

Nurses' responses to expert patients: the rhetoric and reality of self-management in long-term conditions: a grounded theory study.

Patricia M. Wilson*¹

Senior Lecturer
MSc, RGN

Sally Kendall

Director of CRIPACC and Professor of Nursing
PhD, RHV

Centre for Research in Primary and Community Care
University of Hertfordshire
College Lane
Hatfield AL10 9AB
UK

Fiona Brooks

Reader in Primary Care
PhD

Centre for Research in Primary and Community Care
University of Hertfordshire
College Lane
Hatfield AL10 9AB
UK

¹ Department of Nursing & Midwifery, University of Hertfordshire, College Lane, Hatfield AL10 9AB, UK
p.m.wilson@herts.ac.uk Fax: 01707 285995

Acknowledgements

The authors would like to thank Professor Robyn Martin for her comments and advice during drafts of the paper and the anonymous reviewer for the helpful feedback.

ABSTRACT

Background

Against the backdrop in the western world of increasing prevalence of chronic disease, active and informed patients and a policy emphasis on self-management, this English study explored health professionals' responses to expert patients.

Objectives

To:

- Explore how patient expertise is viewed, interpreted, defined and experienced by both patients and health professionals;
- Analyse how patient expertise is promoted and enabled through the self-management process;
- Uncover the mechanisms that enhance or impede the development of patient expertise.

Design

A grounded theory approach was utilised with two concurrent data strands.

Setting

A relatively affluent English county including community, primary and secondary care settings.

Participants

Via purposeful and theoretical sampling 100 health professionals (nurses, doctors, physiotherapists) and 100 adults affected by chronic disease participated.

Methods

Focus groups, interviews and observation.

Results

Nurses were found to be most anxious about expert patients when compared to other professionals, which appeared to be linked with a lack of professional confidence and unfounded fears regarding litigation. However, nurse specialists often provided a negative case for this. As a whole, nurses were most able to meet the emotional needs of patients, but apart from nurse specialists did not articulate this as a skill.

Conclusion

Apart from nurse specialists the majority of nurses appeared limited in appropriately facilitating self-management. It is suggested that this is linked to an ongoing nursing culture of patient as passive, an over-emphasis on empirical knowledge and a feeling of vulnerability on the nurses' part towards expert patients. The findings also indicate a rhetoric rather than reality of autonomous nursing roles within the chronic disease management agenda.

Key words

- **Chronic disease**
- **Expert patient**
- **Nurse's role**
- **Patient participation**
- **Self care**

What is already known about the topic?

- 70-80% of chronic disease management is via supported self care.
- Individuals that are enabled to self manage their long term condition have been shown to have improved health and psychological outcomes.
- Despite the focus on self care, health care professionals often continue to emphasise compliance as opposed to developing a partnership approach with patients.

What this paper adds

- Compared to doctors and physiotherapists, nurses find active and informed self-managing patients particularly challenging citing perceived litigious vulnerability as the cause.
- Nurse specialists provide a contrasting case to general nurses' responses to active and informed patients suggesting that role preparation, definition and context has a significant impact on the way nurses enable patient self management.

- Patients with long term conditions feel their emotional needs are most effectively addressed by nurses, however many general nurses do not perceive this as a key aspect of their role.

INTRODUCTION

Increasing prevalence of chronic illness has become the major resource demand on global health care (Department of Health, 2004, Harwood et al., 2004), resulting in new approaches towards chronic disease management (CDM) (Lewis and Dixon, 2004). Within western health systems one of the most noticeable changes is the emphasis on patient self-management (Bodenheimer et al., 2002, Department of Health, 2002, Kings Fund, 2004, Koch et al., 2004) which in the United Kingdom (UK) has been accompanied by a shift of health professional roles characterised by the extension of the nursing remit in CDM (Health Technology Assessment Programme, 2004). Whilst in reality self-management programmes reach comparatively few (Kralik *et al.*, 2004), in contrast nursing has long been recognised as having a key role to play in helping people to manage chronic illness (Audit Commission, 1999, Kratz, 1978). However, there is evidence of a lack of proactive engagement with this client groups' needs (Gibbon, 1994, Kratz, 1978, Nolan and Nolan, 1995) and until recently nursing in the UK was acknowledged as not fully realising its potential to meet the needs of the chronically ill (English National Board, 1998, Nolan and Nolan, 1999). In addition the nursing response to patient self-management is unclear (Wilson, 2002, Wilson, 2001). The UK Expert Patient Programme (EPP) (Department of Health, 2001), a lay-led self-management course for generic long-term conditions based on the Lorig model (Lorig *et al.*, 1996) is currently being evaluated, preliminary findings suggesting a significant lack of engagement from health professionals (Kennedy *et al.*, 2004).

This paper presents a UK study exploring professional responses to active and informed patients. Whilst there were a number of outcomes the paper will focus in-depth on the results suggesting that nurses have particular issues with self-management. The findings appear to contradict the espoused international nursing position towards informed patients (International Council of Nurses, 2003), and the significance will be discussed within the context of ongoing nursing role expansion.

BACKGROUND

Self-care and self-management in long-term conditions

A common theme in defining self-care and self-management is that it is a hallmark of chronic illness management (Department of Health, 2002), requiring the acquisition of new knowledge and skills (Watt, 2000).

A search of the literature on self-care and self-management reveals a confused picture with the terms self-care and self-management often used interchangeably or simultaneously. An all encompassing definition of self-care is “...*the things people do because of ...*” a health problem (O'Hara et al., 2000). Self-care consists of the ability to evaluate one's state of health and adjust one's behaviour (Makinen et al., 2000). Orem (Orem, 1995), describes six learned self-care activities (Ricka et al., 2002) (figure 1). Whilst these activities can be seen to form the basis of self-care and self-management, there are a number of ways that they can be enacted. Chapple and Rogers (1999) put forward four types of self-care behaviour: regulatory, preventative, reactive, and restorative, with Toljamo and Hentinen (2001) describing four differing modes of self-care: flexible,

regimen adherent, self-planned or neglect. Not all these modes are professionally set, and professional approval is unlikely to be gained by neglect, or even in some cases self-planned self-care. As in Orem's work, other authors closely link self-care with self-development. Self-care is seen as an active, responsible and flexible process that will result in personal development (Corner, 2001, Ricka et al., 2002).

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 and Hentinen, 2001), but a newer area of self-management in the UK is in anticoagulation where some patients self-test and self-dose (Fitzmaurice and 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.

Definitions of self-management (figure 2) 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 is also argued as empowering for the patient (Corner, 2001).

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 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 paradoxically concurrent idea of self-care being the performance of professionally set behaviours (Baker and Noerager Stern, 1993). This contradiction echoes concerns that whilst the notion of concordance is espoused (Royal Pharmaceutical Society of Great Britain, 1997) professionals continue to think in terms of compliance (Raynor et al., 2001) resulting in the continuing labelling of those who do not adhere to professional-set treatment regimes as non-compliant (Playle and Keeley, 1998). In contrast although the principles of concordance aim to improve medical outcomes via a partnership approach, it also acknowledges that the patient's informed decision to refuse treatment should not be viewed negatively (Wilson, 2001). Nevertheless, intelligent reasoned choices by individuals regarding the instructions they receive about treatment (World Health Organization, 2003) may be refuted by professionals, thus setting patients the near impossible task of being simultaneously self-reliant and compliant (Thorne et al., 2000). Whilst non-compliance is professionally defined, actions that may be viewed as non-

compliant by a professional do not necessarily lead to poor health outcomes (Roberson, 1992). A recent study by Koch et al (2004) illustrates this. In exploring perceptions of self-management in a group of elderly people with asthma, the researchers identified three types of self-management. Firstly, the medical model of self-management was characterised by objectification of the individual as a passive patient, with a narrow focus on taking prescribed medication. Secondly, a collaborative model of self-management was identified which whilst based on the medical model acknowledged the individual as a client and partner in the process. Lastly, the authors suggest a third model; the self-agency model of self-management. This is developed through the years of experience in living with a condition, and often includes activities that professionals may not approve of such as adjusting drug dosage. Whilst the medical and collaborative models of self-care and self-management are perceived by professionals as a legitimate and expected patient behaviour (Coates and Boore, 1995), there appears to be contrasting anxiety from the patient's perspective as to whether professionals see their self-care as legitimate (Stevenson et al., 2003). It should also be acknowledged that some patients may prefer to be managed rather than to self-manage (Woodward, 1998), and within the current policy climate of self-management not only being regarded as a right but also an obligation (Gilbert, 2005) there is always the potential for promotion of self-management being coercive.

Nurses and self-management

Nursing is seen as having a key role to play in CDM both within the UK (Department of Health, 2005) and globally (Bodenheimer et al., 2005) which implicitly will include the enablement of self-management (Department of Health, 2005). Theoretically such a role ideally suits nursing, underpinned by a focus on the patient perspective and the lived experience of being affected by a chronic condition (Benner and Wrubel, 1989, Kitson, 2002, Tarrant et al., 2003).

Consequentially nurses should be able to adapt their role to be congruent with the patient's needs along the self-care to dependency continuum (Department of Health, 2005). There are an expanding range of nursing roles developing partly as a response to changing patterns of morbidity (Bryant-Lukosius et al., 2004), with for example, advanced nursing roles in diabetes care having a clear focus on the development of patient self-management skills (Sigurdardottir, 1999) and effectiveness in terms of patient health outcomes (Bodenheimer et al., 2005).

Whilst there is a growing acknowledgement within nursing literature that patient expertise within chronic illness not only should be promoted (Hughes, 2004) but also acknowledged (Fox, 2005, Wilson, 2002), 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 expert patient and self-management there has been little previous research in the UK exploring nurses' responses towards active and informed patients.

THE STUDY

Against the backdrop of the implementation of pilot EPPs throughout England and Wales, the study focused on health professionals' responses to active and informed patients (for the remainder of the paper termed expert patients) as espoused by the policy initiative (Department of Health, 2001, Jones, 2003). Using a grounded theory approach (Strauss and Corbin, 1990), the setting was a county in the south east of England, a relatively affluent area comprising of both urban and rural habitation. Whilst considerable work has been undertaken to evaluate patient outcomes on the EPP and similar courses in the UK (Barlow et al., 1998, Barlow et al., 1999, Kennedy et al., 2004), there has been a corresponding lack of research on the professional response to such programmes, and yet work from elsewhere indicates that this may be an issue (Bodenheimer et al., 2002, Paterson, 2001, Thorne et al., 2000). The aims of the study were therefore to explore how patient expertise is viewed, interpreted, defined and experienced by both patients and health professionals, to analyse how patient expertise is promoted and enabled through the self-management process, and to uncover the mechanisms that enhance or impede the development of patient expertise. For the purpose of this paper, categories arising out of the data collected from the nurses will be discussed. However data from the other respondents will be drawn upon as appropriate in order to illuminate the analysis.

STUDY DESIGN AND DATA COLLECTION

Sample

Following research ethics, management and governance approval and informed consent from participants, two concurrent data collection strands were employed

to facilitate comparative analysis (Glaser and Strauss, 1967) (figure 3). In order to start investigating the areas identified in the research questions an initial purposeful sample (Cutcliffe, 2000) 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 were expected to be nurses and doctors. Theoretical sensitivity was enhanced by an initial set of focus groups, with emerging themes used to guide theoretical sampling within further focus groups, interviews and observation (Strauss and Corbin, 1990). Two groups of patients affected by cardiac disease (n=7) and diabetes (n=6) were recruited via patient self-help organizations. Three groups of nurses (n=38) were recruited via post-registration courses in diabetes, respiratory and anticoagulation care, with experience ranging from three to twenty five years in practice. Within the UK nursing career structure the nurses ranged from E to G grade meaning that they were no longer at post qualification novice level, with a significant proportion of them deemed to be advanced practitioners with proven competencies in leadership and management. Although attending a course at one university, the nurses were from all regions of the UK with an approximate ratio of 1:3 primary to secondary care backgrounds, and were in posts characteristic of the extended role in CDM (Department of Health, 2002). The nurses working in primary care were either district (home care) nurses or General Practice Nurses (GPN) who are based at a General Practitioner's (GP) Health Centre. Examples of roles were GPN's running diabetes clinics, or nurses who had replaced haematologists in running routine anticoagulation clinics within hospital out-patient departments. Whilst it

was not possible to recruit doctors for a focus group, two General Practitioners (GPs) and one Consultant Physician in Diabetes formed part of the initial purposeful sample. The purposeful sample also included interviews with eleven patients, one EPP lay tutor, two GPNs, and two Nurse Specialists in diabetes. The latter two had undertaken post-registration courses in diabetes care 3-5 years previously and were working at the senior level of clinical nurse grades within the UK career structure (grades G and H). Theoretical sampling (Glaser and Strauss, 1967) was employed as the evolving theory started to emerge, with an active seeking of cases that were likely to contain concepts of theoretical relevance (Strauss and Corbin, 1990). A focus group of patients and carers affected by Parkinson's disease (n=9) was recruited to confirm the theoretical relevance of themes surrounding the experience of long-term conditions, two further groups of nurses (n=35) from the post-registration courses were theoretically sampled to confirm the theoretical relevance of litigation and trust, as was a further GPN for interview. In addition, as the data from the patients suggested that therapists played a significant role in self-management, two focus groups of physiotherapists (n=30) and two physiotherapists for interviews were also recruited via Primary Care Trusts (PCTs). Theoretical sampling was completed when data saturation was achieved (Glaser and Strauss, 1967). In addition to that described above, the final sample also included a further Consultant Physician, GP, eight patients and one EPP lay tutor. In total within all the data strands including the observation, more than one hundred health professionals and one hundred patients and carers participated in the study.

Focus groups

The focus groups with nurses and physiotherapists were significantly larger than the indicative 6-10 participants (Morgan, 1997), although as they were modified to be part of a practice development event a larger size was appropriate (Morgan, 1997). The focus group format was adapted to be an iterative process (Van Eyk and Baum, 2003) with a semi-formal presentation on the EPP followed by an appropriate patient scenario to trigger discussion (appendix 1). Group size of the patient focus groups followed the more usual format in structure of homogeneity and moderator involvement (Morgan, 1997), with a series of prompt questions used to trigger discussion. Discussion was audio-taped and transcribed.

Interviews

Interviews are seen as well suited to the exploration of values and beliefs (Barriball and While, 1994), and particularly appropriate in studies focusing on long term conditions where detailed individual chronicles are of use (Charmaz, 1990). Semi-structured interviews were conducted with 22 adult individuals with a physical long-term condition, 3 general medical practitioners (GP), 2 physiotherapists, 3 GPNs, 2 nurses (nurse specialists) and 2 medical consultants specialising in a long-term condition and 2 EPP lay tutors. Each interview utilised an interview guide (Duffy et al., 2004, Kvale, 1996) which contained the list of topics to be covered but could be re-sequenced with the flow of the interview. In order to facilitate comparison with the focus group data, interviews with professionals included their response to a relevant scenario (appendix 1). The interviews were audio-taped and transcribed.

Observation

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). There was concurrent observation of out-patient clinics for diabetes and dermatology (both consultant and specialist nurse led), GPN led chronic disease management clinics, a professional-led self-management course and an EPP. Participants were recruited via PCTs, hospital acute trusts and patient organizations. Contemporaneous field notes were recorded and a reflexive researcher audio-diary was recorded and transcribed.

Data analysis

Data from professionals and patients were analysed separately (Maijala *et al.*, 2003) in order to facilitate the constant comparative method (Eaves, 2001). Computer software was not used in the process of analysis for whilst it is acknowledged as a useful assistive tool (McPherson *et al.*, 2004) it can also impede intimacy with the data (Pope *et al.*, 2000, Webb, 1999), therefore data was manually open coded from which conceptual codes and axial coding was developed (Donovan, 1995, Strauss and Corbin, 1990). Consensus regarding the emerging categories was achieved through discussion within the research team to aid inter-rater reliability (Pope *et al.*, 2000). Interpretation of the data was presented to patient and professional groups for member checking (Lincoln and Guba, 1985).

FINDINGS

Five major categories emerged from the nurses' data: using physical measurement as a key criterion in trusting the patient; the time resource needed for expert patients; professional confidence; litigation in self-management; the emotional consequences of chronic illness.

Physical measurement: a key criterion in trusting the patient

The study suggests that all the participating professionals relied on physical measurement such as haemoglobin A1c (HbA1c), International Normalised Ratio (INR) and peak flow readings to define levels of patient expertise, confirming previous research (Pill *et al.*, 1999).

“...there are some patients who think they are expert...and yet her HbA1c shows she's very far from it...she knows that that measurement is important and she knows that she's judged upon that measurement when she goes to clinic”

Nurse Focus Group 1

During the observation of the consultant and nurse led diabetes clinics it was apparent that the professionals would check the HbA1c level before the patient walked into the room. If it was perceived high the consultation was framed by a disciplinary discourse, with one patient commenting when the nurse had left the room briefly that he felt a complete failure. Whilst this sole reliance on a physical measurement was common to all professional groups in the study, the nurses' particularly linked it to concerns on how trustworthy the patient was in self-management:

“...they'll get up to anything and think they can just change their INR”.

Nurse Focus Group 3

Both the nurses and physiotherapists described patients as commonly appearing to know more than they actually did:

“...people can have a certain amount of knowledge that would fool you into thinking they know what they are doing.”

Nurse Focus Group 2

In contrast the majority of patients participating in the study appeared to have a sound knowledge of their condition and treatment, and also clearly articulated evaluative skills of information sources:

“I know what my HbA1C is and if I’ve had liver tests and things like that...”

Patient F5

“I always read those information sheets with the drugs ... Usually they’re over dramatic I think, on most of these pill things, over dramatise it and you think ‘I’m going to be sick, I’m going to be dizzy, I don’t drive, I won’t be able to drink’ and you find, well the two first things don’t affect you, you haven’t got all of them, so I think it’s nice to know what you’re taking and what for, don’t you?”

Patient F6

“...the general thing is that people don’t read the sheet and I think ‘No, I’m putting it into my body, so I’m responsible’”

Patient F15

Time resource

The majority of the nurses were concerned with the time implications of patients' actively seeking information and entering into discussion about treatments:

"...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 so I would have thought it would be somebody who would take longer to consult"

Nurse Focus Group 2

The expectation of nurses that expert patients took up more time was one of the three indicators of divergent views between the professional groups, with doctors and physiotherapists describing initial lengthy consultations as an investment for future reductions on their time. However, the nurse specialists were the exception to this, expressing a similar view to the other professionals that the initial time spent with a patient was an investment in reducing time later. Indeed the nurse specialists were very keen to encourage patients to attend for more clinic appointments, feeling it was often the patient that was not investing enough time.

Professional confidence

A striking response unique to the nurses in the study was their frequently articulated feelings of discomfort with expert patients:

"...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

Despite some of the nurses expressing the view that the years of “nurse knows best” had gone, the majority were nevertheless uncomfortable with the idea of being challenged by knowledgeable patients:

“...they do challenge you much more and they have more resources available to them you know with the Internet now. You know those dreaded words “I’ve been reading up on”. You think ‘Oh no’...”

GPN 01

“He’s challenging our medical knowledge, what causes asthma, how we can control asthma”

Nurse focus group 2

In contrast the nurse specialists appeared less anxious about 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 ...”

Nurse specialist 02

Neither doctors nor physiotherapists expressed feelings of being threatened by expert patients, however there appeared to be different reasons for this. The physiotherapists articulated a clear confidence in their own skills that negated the feelings of threat:

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

Physiotherapist focus group 2

GPs appeared comfortable in acknowledging patient expertise:

“...Doctors are a lot more prone to ... saying “Well you know you probably do know a lot more about this condition than I do”...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, 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"

GP F1

Consultants felt confident in their levels of knowledge about the condition and appeared very positive about patients being as informed as possible. Interestingly the majority of expert patients interviewed were very aware of the need to develop a non-threatening rapport with health professionals:

"...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"

Patient M6

Accountability and litigation

The second striking response of the nurses in direct contrast to the other professionals was the expression of concern around accountability and litigation in self-management. Nurses suggested that they would be held accountable for a patient's self-management:

"...people would say he saw an asthma nurse and she agreed to this...we'll get blamed for their self-management"

Nurse focus group 2

"I can hear the patient saying "My nurse said I could do that!""

GPN 03

The physiotherapists and doctors held no concerns regarding litigation in self-management, suggesting that as long as the patient had been fully informed the choice was theirs:

“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 2

“...providing that you are giving people a reasonable level of information and knowledge to be able to self-adjust, if something goes wrong, something goes wrong and you’re not accountable for it but they aren’t either so I don’t see that as a problem”

Consultant 01

Emotional consequences of chronic illness

Many of the patients interviewed described the emotional consequences of living with a long-term condition such as anger and a sense of loss. Alongside those feelings were experiences of trying to express these emotions to professionals, with many finding that doctors in particular did not respond in an effective manner.

“... I got quite upset to my doctor who then said “Oh I didn’t know you were like that” because I started to cry in the surgery, he 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”

Patient F3

This finding was reinforced by the data from the GPs who described difficult patients as those who cry, are hysterical or over emotional. In contrast nurses were viewed by patients as being most effective in meeting their psychological needs:

“...and a lovely nurse, I mean the nursing profession, she was a credit to it all right, she sat with me all night holding my hand and talking and she was lovely and I could never thank her because the next day she’d gone off duty”

Patient F8

Paradoxically it was only the nurse specialists who articulated this as a skill.

“I think you’ve got to build a rapport with the patient so you tend to 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 so as long as you listen to them”

Nurse specialist 01

“She cried. And you know that’s important to me because she can actually express herself...”

“I’ve had men in tears and talk about things which perhaps, maybe it’s difficult for them ... erectile dysfunctions are very difficult but I can sort of

say, well I'm not an expert but I'm very honest about that, and I suggest if they're comfortable to go down and see the GP to have their levels taken, and it may not be as bad as they think"

Nurse specialist 02

In contrast the other nurses often articulated the same response as GPs towards patients with overt emotional needs:

"...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"

GPN 02

This dichotomy between patients experiencing nurses as displaying the most appropriate responses to emotional needs contrasting with many nurses articulating the same values and attitudes as GPs to emotional needs was explored in the later theoretically sampled nurse focus groups. Whilst many acknowledged that they did see psychological support as a key skill there was also a commonly expressed view:

"...if that's all we're seen good at it doesn't say much for nursing".

Nurse focus group 5

For many of the patients having a professional who was able to listen to them and able to cope with tears without a reflex response to prescribing tranquillisers was seen as key in a therapeutic relationship.

DISCUSSION

The nurse specialists articulated differing responses towards expert patients than the other nurses within the study. Compared to the other nurses they could describe a clearer definition of their role that was both unique and complimentary to their colleagues within a cohesive multi-disciplinary team. There was validation of their role in meeting the psychosocial needs of patients that as presented earlier was often of key importance to patients. However, as with the other nurses there were still concerns expressed about accountability, and the discussion will now focus on the relationship between role definition, perceived threats to professional power and concerns regarding accountability.

Professional role definition and response to expert patients

Nurses appeared to find expert patients more threatening and had significantly more concerns about litigation and the self-managing patient. It is suggested that the triggering factor for these differing perceptions was the articulation of clear role boundaries and areas of specific expertise. Doctors invariably defined their expertise as diagnosis, whilst physiotherapists described treatment as their specific area of expertise. In contrast the majority of nurses appeared to have difficulties in defining their role (often because it was specified by other professionals such as doctors) and expertise but unlike the doctors in the study suggested that they should have authoritative knowledge compared with patients. Whilst nurses often found it difficult to clearly articulate their specific expertise they also appeared to perceive that expert patients bring a wider clinician-like

expertise to the clinical encounter (as opposed to personal expertise) than is likely to be the case (Department of Health, 2001, Paterson et al., 2001).

The difficulties in the quest for nursing professionalism has been extensively described elsewhere (Davies, 1995), and in particular the search for definitions of discrete expertise (Aggleton and Chalmers, 2000). Many of the problems nursing has faced in seeking professional status has been attributed to omnipresent medical dominance (Cott, 1997), and within the feminist paradigm the notion of expertise and professionalism critiqued as a masculine gendered concept (Davies, 1995). All the nurses in the study described their work as being part of a multidisciplinary team. Whilst the development of such teams was seen as a way of flattening professional hierarchy, there is evidence that strong demarcation of power continues to exist resulting in many nurses continuing to work in a mechanistic, task focussed way (Cott, 1997). The findings of this study suggest the nurses' perception of a lack of clear role definition and distinct expertise within their working environment directly influenced their responses to expert patients. Firstly many nurses appeared unable to work in a flexible partnership with self-managing patients, and secondly their unease with expert patients both caused and resulted in an over concern regarding litigation.

Expert patient as threat

The majority of nurses interviewed and from the focus groups regarded the patients presented in the scenarios (appendix 1) as a threat. In contrast to the other professionals there was also a tendency by nurses to make assumptions and 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 articulated feelings of being left with the patient who wanted to self-manage, but according to the nurses would not be allowed to by the doctor.

Nurses often described situations of the “problem” patient being passed on to them by the consultant or GP, with one consultant clearly identifying the nurse specialist role as taking on the more time consuming patients. As highlighted earlier, this was a clearly acknowledged role within this particular team which appeared to achieve a sense of coherence for the nurses (Housley, 1999).

However, a significant number of the nurses appeared to feel left with the more time consuming patient, often reframing them as the difficult “*know-it-all*”.

It was apparent that whilst all the nurses in the study were carrying out an extended role within CDM, for the majority this was bound by tight bureaucratic cords. Many nurses articulated their role as 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). Far from being expanded, the restrictive nature of their role appeared to cause feelings of resentment that was quite frequently directed at expert patients, with nurses exhibiting oppressive practices (Daiski, 2004, Roberts, 1983) such as failing to advocate for patient self-management and preserving the status quo. However, it was clear in the study that the nurses ascribed their concerns regarding self-management to perceived litigious vulnerability.

The myth of litigation

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 giving 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), 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 they were the most likely victims of organizational blame 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.

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, 2004), with self-management seen as a right (EPDA, 2003, Martin, 2004). 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, 2004). 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 the nurse it would need to be demonstrated that the nurse 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 nurse's negligence rather than the patient's behaviour (Martin, 2003).

Whilst further clarity in the legal framework of self-management would be welcome, it is concerning that the nurses attributed their concerns not to the lack of legal clarity, but to the assumption that expert patients would be likely to bring litigation against the nurses.

LIMITATIONS OF THE STUDY

As with all qualitative research the generalisability of the findings is limited by the specificity of the study site cultural location (Koch and Harrington, 1998).

However, the results are transferable and therefore meaningful to similar settings (Chiovitti and Piran, 2003), in particular white middle class populations. Whilst overall the sample size was reasonably large for a qualitative study, it should be noted that comparatively few doctors as compared to the other professional groups participated. In addition the study may have been further enhanced by inclusion of other professional groups involved in self-management, for example pharmacists.

IMPLICATIONS FOR NURSING PRACTICE

The findings of this study raise 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, 2005), and obligation (Salter, 2004) in CDM.

Previous studies have identified the characteristics of patients perceived as problematic by British nurses (Kelly and May, 1982, Stockwell, 1984), and more recently have linked the concept with value judgements made by the nurses (Johnson and Webb, 1995) and nurses' perceptions of patient's refutation of their competence (Breeze and Repper, 1998). However, what appears unique to this study is that 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). Nurses' assumptions regarding the patients not only stemmed from a paternalistic viewpoint (Raynor et al., 2001) but also appeared contradictory to professional standards, with respect both for the patient as a partner and their contribution to care as fundamental (Nursing and Midwifery Council, 2004). 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 and 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 and 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 and Repper, 1998).

However, the study did reveal that specific nurses felt less challenged by expert patients and were consequently able to enter an appropriate therapeutic relationship with them (Wilson and Miller, 2004), and it is suggested that the characteristics of these nurses should not only be used as a model for practice, but also as the platform for further research on differences in role preparation and working environments of generalist and specialist nurses, particularly the impact on the nurses' contrasting responses. 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 key 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, 2004). Secondly, 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. In contrast the majority of nurses in this study 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, 2005) but also from patients (Hicks and 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 and 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 and McGauley, 2005, Coulter, 2002, Edwards *et al.*, 2004, 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, 2004), there still appears to be room for improvement. In particular, although attitudes may be affected by paper exercises and pedagogic approaches, skills training and working with role models is essential (Peden-McAlpine *et al.*, 2005, Thistlethwaite *et al.*, 2003), 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 and Eggly, 2004, Assal, 1999, Hale, 2002), continuing professional development is also of key importance (Gilbert, 2005). Both basic and post-basic education would benefit from utilising the skills of expert patients as a key resource to challenge assumptions (Coles, 1995,

Wykurz and Kelly, 2002), and may benefit from adopting approaches from consumer orientated service industries (Nursing Times, 2004).

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 (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).

CONCLUSION

Against the duality of rising prevalence of chronic disease and self-managing expert patients, this paper has presented findings pertaining to nurses in a grounded theory study exploring professionals' responses to expert patients. The

study suggested that nurses find expert patients a particular challenge, not least because of a perceived litigious vulnerability. Whilst the case has been put that this vulnerability appears based on myth, the paper raises questions about nurses' responses to self-managing patients, an issue likely to become more significant as the role of the nurse within CDM continues to expand, and the ongoing UK government agenda of patient choice. Implications have been raised regarding educational preparation for nurses in order to facilitate appropriate responses to expert patients, and organizational issues have been discussed. However, further work is necessary to explore the organizational constraints, education and culture of nurses in the UK if they are to be more confident about self-managing patients and move beyond feelings of having twenty four hour responsibility for people who are well able to manage their own condition. In particular, in-depth exploration of the factors that shape the differing responses of specialist as opposed to generalist nurses may be fruitful in illuminating ways of helping nurses to respond more appropriately to expert patients.

REFERENCES

- Aggleton, P., Chalmers, H., 2000. *Nursing Models and Nursing Practice*. Macmillan Press Ltd, Basingstoke.
- Apker, J., Eggly, S., 2004. Communicating Professional Identity in Medical Socialization: Considering the Ideological Discourse of Morning Report. *Qualitative Health Research* 14 (3), 411-429.
- Assal, J.P., 1999. Revisiting the approach to treatment of long-term illness: from the acute to the chronic state. A need for educational and managerial skills for long-term follow up. *Patient Education and Counselling* 37, 99-111.
- Audit Commission, 1999. *First Assessment. A review of district nursing services in England and Wales*. Audit Commission, London.
- Baker, C., Noerager Stern, P., 1993. Finding Meaning in Chronic Illness as the Key to Self-Care. *Canadian Journal of Nursing Research* 25 (2), 23-36.
- Barlow, J.H., Turner, A.P., Wright, C.C., 1998. Longterm outcomes of an arthritis self-management programme. *British Journal of Rheumatology* 37, 1315-1319.
- Barlow, J.H., Williams, B., Wright, C.C., 1999. "Instilling the strenght to fight the pain and get on with life": learning to become an arthritis self-manager through an adult education programme. *Health Education Research* 14 (4), 533-544.
- Barriball, K.L., While, A., 1994. Collecting data using a semi-structured interview: a discussion paper. *Journal of Advanced Nursing* 19, 328-335.
- Benner, P.E., Wrubel, J., 1989. *The primacy of caring: stress and coping in health and illness*. Addison-Wesley Publishing Company, Menlo Park, California.

- Bodenheimer, T., Lorig, K., Holman, H., Grumbach, K., 2002. Patient Self-management of Chronic Disease in Primary Care. *Journal of the American Medical Association* 288 (19), 2469-2475.
- Bodenheimer, T., MacGregor, K., Stothart, N., 2005. Nurses as leaders in chronic care. *British Medical Journal* 330, 612-613.
- Breeze, J.A., Repper, J., 1998. Struggling for control: the care experiences of "difficult" patients in mental health services. *Journal of Advanced Nursing* 28 (6), 1301-1311.
- Bryant-Lukosius, D., DiCenso, A., Browne, G., Pinelli, J., 2004. Advanced practice nursing roles: development, implementation and evaluation. *Journal of Advanced Nursing* 48 (5), 519-529.
- Campbell, C., McGauley, G., 2005. Doctor-patient relationship in chronic illness: insights from forensic psychiatry. *British Medical Journal* 330, 667-670.
- Chapple, A., Rogers, A., 1999. "Self-care" and its relevance to developing demand management strategies: a review of qualitative research. *Health and Social Care in the Community* 7 (6), 445-454.
- Charmaz, K., 1990. "Discovering" Chronic Illness: Using Grounded Theory. *Social Science and Medicine* 30 (11), 1161-1172.
- Chiovitti, R.F., Piran, N., 2003. Rigour and grounded theory research. *Journal of Advanced Nursing* 44 (4), 427-435.
- Coates, V.E., Boore, J.R.P., 1995. Self-management of chronic illness: implications for nursing. *International Journal of Nursing Studies* 32 (6), 628-640.

- Coles, C., 1995. Educating the health care team. *Patient Education and Counselling* 26, 239-244.
- Colledge, M., Eve, R., Mares, P., Robinson, M., 2003. Implementing the National Service Framework for Coronary Heart Disease at Primary Care Trust and General Practice Level. A study of barriers and opportunities. www.innovate.org.uk, The Centre for Innovation in Primary Care/Nuffield Institute of Health.
- Colyer, H.M., 2004. The construction and development of health professions: where will it end? *Journal of Advanced Nursing* 48 (4), 406-412.
- Corner, J., 2001. *Between You and Me*. Stationary Office, London.
- Cott, C., 1997. "We decide, you carry it out": A social network analysis of multidisciplinary long-term care teams. *Social Science and Medicine* 45 (9), 1411-1421.
- Coulter, A., 2002. *The Autonomous Patient. Ending paternalism in medical care*. The Stationary Office, London.
- Crowe, M., 2000. The nurse-patient relationship: a consideration of its discursive context. *Journal of Advanced Nursing* 31 (4), 962-967.
- Cutcliffe, J.R., 2000. Methodological issues in grounded theory. *Journal of Advanced Nursing* 31 (6), 1476-1484.
- DAFNE Study Group, 2002. Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: dose adjustment for normal eating (DAFNE) randomised controlled trial. *British Medical Journal* 325, 746-752.

- Daiski, I., 2004. Changing nurses' dis-empowering relationship patterns. *Journal of Advanced Nursing* 48 (1), 43-50.
- Davies, C., 1995. *Gender and the Professional Predicament in Nursing*. Open University Press, Buckingham.
- Davies, C., 1996. A new vision of professionalism. *Nursing Times* 92 (46), 54-56.
- Department of Health, 2003. *Advanced Primary Nurse Competencies*. Modernisation Agency, London.
- Department of Health, 2002. *Chronic disease management and self-care*. National Service Framework. Stationary Office, London.
- Department of Health, 2001. *The expert patient - a new approach to chronic disease management for the 21st Century*. Stationary Office, London.
- Department of Health, 2004. *Improving Chronic Disease Management*. Department of Health, London.
- Department of Health, 2002. *Liberating the Talents. Helping Primary Care Trusts and nurses to deliver The NHS Plan*. Department of Health, London.
- Department of Health, 2005. *Self Care - A Real Choice*. Department of Health, London.
- Department of Health, 2005. *Supporting People with Long Term Conditions. An NHS and Social care Model to support local innovation and integration*. Department of Health, London.
- Department of Health, 2005. *Supporting People with Long Term Conditions. Liberating the talents of nurses who care for people with long term conditions*.
- Donovan, J., 1995. The process of analysis during a grounded theory study of men during their partners' pregnancies. *Journal of Advanced Nursing* 21, 708-715.

- Dowling, S., Martin, R., Skidmore, P., Doyal, L., Cameron, A., Lloyd, S., 1996. Nurses taking on junior doctors' work: a confusion of accountability. *BMJ* 312 (7040), 1211-1214.
- Duffy, K., Ferguson, C., Watson, H., 2004. Data collecting in grounded theory - some practical issues. *Nurse Researcher* 11 (4), 67-78.
- Eaves, Y.D., 2001. A synthesis technique for grounded theory data analysis. *Journal of Advanced Nursing* 35 (5), 654-663.
- Edwards, I., Jones, M., Higgs, J., Trede, F., Jensen, G., 2004. What is collaborative reasoning? *Advances in Physiotherapy* 6 (2), 70-83.
- English National Board, 1998. *New Directions in Rehabilitation: exploring the nursing contribution*. English National Board, London.
- Entwistle, V., 2004. Trust and shared decision-making: an emerging research agenda. *Health Expectations* 7, 271-273.
- EPDA, 2003. The Global Declaration on PD. <http://www.epda.eu.com/globalDeclaration-About.shtm>, accessed 6/1/05.
- Fishwick, D., D'Souza, W., Beasley, R., 1997. The asthma self-management plan system of care: What does it mean, how is it done, does it work, what models are available, what do patients want and who needs it? *Patient Education and Counselling* 32, s21-s33.
- Fitzmaurice, D.A., Machin, S.J., 2001. Recommendations for patients undertaking self management of oral anticoagulation. *British Medical Journal* 323, 985-989.
- Fox, J., 2005. The role of the expert patient in the management of chronic illness. *British Journal of Nursing* 14 (1), 25-28.

- Gibbon, B., 1994. Stroke nursing care and management in the community: a survey of district nurses' perceived contribution in one health district in England. *Journal of Advanced Nursing* 20, 469-476.
- Gilbert, T.P., 2005. Impersonal trust and professional authority: exploring the dynamics. *Journal of Advanced Nursing* 49 (6), 568-577.
- Glaser, B.G., Strauss, A.L., 1967. *The Discovery of Grounded Theory: strategies for qualitative research*. Aldine Publishing Company, Chicago.
- Hale, C., 2002. *Questioning the Conventional Wisdom*. Institute of Public Policy Research, Future Health Worker Project.
- Harwood, R.H., Sayer, A.A., Hirschfeld, M., 2004. Current and future worldwide prevalence of dependency, its relationship to total population, and dependency ratios. *Bulletin of the World Health Organization* 82 (4), 251-258.
- Health Technology Assessment Programme, 2004. *Extending the nursing role*. Health Technology Assessment Programme, Southampton, pp. 1-4.
- Henderson, S., 2003. Power imbalance between nurses and patients: a potential inhibitor of partnership in care. *Journal of Clinical Nursing* 12 (4), 501-508.
- Hicks, C., Fide, J., 2003. The educational needs of non-specialist breast care nurses. *Nurse Education Today* 23, 509-521.
- Housley, W., 1999. Role as an interactional device in multidisciplinary team meetings. *Sociological Research Online*
<http://www.socresonline.org.uk/socresonline/4/3/housley.html>.
- Hughes, S.A., 2004. Promoting self-management and patient independence. *Nursing Standard* 19 (10), 47-52.

- International Council of Nurses, 2003. Position Statement: Informed Patients. ICN, <http://www.icn.ch/psinfo/patients03.htm>.
- Johnson, M., Webb, C., 1995. Rediscovering unpopular patients: the concept of social judgement. *Journal of Advanced Nursing* 21, 466-475.
- Jones, N., 2003. How are expert patients different? *EPP Update* 8 1 (8), 3.
- Jorgensen, D.L., 1989. Participant observation. A methodology for Human Studies. Sage, California.
- Kelly, M.P., May, D., 1982. Good and bad patients: a review of the literature and a theoretical critique. *Journal of Advanced Nursing* 7, 147-156.
- Kennedy, A., Gately, C., Rogers, A., 2004. Assessing the process of embedding EPP in the NHS. Preliminary survey of PCT pilot sites. University of Manchester. NPCR&DC, Manchester.
- Kings Fund, 2004. Managing Chronic Disease. What can we learn from the US experience? Kings Fund, London.
- Kitson, A., 2002. Recognising relationships: reflections on evidence-based practice. *Nursing Inquiry* 9 (3), 179-186.
- Koch, T., Harrington, A., 1998. Reconceptualizing rigour: the case for reflexivity. *Journal of Advanced Nursing* 28 (4), 882-890.
- Koch, T., Jenkin, P., Kralik, D., 2004. Chronic illness self-management: locating the "self". *Journal of Advanced Nursing* 48 (5), 484-492.
- Kraetschmer, N., Sharpe, N., Urowitz, S., Deber, R.B., 2004. How does trust affect patient preferences for participation in decision-making? *Health Expectations* 7, 317-326.

- Kralik, D., Koch, T., Price, K., Howard, N., 2004. Chronic illness self-management: taking action to create order. *Journal of Clinical Nursing* 13, 259-267.
- Kratz, C.R., 1978. *Care of the long-term sick in the community*. Churchill Livingstone, Edinburgh.
- Kvale, S., 1996. *InterViews. An introduction to qualitative research interviewing*. Sage, Thousand Oaks.
- Lahdensuo, A., 1999. Guided self management of asthma - how to do it. *British Medical Journal* 319, 759-760.
- Lahdensuo, A., Haahtela, T., Herrala, J., Kava, T., Kiviranta, K., Kuusisto, P., Peramaki, E., Poussa, T., Saarelainen, S., Svahn, T., 1996. Randomised comparison of guided self management and traditional treatment of asthma over one year. *British Medical Journal* 312, 748-752.
- Lewis, R., Dixon, J., 2004. Rethinking management of chronic diseases. *British Medical Journal* 328, 220-222.
- Lincoln, Y.S., Guba, E.G., 1985. *Naturalistic Inquiry*. Sage Publications, Beverly Hills.
- Lorig, K., Stewart, A., Ritter, P., Gonzalez, V., Laurent, D., Lynch, J., 1996. *Outcome Measures for Health Education and other Health Care Interventions*. Sage Publications, Thousand Oaks.
- Maijala, H., Paavilainen, E., Astedt-Kurki, P., 2003. The use of grounded theory to study interaction. *Nurse Researcher* 11 (2), 40-57.
- Makinen, S., Suominen, T., Lauri, S., 2000. Self-care in adults with asthma: How they cope. *Journal of Clinical Nursing* 9, 557-565.
- Manthey, M., 1992. *The Practice of Primary Nursing*. Kings Fund, London.

- Martin, R., 2004. Patient power, human rights and access to primary health care services in a NHS system. *Primary Health Care Research and Development* 5, 187-190.
- Martin, R., 2003. Potential legal issues in patient self-management. Paper presented by Research Professor in Public Health Law. Unpublished paper, University of Hertfordshire.
- Martin, R., 2004. Rethinking primary health care ethics: ethics in contemporary primary health care in the United Kingdom. *Primary Health Care Research and Development* 5, 317-328.
- McDonald, R., 2004. Individual identity and organisational control: Empowerment and Modernisation in a Primary Care Trust. *Sociology of Health and Illness* 26 (7), 925-950.
- McPherson, K.M., Brander, P., Taylor, W.J., McNaughton, H.K., 2004. Consequences of stroke, arthritis and chronic pain - are there important similarities? *Disability and Rehabilitation* 26 (16), 988-999.
- Morgan, D.L., 1997. *Focus Groups as Qualitative Research*. Sage Publications Inc., Thousand Oaks.
- Morse, J.M., 1991. Negotiating commitment and involvement in the nurse-patient relationship. *Journal of Advanced Nursing* 16, 455-468.
- Nolan, M., Nolan, J., 1999. Rehabilitation, chronic illness and disability: the missing elements in nurse education. *Journal of Advanced Nursing* 29 (4), 958-966.
- Nolan, M., Nolan, J., 1995. Responding to the challenge of chronic illness. *British Journal of Nursing* 4 (3), 145-147.

- Nolan, M.R., 2005. Reconciling tensions between research, evidence-based practice and user participation: Time for nursing to take the lead. *International Journal of Nursing Studies* 42, 503-505.
- Nursing and Midwifery Council, 2004. The NMC code of professional conduct: standards for conduct, performance and ethics. NMC, London.
- Nursing and Midwifery Council, 2004. Standards of proficiency for pre-registration nursing education. NMC, London.
- Nursing Times, 2004. Half of Scotland's specialist nurses have no job description. *NT nursing recruitment* 10, 5.
- Nursing Times, 2004. Private companies to give NHS staff lessons in service. *NT nursing recruitment* 10, 2.
- O'Hara, L., De Souza, L.H., Ide, L., 2000. A Delphi study of self-care in a community population of people with multiple sclerosis. *Clinical Rehabilitation* 14, 62-71.
- Orem, D.E., 1995. *Nursing: Concepts of Practice*. C.V. Mosby, St. Louis.
- Partridge, M.R., 1997. Introduction. *Self-Management in Adults with Asthma*. *Patient Education and Counselling* 32, s1-s4.
- Paterson, B., 2001. Myth of empowerment in chronic illness. *Journal of Advanced Nursing* 34 (5), 574-581.
- Paterson, B.L., Russell, C., Thorne, S., 2001. Critical analysis of everyday self-care decision making in chronic illness. *Journal of Advanced Nursing* 35 (3), 335-341.
- Peden-McAlpine, C., Tomlinson, P.S., Forneris, S.G., Genck, G., Meiers, S.J., 2005. Evaluation of a reflective practice intervention to enhance family care. *Journal of Advanced Nursing* 49 (5), 494-501.

- Pill, R., Rees, M.E., Stott, N.C.H., Rollnick, S.R., 1999. Can nurses learn to let go? Issues arising from an intervention designed to improve patients' involvement in their own care. *Journal of Advanced Nursing* 29 (6), 1492-1499.
- Playle, J.F., Keeley, P., 1998. Non-compliance and professional power. *Journal of Advanced Nursing* 27, 304-311.
- Pope, C., Ziebland, S., Mays, N., 2000. Analysing qualitative data. *British Medical Journal* 320, 114-116.
- Raynor, D.K., Thistlethwaite, J.E., Hart, K., Knapp, P., 2001. Are health professionals ready for the new philosophy of concordance in medicine taking? *International Journal of Pharmacy Practice* 9, 810-884.
- Ricka, R., Vanrenterghem, Y., Evers, C.M., 2002. Adequate self-care of dialysed patients: a review of the literature. *International Journal of Nursing Studies* 39, 329-339.
- Roberson, M.H.B., 1992. The Meaning of Compliance: Patient Perspectives. *Qualitative Health Research* 2 (1), 7-26.
- Roberts, S.J., 1983. Oppressed group behaviour: implications for nursing. *Advances in Nursing Science* 5 (4), 21-30.
- Royal Pharmaceutical Society of Great Britain, 1997. *From Compliance to Concordance: Achieving Shared Goals In Medicine Taking*. RPSGB, London.
- Salter, B., 2004. *The New Politics of Medicine*. Palgrave Macmillan, Basingstoke.
- Salvage, J., 2002. *Rethinking Professionalism: the first step for patient-focused care?* Institute for Public Policy Research, Future Health Worker Project.

- Sigurdardottir, A.K., 1999. Nurse specialists' perceptions of their role and function in relation to starting an adult diabetic on insulin. *Journal of Clinical Nursing* 8, 512-518.
- Speed, S., Luker, K.A., 2004. Changes in patterns of knowing the patient: the case of British district nurses. *International Journal of Nursing Studies* 41, 921-931.
- Stevenson, F.A., Britten, N., Barry, C.A., Bradley, C.P., Barber, N., 2003. Self-treatment and its discussion in medical consultations: how is medical pluralism managed in practice? *Social Science and Medicine* 57, 513-527.
- Stockwell, F., 1984. *The Unpopular Patient*. Croom Helm, Beckenham.
- Strauss, A., Corbin, J., 1990. *Basics of Qualitative Research. Grounded Theory Procedures and Techniques*. Sage Publications, Newbury Park, California.
- Tarrant, C., Windridge, K., Boulton, M., Baker, R., Freeman, G., 2003. Qualitative study of the meaning of personal care in general practice. *British Medical Journal* 326, 1310-1318.
- Thistlethwaite, J.E., Raynor, D.K., Knapp, P., 2003. Medical students' attitudes towards concordance in medicine taking: Exploring the impact of an educational intervention. *Education for Health* 16 (3), 307-317.
- Thorne, S.E., Ternulf Nyhlin, K., Paterson, B.L., 2000. Attitudes toward patient expertise in chronic illness. *International Journal of Nursing Studies* 37, 303-311.
- Tinetti, M.E., Bogardus, S.T., Agostini, J.V., 2004. Potential pitfalls of disease-specific guidelines for patients with multiple conditions. *New England Journal of Medicine* 351 (27), 2870-2874.

- Toljamo, M., Hentinen, M., 2001. Adherence to self-care and glycaemic control among people with insulin-dependent diabetes mellitus. *Journal of Advanced Nursing* 34 (6), 780-786.
- Van der Palen, J., Klein, J.J., Seydel, E.R., 1997. Are high generalised and asthma-specific self-efficacy predictive of adequate self-management behaviour among adult asthma patients? *Patient Education and Counselling* 32, s35-s41.
- Van Eyk, H., Baum, F., 2003. Evaluating Health System Change - Using Focus Groups and a Developing Discussion Paper to Compile the "Voices From the Field". *Qualitative Health Research* 13 (2), 281-286.
- Watt, S., 2000. Clinical decision-making in the context of chronic illness. *Health Expectations* 3, 6-16.
- Webb, C., 1999. Analysing qualitative data: computerized and other approaches. *Journal of Advanced Nursing* 29 (2), 323-330.
- Williams, G.C., McGregor, H.A., King, D., Nelson, C.C., Glasgow, R.E., 2005. Variation in perceived competence, glycemic control, and patient satisfaction: relationship to autonomy support from physicians. *Patient Education and Counselling* 57, 39-45.
- Wilson, P.M., 2002. The expert patient: issues and implications for community nurses. *British Journal of Community Nursing* 7 (10), 514-519.
- Wilson, P.M., 2001. A policy analysis of the Expert Patient in the United Kingdom: self-care as an expression of pastoral power? *Health and Social Care in the Community* 9 (3), 134-142.

- Wilson, P.M., Miller, S., 2004. Therapeutic relationships. In: Chilton, S., Melling, K., Drew, D., Clarridge, A. (Eds.), *Nursing in the Community: an essential guide to practice*. Arnold, London, pp. 41-51.
- Woodward, V.M., 1998. Caring, patient autonomy and the stigma of paternalism. *Journal of Advanced Nursing* 28 (5), 1046-1052.
- World Health Organization, 2003. *Adherence to Long-term Therapies, Evidence for Action*. WHO, Geneva.
- Worth, H., 1997. Self management in COPD: One step beyond? *Patient Education and Counselling* 32, s105-s109.
- Wykurz, G., Kelly, D., 2002. Developing the role of patients as teachers: literature review. *British Medical Journal* 325, 818-821.

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.

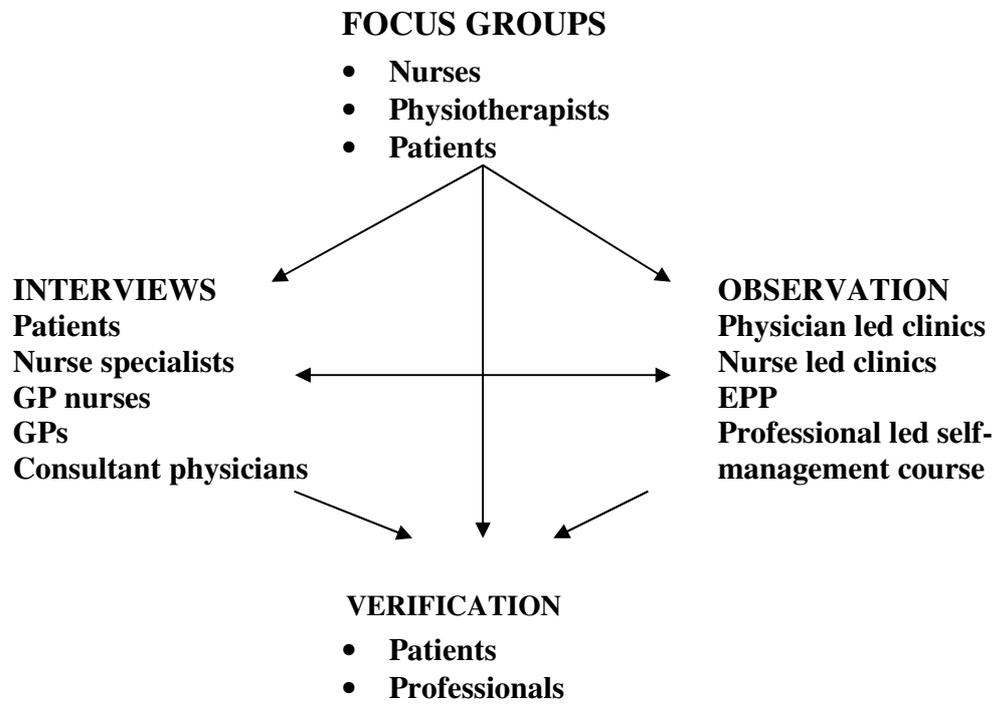
Orem's six self-care activities (Ricka et al., 2002)

Figure 1

- 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 and Machin, 2001)

Definitions of self-management

Figure 2



Concurrent data strands

Figure 3

APPENDIX 1 : PATIENT SCENARIOS

John

John 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 salbutamol (albuterol) and corticosteroid inhalers and monitors his peak flow regularly. Recently he has used the Buteyko technique to control his breathing. He doesn't wish to continue with his corticosteroid or salbutamol inhalers as his peak flows have remained stable for the past 6 months without using them whilst practising Buteyko. However, he is prepared to take the inhalers if he gets a cold.

Eric

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.

Simon

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.

Claire

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 (Wilson, 2002).

Peggy

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.