived it as very important to exhibit an appearance of cheerfulness or stoicism. In practical terms this sometimes meant people felt it necessary to hide feelings of anxiety or “feeling low” when dealing with some professionals.
- **Inner resourcefulness:** Many of you recounted years of persistence in getting investigations done or referrals to specialist centres, this was more common in the “more difficult to diagnose and treat” conditions.
- **Self-educating:** Many invested time, money & energy in obtaining books, attending conferences or courses about their condition.

Report for patients

- **Sense of responsibility:** many of you described it in terms of a duty to put something back into society. This usually took the form of active involvement in support groups or teaching health professionals. There was often a great willingness to provide active lay contributions within statutory health services, particularly if time allowed such as in retirement.
- **Logical and well-organised:** a lot of people kept information files and prepared carefully for a doctors appointment.
- **Risk assessment skills:** Many expert patients could give well-informed and balanced reasons for adapting their treatment strategies between consultations.
- **Relationship with professionals:** the majority of expert patients saw it as vital to develop a rapport with professionals

"...if you've got a long-term situation, well it's to your own advantage to create a rapport...you think of them as your friends rather than your foes."

Patient M6

4. What were your views about professionals?

People had strongest views about doctors, either describing the relationship they had with them as particularly helpful or very unhelpful. Views about other professionals were less frequently stated with a variety of experiences described. The practical nature of help from both nurses and therapists was often cited, with emotional support seen as a key strength of nurses. A summary of participants' perceptions of good and bad characteristics of a professional is shown below.

Positive characteristics	Negative characteristics
<ul style="list-style-type: none"> • Makes you feel good in yourself • Encourages you to try things out • Removes barriers • Helps you reach your goals • Knows your feelings & experiences 	<ul style="list-style-type: none"> • Lacks time for you • Brutally frank • Just deals with one problem at a time, not holistic • Does not know you • Lack of continuity • Inhibits emotional release • Makes you feel neurotic

Report for patients

<ul style="list-style-type: none"> • Open to requests • Open to complimentary therapy • Gives you choices • Asks your opinion • Honest but kind advice • Good listener • Gives information • Accessible • Helps you keep things in proportion • Helps you to take responsibility for own health • Chases things up • Keeps in touch with you when things are bad • Caring • Sees you as a partner in care 	<ul style="list-style-type: none"> • Dishonest • Poor communicator • Lacks clinical competence • Inflexible • Treats you with a lack of respect • Lack of interest • Does not suggest a plan
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5. Other common experiences

- **Diagnosis;** many of you described a long period of vague symptoms before diagnosis with the exception being people with heart conditions who often had little warning of a problem. For the majority being told the diagnosis was a shock although there were a few people who felt relief because either their problem had been given a name and treatment could start, or some people had feared “something worse”. Occasionally people guessed the diagnosis because the condition ran in the family or they knew someone else with the disease.
- **Private or NHS?:** Some of you had experienced such long waiting lists (most commonly people with heart conditions) or felt that not all that could was being done (most commonly people with back conditions) that you opted to have private health care treatment. Overall, private care was seen as better in providing an individual service and quick treatment, but poorer in providing longer term rehabilitation. Some participants also opted to pay for complimentary or alternative therapies, discussed below.
- **Complimentary and alternative therapies:** Many people found alternative therapies such as reflexology, osteopathy and homeopathy very helpful, particularly when it was felt that conventional medicine

Report for patients

had little to offer. However, several had very different experiences and the cost was often prohibitive. A significant number of people felt unable to discuss using alternative therapies with their doctor.

- **Developing knowledge:** Several sources of knowledge were cited but the internet was rather unexpectedly not the major one. A frequently described source was the health page of the *Daily Mail*, this source was also described by many of the GPs and practice nurses in the study as they had noticed the day after publication they would see a noticeable increase in queries regarding the condition focussed upon in that edition. Support groups for many were the major source of information, friends and family were also mentioned frequently. Very few people felt they had developed their knowledge via a health professional.
- **Involvement in care:** The majority wanted to feel very involved in planning how their condition was managed, appreciating when their opinions were taken into account and being copied into any medical communication. There were a minority who did not want to be involved at such a level, some saying that the language used in doctors letters was too anxiety provoking and others feeling that they would prefer to let the “experts” get on with it.
- **Living with the condition:** Everyone had adapted their life in some way to live with their condition. This ranged from changing the physical environment (such as adapting kitchens and bathrooms), changing diet (such as giving up caffeine), or taking up exercise. Many described that after a time they had mentally adapted to living with the condition and “just got on with it”.

6. Suggestions from expert patients

Many of you had suggestions about how the health service could be improved which we have grouped together below.

- **Patient centred approaches:** The most recurring theme was the need for individualised approaches by professionals, helping people to be involved throughout their care, being non-judgemental and open to suggestions such as complimentary or alternative medicines,

Report for patients

and enabling the feeling that the patient, not the professional is in charge of the condition. For many people the worst experiences were described as being admitted to a General Hospital and having to cope with staff who had limited knowledge of their condition and being refused permission to continue their normal self-care practices.

The greatest thing we fear is going into hospital because they are going to take all the drugs away...

Parkinson's disease focus group

For others such as those with heart disease, it was the time at home following heart surgery that was most difficult with a huge sense of isolation before cardiac rehabilitation started, and suggestions were made about support during this period.

- **Professionals' responses:** Another issue for many people were perceived inappropriate responses to any expression of emotional distress. Many cited nurse specialists as providing a good example of appropriate responses; easily accessible, takes time to listen and offers practical advice where appropriate.
- **Support groups:** The majority of participants saw voluntary organizations as the most effective source of support, particularly emotional, but would like to see greater knowledge & dissemination of information by professionals about the groups and closer links with statutory services. There were a few people that had very different views about support groups which appeared to stem from poor experiences with a group.
- **Nutritional advice:** Several people (not exclusively those living with diabetes) felt that health services were poor in delivering nutritional advice in long-term conditions and felt this should be improved.
- **Other advice:** It was suggested by some people that written information should be provided about the different services available and how to access them, and also clearer advice on financial issues in long-term conditions.

Report for patients

- **Public involvement:** whilst there was a willingness to become involved in health service organizations two barriers were identified. Firstly, jargon used at, for example Primary Care Trusts' open meetings was perceived by some as a problem, and secondly there was a perception by some people that patients were "hand picked" for patient forums.

6. Professionals' responses to expert patients

A number of themes emerged from the data;

- **Time resource:** all the professionals felt that expert patients might take more time in consultations. However, both the doctors and physiotherapists described this as an initial investment that would save time in the long-term because queries would be dealt with. In contrast some nurses felt they did not have enough time to give to expert patients, apart from the diabetes nurse specialists who described part of their role as giving more time to people, and indeed observation of the nurse-led clinics appeared far less rushed for the patient, with nurses actively facilitating opportunities for patient discussion.
- **Physical measurement:** all professionals relied on a physical measurement to judge how well a condition was being managed, for example HbA1c readings were described and observed as forming the basis of consultations with people living with diabetes. Many of you were aware of this but sometimes it contrasted with your key issue and the need for an individualised, patient centred consultation.
- **Responsibility for self-management:** Whilst doctors and physiotherapists were comfortable with the idea that if someone wanted to self-manage³ and was able to then they should be helped to do so, many nurses had concerns in this area. The concerns appear to stem from the perception that even in cases where people are competent, fully informed and have chosen to self-manage, any errors will be blamed on the nurse involved. This was not the case with the

³ We use the term self-manage to describe the situation when some people are taught how to adjust their drug dosages. This is becoming increasingly common for people with conditions like diabetes and asthma.

Report for patients

diabetes nurse specialists who were used to working in a Multi Disciplinary team where there was a shared understanding and history of informed patients self-managing their long-term condition.

- **Feeling challenged by informed patients:** Physiotherapists and doctors in the study had little concern about expert patients, and indeed the doctors appeared to welcome active and informed patients as it made explaining things easier. Some nurses did feel a little challenged by knowledgeable patients and this appeared to be a particular issue for the more recently qualified nurses.
- **Responses to emotional needs:** Many of you described the negative emotional consequences of living with a long-term condition, but sometimes felt unable to share this with your doctor. For people who did discuss their feelings with medical practitioners there were frequent descriptions of what they perceived as inappropriate responses. Examples of these were being referred for counselling or prescriptions for anti-depressants, whereas people stated all they really wanted was to be listened to just for that one consultation and for their feelings to be acknowledged. GPs acknowledged that they often found this side of their work the most difficult, whereas nurses were clearly comfortable in dealing with the emotional consequences of the condition and were often identified by people as being the most responsive to this need. Some of you also cited physiotherapists as providing appropriate responses, particularly if the physiotherapist was outside of the normal time limited provision provided within the National Health Service.

What has happened to the study results?

A number of recommendations arising from the results have been presented to the Primary Care Trusts involved. They cover issues surrounding the delivery of the Expert Patient Programme, initial and in-service professional education, and service delivery. We are continuing to analyse the data and hope to carry out some further research about the issues arising out of this study. Examples of possible future research are:

Report for patients

- Looking in more detail at the role of the nurse in chronic disease management
- Looking at ways of preparing general nurses to help people maintain their self-management activities (such as giving their own insulin, or taking medication for Parkinsons Disease when needed) when admitted to a General Hospital
- Exploring how people with unusual moles learn to tell when medical treatment is required.

References

Department of Health (2001) *The expert patient - a new approach to chronic disease management for the 21st Century*. Stationary Office, London.

Jones N. (2003): How are expert patients different? *EPP Update* 8 1, 3.

University Ethics Committee Approval

UNIVERSITY OF HERTFORDSHIRE

RESEARCH ETHICS COMMITTEE

for

NURSING, MIDWIFERY, PARAMEDIC SCIENCES, SOCIAL WORK AND COUNSELLING

FEEDBACK

Applicant Patricia Wilson

Study Patient empowerment in primary care: an evaluation of the Expert Patient

Reference Number: NMPSC/2002/37

Date of REC 25.03.03

Item	Comments	Revision Major /Minor
1. Title of study	✓	
2a. Applicant - name	✓	
2b. Applicant - address e-mail	✓	
2c. Status applicant1	✓	
2d. Status applicant2	N/A	
2e. Status applicant3	N/A	
3a. Name supervisor	✓	
3b. Status supervisor	✓	
3c. UH Department	✓	
3d. HoD	✓	
3e. Collaborating Inst.	N/A	
3f. Collaborating Staff	N/A	
3g. UH Link Lecturer	N/A	
4a. Literature review	✓	
4b. Aim	✓	
4c. Methods	✓	
4d. Data collection tools	Please note there is a typo in the 2 nd question for Claire (ie his)	
4e. Description of subjects	✓	

University Ethics Committee Approval

4f. Access to subjects	✓	
4g. Number of subjects	✓	
4h. Data analysis	✓	
4i. Expected duration of study	✓	
5a. Distress	✓	
5a1. Potential cause of distress	✓	
5a2. Precautions	✓	
5a3. Steps if harm is caused	✓	
5b. Informed consent procedure	✓	
5c. Consent from "vulnerable"	✓	
5d. Timing of consent	✓	
5e. Questions	✓	
5f. No obligation/withdrawal	✓	
6. Financial reward	N/A	
7a. Details of personal data	✓	
7b. Security of data	✓	
Declaration by applicant Name Signature	✓	
Declaration by supervisor Name Signature	✓	
Support HoD/Unit/Centre Name Signature	✓	

University Ethics Committee Approval

Overall comments

REC decision:

Approved

Your study is registered with approval number : **NMPSC/2002/37A**

Please note that if any significant changes are to be made to the methodology the Committee must be informed.

The enclosed Quality Monitoring Form must be completed and returned to the Secretary to the Committee, Post-graduate Office, 1F264, Wright Building, Hatfield Campus, immediately the study is finished.

Johnis Maddison
AP Jane Smith
Chair of REC

c.c. Sally Kendall - CRIPACC

Ref: EC03638

LREC

17th April 2003

Tricia Wilson
PhD Student,
Senior Lecturer
University of Hertfordshire
Hatfield Campus
College Lane
Hatfield
Herts AL10 9AB

Direct Dial: 0
Direct Fax: 01.

Dear Ms Wilson

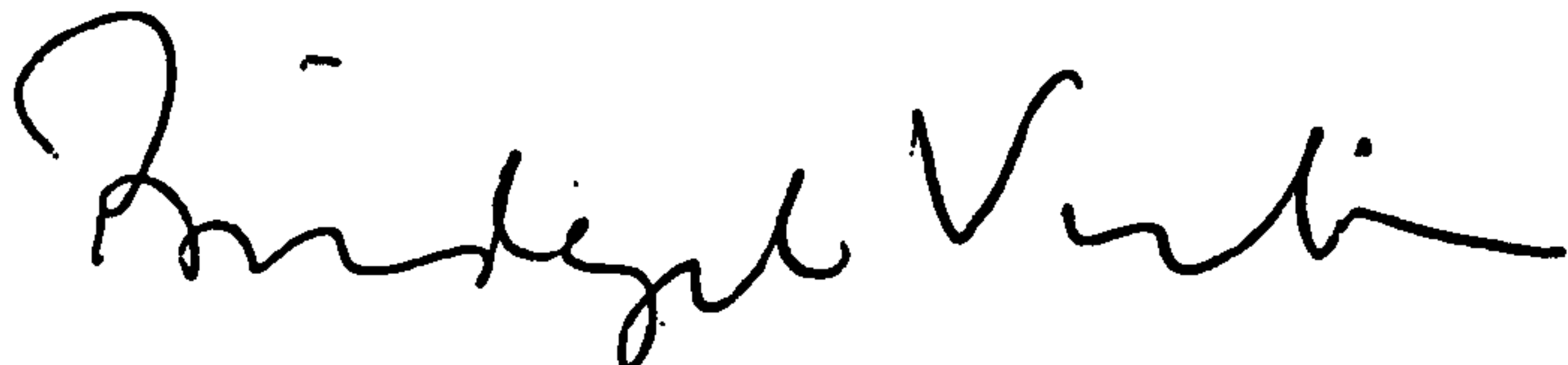
Re: Patient Empowerment in primary care: an evaluation of the Expert Patient

As requested by the committee following their meeting on 19th March 2003 they reviewed your letter dated 1st April 2003 addressing the issues regarding the above study and at last night's meeting, (16th April 2003), and have given it full ethical approval.

The Committee wishes you well with the study and looks forward to receiving regular updates on progress.

This local research ethics committee is organised and operates according to GCP and applicable laws and regulations as required by section 5.11.1 (b) of the ICH GCP Guidelines.

Yours sincerely,



Bridget Vickers (Mrs)
Chair

Local Research Ethics Committee

Primary Care Trust

Honorary Contract

Between:

Primary Care Trust
And

Patricia Wilson

1. I am instructed by the Primary Care Trust to offer you an Honorary Contract in the capacity as a researcher.
2. This post allows you to undertake the duties on the premises and using facilities of Primary Care Trust. If your duties involve clinical or administrative duties connected with patient care you are granted access to the associated records.
3. If in the course your duties you undertake any form of research, you agree to make yourself familiar with the Research Governance Framework, the PCT research management and governance policy and agree to accept the responsibilities associated with your role that are outlined within it. Primary Care Trust manages all research in accordance with the requirements of the research Governance Framework. As a contract holder of Primary Care Trust you agree to comply with all reporting requirements, systems and duties of action put in place by the Trust to deliver research governance.
4. You and your employer recognise the Trust's right to benefit from intellectual property arising from work undertaken under this contract in accordance with the Health and Social Care Act 2001. In circumstances where there is potential IP you are required to notify the Director of Public Health, Dr Raymond Jankowski. Specific intellectual property agreements will be negotiated on an individual care-by-care basis.
5. You are required to observe the policies and procedures of the and Primary Care Trust in so far as they apply to this appointment and to observe all NHS policies and procedures in respect of clinical and research activities.
6. You are required to be registered with your professional organisation and remain so for the tenure of your appointment with the trust. This Honorary Contract will be terminated should you cease to be registered with your professional organisation. You should forward a copy of your current registration certificate to the Human Resources Department of Primary Care Trust.

APPENDIX 24

PCT Research Governance Approval

7. You must act at all times in accordance with the Trust's Policies, Procedures and Guidance, copies of which are available in the Human Resources Department. The Trust reserves the right to terminate the Honorary Contract where your conduct is inconsistent with the high standards of work and behaviour expected in your continued honorary placement with the Trust.
8. You will report to the PCT research lead if you wish to raise any concerns or complaints about your commitments under this Honorary Contract. The agreed procedure for settling differences between you and the Primary Care Trust will be in accordance to the Trust's Grievance Procedure. This information will be fed back to your employing body.
9. The trust accepts liability of your acts and omissions to the degree that those acts and omissions were carried out whilst working on behalf of the trust and in accordance with your appointment under this contract. You must however observe the same standards of care and propriety in dealing with patients staff, visitors, equipment and premises as is expected of any other contract holder. You must also act appropriately and responsibly at all times.
10. Whilst undertaking officially sanctioned NHS duties, you are covered by the NHS indemnity against claims for negligence. In other circumstances (e.g. when providing services for which you receive a separate fee, or if undertaking research which has not received Trust approval) you are not covered by the indemnity. If you intend to treat private patients on Trust premises you must have a valid indemnity. Medical practitioners are advised to maintain membership of a medical defence organisation and submit a copy of current membership to the Human Resources Department.
11. You are required to ensure the security and confidentiality of all information regarding patients or staff at all times. You should not release any such information to anyone other than an approved person in the course of your duties. If an honorary contract holder you handle patient or staff related information stored on computers, you must ensure that it remains Trust owned computers and is not transferred to computers owned by other organisations including those of your substantive employer without appropriate authorisation. This authorisation might be in the form of a formal agreement between Primary Care Trust and your substantive employer with regard to specific types of information or a specific agreement between yourself and the Trust with regard to storage of such information. You should be aware of your responsibilities under the Data Protection Act and only use such information for a registered purpose, not disclosing it to any unauthorised person. You should make yourself familiar with relevant Trust policies.
12. In the event of sickness or unavoidable absence, you must notify Claire Foley at PCT and the Human Resources Department immediately. You must report any accident or injury, however trivial, arising out of or in the course of your activities in the Trust to the Head of Corporate Affairs and make appropriate records and statements as required.
13. **Mandatory Training**
You are responsible for familiarising yourself with the Trust's mandatory training courses such as Moving and Handling, Health and Safety, Fire Training etc. For further information and to book training, please contact Tanith Ellis in the safety department.
14. Please ensure that you wear your ID badge at all times, or be able to prove your identity if challenged.

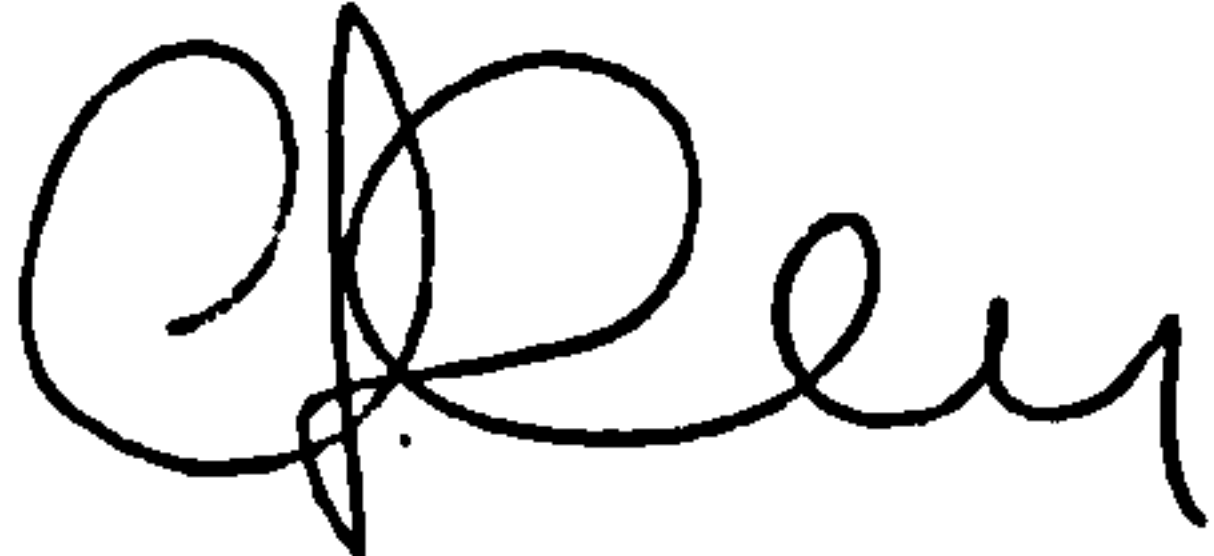
Dress Code

APPENDIX 24
PCT Research Governance Approval

The Trust wishes to ensure a smart, professional image to be conveyed at all times to the patients and other visitors.

If you agree to accept this Honorary Contract on the terms specified above, please sign the form of acceptance at the foot of this page and return it to the Research Collaborative Administrator. A second copy of this letter is attached, where you should also sign and keep for further reference.

Yours sincerely



Claire Foley
Research Collaborative Administrator & Audit Officer
On behalf of Dr Peter Bennett, Research Lead,

PCT

PLEASE DO NOT DETACH

I have read and agreed to the above conditions & I enclose a copy of my current professional registration certificate.

Signed.....P.M. Webb.....Date...4/2/04...

Primary Care Trust

Patricia Wilson
Senior Lecturer/PhD Student
CRIPACC
University of Hertfordshire
Hatfield Campus
College Lane
Hatfield,
Herts. AL10 9AB

Tel: 0
Ext:
Fax: 6

Direct Line: 01

Ref: MB/cr

04 June 2003

Dear Trisha

Re: Research Study Evaluating the Expert Patient as a Way of Empowering Patients in Primary Care.

Thank you very much for your letter regarding your above research study. As I am sure you are already aware I fully support the Primary Care Trust's participation with your study and feel that it is highly beneficial, however, I will need to take this to the PEC for their agreement as it involves GP practices. Although the PEC might well provide support to your research it will be up to each individual practice as to whether or not they wish to participate. To facilitate this I will, with your permission, be sending out your letter and research proposal to gain the views of the practices.

I know that you and Sharon have been working very closely with this and I am sure that this relationship will continue. I would also like to thank you for your participation and support in the workshops that have recently been undertaken for our community nurses.

I wish you all the best with your research and look forward to hearing about the findings.

Yours sincerely



Maureen Brierley
Director of Nursing

ed PCT

Patricia Wilson
Senior Lecturer
CRIPACC
University of Hertfordshire
Hatfield Campus
College Lane
Hatfield
Herts
AL10 9AB

Tel:
Fax: 01438 612345

13th June 2003

Dear Patricia

Thank you for forwarding your request for support for the research Study evaluating the Expert Patient as a way of empowering Patients in primary care.

In principle Primary Care Trust is happy to work with you on this project.

Please liaise with either Jo Poole or myself to arrange local focus groups and to facilitate access to the PCT. Venues in Hatfield are at a premium so please set dates as early as possible. There is a strong voluntary agency input in Hatfield and Jo Poole has started to make links with them, so will continue to be a valuable link

Please contact me if you require further information at this time.

Yours sincerely

Tanith Ellis
Head of Corporate Affairs

2nd October 2003

Direct Dial: 01462 90003
Direct Fax: 01462 70003
E-mail: research@pct.nhs.uk

Patricia Wilson
Centre for Research in Primary & Community
Care
University of Hertfordshire
Hatfield
Herts
AL10 9AB

Dear Patricia

Re: PERMISSION FOR RESEARCH PROJECTS

Following the recent clinical governance sub-committee meeting I am pleased to tell you that your project has been approved. I am sorry that this has taken a while, but we are now more familiar with the new research governance framework and hopefully future projects will be approved more quickly. I wish you success with your project.

Yours sincerely,



Ann Wagg
Research Governance Lead

**APPENDIX 24
PCT Research Governance Approval**

6 November 2003



Primary Care Trust

Head Office

Patricia Wilson
Centre for Research in Primary & Community Care
University of Hertfordshire
College Lane
Hatfield
AL10 9AB

Tel: 0
Fax: 0

www: .pct.nhs.uk

Dear Patricia Wilson

RE; Expert Patient Study

Thank you for your communication with enclosures requesting permission to carry out the above research within the PCT area.

Your research project has local LREC approval, RM & G approval from the PCT Research Collaborative and it fits in with the workplan of this PCT. I am happy to endorse this piece of research and I therefore write to inform you that you have full permission to undertake this research within Primary Care Trust..

I understand that your project is already running with a number of other local PCT's and I assume that an Honary Contract for the researcher has already been prepared by our shared HR service. This letter should be sufficient to extend this to our area.

I wish you well with your research and ask that you keep the PCT research officers informed of your progress .Thank you.

Yours sincerely

**Steve Knighton
Chief Executive**

Primary Care Trust

Tricia Wilson
Centre for Research in Primary and Community Care
University of Hertfordshire
Hatfield Campus
College Lane
Hatfield
Herts AL10 9AB

Tel: 0
Fax: C

6 November 2003

Dear Tricia

Subject – Patient Empowerment in Primary Care: An Evaluation of the Expert Patient

Thank you for notifying us about the above project. I have had confirmation from HertNet who work for our Research Collaborative, that you have met the various RM&G criteria and that the project has been recommended for approval.

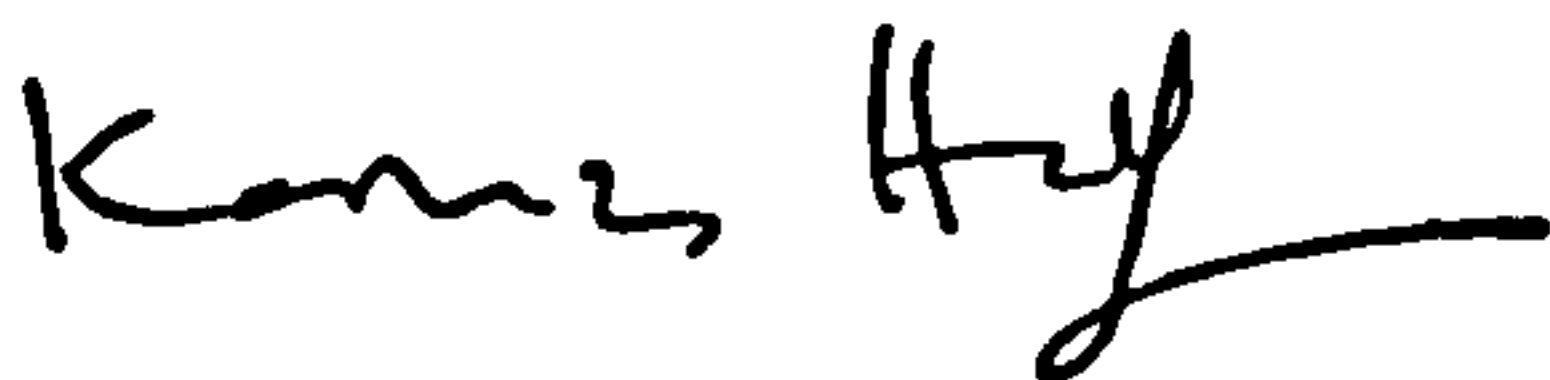
Further to your enquiry seeking the Trust's permission to carry out the above Research project in our area, I am confirming our approval for the project to commence.

Thank you for attending our Community MS team meeting the other week and I am glad that you found it useful in terms of making contact with potential staff keen to take part in the study.

I would be grateful if you could keep us up to date with progress on the project, via Claire Foley, our Collaborative Research Administrator and Audit Officer, who is based at V Primary Care Trust's Head Office in V

Claire's phone number is (ext 2068 should you have any further queries or please do not hesitate to contact myself at the above address.

Best wishes.



Katrina Hall

**Director
PCT Lead for Research Management and Governance**

cc. Claire Foley
Sally Pollitt
Rachel Allen

9th February 2004

Mrs Tricia Wilson
Centre for Research in Primary and Community Care
University of Hertfordshire
College Lane
Hatfield
AL10 9AB

Dear Mrs Wilson,

RE: EC 03638 HHA LREC – Patient Empowerment in Primary Care: An evaluation of the Expert Patient – NLR 028

Thank you for completing the Part D of the NHS Research Ethics application for your "no local researcher" project. This project has been approved by the Research and Development Department.

Should you have any queries or require further information from the R&D department please do not hesitate to contact Fiona Smith, Manager on the above numbers.

Best wishes for a successful project.

Yours sincerely,



Dr Adam Young
Associate Medical Director R&D

cc. Dr C Johnston

Back Fitness Course Content

Back Fitness Course
2 hours per week
Week 1
1 hour Gym based exercise
1 hour introduction to the course
Week 2
1 hour Gym based exercise
1 hour goal setting
Week 3
1 hour Gym based exercise
1 hour stress management
Week 4
1 hour Gym based exercise
1 hour relaxation
Week 5
1 hour Gym based exercise
1 hour "What is pain?"
Week 6
1 hour Gym based exercise
1 hour pain reducing strategies
Week 7
1 hour Gym based exercise
1 hour relaxation and goals
Week 8
1 hour Gym based exercise
1 hour review of course

Participant identifying code	Age band	Diagnosis (es)	Length of time since diagnosis of primary condition	Display of exemplifying data
F6	60-70	Osteoporosis	15 years	F6 I'd advised Doctor D that I was doing this, I said you know would he mind just sending the two letters saying he was willing which he did so marvellous co-operation, so em, then I went back to him er, to discuss this and he said "Oh well just keep on" he said "As long as it doesn't upset you". Well thank god you know it doesn't upset me, Fosimax doesn't so much as this stuff. Meantime I've had a bladder problem and we don't know whether it's associated but what I like about Doctor D ... I'm sure is sort of to establish a relationship is that he does ring you.
F9	60-70	1. Diabetes type 2 2. Breast Cancer	2 years 5 years	F9 Blood, blood pressure, that's fine. If anything it's a little bit low but she said "Nothing to worry about and you don't have to do anything about it but we will keep check of it every time you come" which is fine. And em, I go, er, three monthly... F9 They keep an eye on it and that's all you can ask really
M5	70-80	Rheumatoid arthritis	10 years	M5... I've read about this thing that is a cure of everything from America, can't remember what it was. Anyhow I sent for the book on it and I actually sent off to see what it was about. Eighty pound a throw and they reckon 'Well you take it for a month and you're cured' so I spoke to Doctor A and I said "I can't believe this because if it costs eight pounds and every patient is seen to, look at the money that would save" and he said "Well they're very wrong" he said "Because" and it's American, he said "They haven't information on it" he said. "It's not proven" and he said "If it was, we would be using it"
M6	70-80	1. PD 2. insulin dependent diabetes	5 years	M6... I'm a fairly good communicator and er, and I, I get on quite well with most people and the whole idea if you've got a long-term situation, well it's to your own advantage to create a rapport, if it's little bit by little bit so that, so that you think of them as your friends rather than your foes. Professor L's clinic is, is staffed by em, a whole range of people but apparently because of his worldwide em status, to be, to have a research fellow under his wing, in other words be one of the neurologists that you look at, is very promising so I mean I, there was a lovely Italian lady that looked after me for a year and er, and you know er I had one session with one of the blokes but trouble is I could hardly

					walk so if you don't ask you don't get, I rang her and she said "Well come and see me tomorrow". You know I mean, I'm nothing special.
F11	40-50	Psoriatic arthritis	17 years		F11 It's more, I think more of a partnership em thing now where you've got your consultant and yourself and the more information you can give your consultant and tell him or how exactly how you're feeling, they can then er tailor your medication to your needs. Em, it's quite useful if you draw an outline of your body if you've got pain in lots of areas and then just mark in the most pain, the pain where it's quite strong and maybe mark in a different colour where it's not so strong and then the consultant will get an overall picture.
F13	70-80	1. Liver disease 2. bowel cancer 3. arthritis 4. breast cancer	5 years		F13 I mean I think the medication and how he, em, how he watches it, you know keeps an eye on it, I think that, I don't have any qualms there at all because he gives me the opportunity to say "No" or "Yes" because I was having particular trouble with my bowels a couple of months ago, he said that he'd like me to have an examination and I em, I suppose I pulled a face and he said "Well, we'll leave it for a month then and we'll see how it is" because he changed my medication, he give me a different medication.
T2	30-40	endometriosis	10 years		T2... each time I had an appointment with someone, I would have written it all down, exactly what I wanted to know and what if this and lalala, and I wouldn't be ashamed. I'd go in there with my sheet of paper and I'd go through it and (<i>pause</i>) I never had a problem with that. I didn't have Consultants who were (<i>pause</i>) flippant or anything. You know they were fine with it
OPm11	30-40	Diabetes type 2	5 years		OPm11 Medical jargon, negotiating change, seeking self-management, has a clear agenda, speaks as an equal, uses first names to identify other medics and to give C message that he knows other medics. Very knowledgeable. States clearly what he wants. Gives appropriate background info. Re his lifestyle. OP11m " <i>I'd like to see you in 6 months please</i> " OVERALL characteristics: *v.knowledgable, *negotiation+++ *equalised approach, *grown up, *first names++, *medical discourse++
OP20f	30-40	1. Insulin dependent diabetes 2. Addison's Disease	17 years		OP20f V. understanding of what is being said. Discussed changes in insulin to get BS & HbA1c down to have fewer hypo's. Quite a complicated case, s/b a number of other clinics. C1 offered to get her endocrine clinic transferred so that all was under the same hospital. She refused - she likes to keep clinics in separate hospitals so that she doesn't get confused. Co-morbidity+++ V. complex regimen & 2 young children (6&3), proficient in self-management. " <i>You just have to get on with it</i> ".
OPC2m24	70-80	1.Solar	1. 1 year		OPC2m24 Well prepared for OPA. Brings repeat prescription list, articulate and gives a

		keratosis 2. hypertension 3. CVD	2 & 3. 20 years	succinct history. Has been carefully observing changes in skin and actively asks questions.
OPC2f28	30-40	Atypical mole syndrome	10 years	OPC2f28 describes how she learned to observe for changes many years ago, able to articulate quite clearly what to expect. Has extensively researched the condition. Consultation is like a conversation between peers, both say they expect the changed mole is a melanoma.
OPC2m33	30-40	Atypical mole syndrome	18 years	OPC2m33 consultation feels like a real partnership, takes in his own photos of his moles and compares them with the consultant's ones. They discuss together how frequent sunburn as a child was a major factor.
OPC2m34	20-30	Psoriasis	15 years	OPC2m34 very knowledgeable about condition. C2 and he discuss options for reoccurrence together.

Participant identifying code	Age band	Diagnosis (es)	Length of time since diagnosis of primary condition	Display of exemplifying data
F2	40-50	Rheumatoid Arthritis	5 years	<p>F2 ... my consultant said she wanted me to take um, HRT, to protect the bones when I hit the menopause</p> <p>R Yeh</p> <p>F2 Um, and I said to my G.P. I said "I'm an adult and I really do not want to take it" and he said "You don't have to take it", he said "You know there are other things that you can take, you don't have to take HRT" um, but she kept on saying to me about it and I kept lying so she doesn't know that I've reached the menopause and gone through it and <i>(laughing)</i> she doesn't know</p>
F8	30-40	MS	20 years	<p>F8... I had access to a lot of books, the BMJ, em the British National Formula. I looked up the tablets. Um, it did say, I shouldn't have done, but you have to you know. Um, I had a boss who had a cabinet with everything in. I said "Oh do you mind if I borrow some of these books?". "Oh yes sure". He didn't know what I, he'd probably have said no had he known.....</p>

Participant identifying code	Age band	Diagnosis (es)	Length of time since diagnosis of primary condition	Data display
F3	60-70	Lower back pain	20 years	<p>So I got referred down to a lovely private hospital, the same consultants who had seen me elsewhere I now see privately em, he er looked at me, advised various treatments, none of which I was very happy, I kept thinking "This doesn't sound right and I'm not happy with this", spoke to my doctor who said "If you're not happy with what he's saying you don't have to do it you know" and meanwhile this private consultant also referred me, he said "Oh well you can have some physiotherapy here privately" and this was in the hands of people I'd never had physio with before who started treating both parts of my spine at the same time. And I was just so ill afterwards, I was sort of laid up for, I think you know, it did an awful lot of damage, I just sort of freaked out after that and thought "I'm not coming back here."</p>
M4	30-40	Medically unexplained symptoms -- abdominal pain	8 years	<p>M4 there are about six of us who still meet up, we go out once a month on a Thursday when we meet up for the Expert Patient Programme and it was on a Thursday. We meet up again once a month on a Thursday, go to a pub for a drink or lunch, which is nice so with that social aspect and it, it has continued on, which is nice. Because we can all have a moan about our G.P.'s (<i>laughs</i>)</p> <p>R Is that the general topic? I mean is that the/</p> <p>M4 Yeh, a lot of the time it is. A lot of the time it is, G.P.'s or Consultants, or waiting times</p>
F5	30-40	Diabetes type 1	25 years	<p>F5 Not anything, not offering anything extra, put it that way, so I don't do that any more. I think I've had a couple of reminder letters in the post and kind of ignored them so they've (<i>practice nurses</i>) left me alone (<i>laughs</i>)</p> <p>R Yes, yes that's interesting isn't it? I mean would you feel able to say to them 'Look this is, there's not a lot of point to this, what's the point of this?'</p> <p>F5 Em (<i>pause</i>) I dunno, I dunno if I'd be that brave or that, you know, to sort of put it like that</p>
T1	50-60	MS	25 years	<p>T1 ...it was a couple of years ago a neurologist said "Right, you've gotta get this sorted but you're going to see the continence nurse now" and I had been to see her twice before and just rang up off my own bat. She kept on saying she was gonna come and see me and then I cried and then she said "Oh, you're moving house" you know so nothing had</p>

				<p>ever happened so I was feeling a bit negative about her. He said "No, you must go and see her now". I went next door and she said "Oh dear. It's all been very difficult for you" and she said "Right, I'm going on holiday but I will ring you when I get back and we'll get it sorted". Well she didn't ring me. I got a letter saying 'I will come and see you on this date' which I couldn't do. I rang her up, she'd given me the wrong telephone number on a printed letter and I rang this woman. She'd been talking to a continence patient for months because she said "Oh, I had a woman last week who was desperate for some pads and wasn't able to get them but I can tell you the number to ring" (<i>laughs</i>) and so I just thought 'This is hopeless' but because of the work I've done and working at the National Hospital I give courses there, I went to the, I rang this MS nurse at the National Centre and said "Look I'm really desperate about my bladder. Can you do anything?". She immediately got me sorted.</p>
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Participant identifying code	Age band	Diagnosis (es)	Length of time since diagnosis of primary condition	Display of exemplifying data
M2	80-90	Venous ulceration	50 years	<p>M2 The chappie on television yesterday or two days ago, um, talking about a dressing which had vac, something vac</p> <p>R Oh yes, um</p> <p>M2 And um she (district nurse) said "Yes, but I used to use a vacuum" and I said "No, this is nothing at all to do with vacuuming" it's a part of the trade name I think</p> <p>R Um</p> <p>M2 But I said "I've got all the paperwork here and you can have all the paperwork but don't lose it because I want to pass it on to my GP"</p>
F4	50-60	1.Diabetes type 2 2.Depression	4 years	<p>It took the M.P. for us to get them, they would not put up a complaint. By law you've got to show what the complaint is, they wouldn't put it up and in fact they got rid of their practise manager 'cos I rang the M.P.</p>
F7	60-70	MS	10 years	<p>F7...so I wrote and asked him whether I could have this new drug, not new drug, this drug because you can't get it without prescription you know</p> <p>R Yes. What kind of response did that?</p> <p>F7 Negative really. Em, I offered to pay for it em, but he just said "I can't prescribe it on the NHS"</p> <p>R Right</p> <p>F7 So, still waiting at the minute</p> <p>R He doesn't give private prescriptions either?</p> <p>F7 Oh, he does really but he hasn't offered me one so I, I've written to em my GP and given him all the information for him to read whenever he can. I'm just waiting for him really to reply</p>
F15	30-40	MS	5 years	<p>F15... it is really ideal to have somebody come to see you at home. I'm not wasting my energy with going out em, and they can then work within the environment and they can then see the problems that you know, I'm using all my energy going up and down the stairs but he can then say "Right, I want you to lean on this work surface or" you know he can see what tools I've got to use in my home</p> <p>R Yes, absolutely</p>

					<p>F15 So it is ideal but I'm probably quite aware that they managed to get/</p> <p>R Yes, you're the first one I've heard of</p> <p>F15 Yeh, that's it. Well yeh that's because I um, I fight and I moan and I complain and I write ...</p>
F16	50-60	1. ME 2. epilepsy	15 years		<p>F16 I had it all written down on a book and I actually questioned him. I didn't let him just go on about anything that didn't, I actually questioned him to the point of fact that I think he might have got a bit fed up but now and again I said "Oh thank you very much for your time" just to sort of, you know, help keep him sweet. I've asked him for a blood test on em, I got quite a lot of them fixed, obviously I've got quite a lot of fillings in my teeth, em, and there is a chance that I might have, em, you know, the in your blood you get a metal toxic so I've asked him for a blood test, er, for that which he was a bit reluctant but then he, he's sending me for it so I had a blood test for that before I had, so I was quite happy that I, because that's one thing I can eliminate but he didn't offer it to me.</p>
OP13m	30-40	Diabetes type 1	15 years		<p>OP13m <i>C have you read anything else?</i> OP13m <i>Yes, statins. Well researched. Married to a GP so reads lots of medical journals. Tells C that Diabetes UK website says all should be on statins C: They don't differentiate between type 1 & 2. Helps OP13m to evaluate information.</i></p> <p>OP13m asks C "<i>why haven't you got a camera?</i>" C <i>yes we have but there are cost resource issues which means we use it for those who don't attend clinic, we just manually screen those who attend clinic, but new government guidelines states all should have photo taken so it will be changing.</i></p> <p>OP13m discusses in a rational, equalised way the difficulties of fitting OPA's with work, wants to get blood test done same day, C explains why this is impossible</p>
OP22f	40-50	Diabetes type 2	16 years		<p>OP22f very informed, knew link between thrush and fungal nails. Came to consultation with all information needed. Had stopped nurse dilating her eyes as she had an eye test recently- assertive when she knows inappropriate action. Questions C1 on whether she should have liver tests when on glibencamide, C1 gives an explanatory and appropriate answer. However, C1 labelled her over anxious but when challenged by me "<i>I'm very different from many of my colleagues in thinking it's better for patients to be knowledgeable and know what they'd like</i>"</p>
OPC2m35	60-70	Myelodysplastic	20 years		<p>C2 says this is an expert patient, so expert that he writes in to say he's not getting the</p>

		syndrome		treatment he thinks he needs!
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Participant identifying code	Age band	Diagnosis (es)	Length of time since diagnosis of primary condition	Data display
F1	70-80	PD Recovering alcohol misuse	9 months	R Yeh. So ... are there any occasions at the moment you're going in and actually, em, in a position to be telling her 'Well they've put me on this and they've said this and they've said that' type of thing F1 No not really. I don't like being ... er ... I'm of the old school where the doctor always knew
F14	70-80	osteoporosis	5 years	F14 Well I think I slipped through the net through no-one's fault. I didn't go to the doctor 'cos there appeared to be no reason, I wasn't pulled in for a Well Woman, perhaps that doesn't happen now
OPC2m31	50-60	Solar keratosis	1 year	OPC2m31 not really engaged with condition, did not ask questions, appeared to have a lack of understanding about the condition.

Publications

LIST OF PUBLICATIONS

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- Wilson P.M. & Mayor V. (2006): Long-term conditions. 2: supporting and enabling self-care. *British Journal Of Community Nursing* 11, 6-10.
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