A grounded theory of patient satisfaction with nurse-led chronic disease management in general practice

Submitted by

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Abstract

This study was an investigation into the process of patient satisfaction with nurse-led management of chronic conditions in general practice. It adds to the theoretical understanding of patient satisfaction by providing an explanation of the processes patients go through to determine their level of satisfaction with chronic disease management provided by a practice nurse (PN) in collaboration with a general medical practitioner (GP). This study was nested within the Practice Nurse Project funded by the Australian Research Council (ARC), which trialled a new model of nurse-led care in three general practices, one in Western Victoria and two in South East Queensland. Three chronic conditions were managed by the PNs in the project; diabetes type 2, Ischaemic heart disease (IHD) and hypertension

A grounded theory approach, underpinned by constructivist ontology and an interpretive epistemology, was used for this study. Participants for the study were drawn from those patients who had consented to be part of the PN Project and who had been randomised to the PN arm of the project. Initially purposive sampling was employed to access men and women with a range of ages and chronic conditions at each of the study locations. As data were analysed, theoretical sampling was used to develop and integrate emerging categories. In-depth interviews were held with 38 participants, some of whom were interviewed more than once. The interview guides were continually revised to reflect developing concepts. Data collection continued until theoretical saturation occurred, that is, all categories were fully developed and integrated into a theory. Constant comparative analysis of the data was

undertaken concurrently with sampling and data collection consistent with grounded theory methods.

The basic social process to emerge from the data was *Navigating Care,* which is comprised of three separate but interrelated processes; *Determining Care Needs, Forming a Relationship* and *Having Confidence*. Navigating care is an on-going and cyclical process and issues with any part of the process can reduce patients' satisfaction or may lead to them opting out of PN-led management. Patients determine their care needs through a process of monitoring and self-assessment. If they consider that the PN is the appropriate person to provide for their care needs, they then proceed to Forming a Relationship with and Having Confidence in the PN. These two processes are concurrent and interdependent. The patient's experience during these processes also provides a feedback loop to further determination of their care needs. The two stages involved in Forming a Relationship are Building Rapport and Working Together. Time, Communication and Continuity are important properties of Forming a Relationship. The confidence that patients have in PN-led chronic disease management is built on Trusting the Model of Care, Trusting the Role of Nurse, Trusting their Doctor and Evaluating the PN. The extent to which each of these processes influence the level of confidence depends on the individual patient. Communication is also an important property of Having Confidence, especially in Evaluating the PN.

The theory of Navigating Care provides an explanation of the processes undertaken by patients in determining their satisfaction with PN-led management of chronic conditions, which adds to the existing

theoretical understanding of patient satisfaction. This understanding can be used to facilitate acceptance of new models of nurse-led care in general practice and assist in identifying patients for whom nurse-led care would be suitable. The findings can also be used to inform nursing practice and inform the development of more sensitive instruments measuring patient satisfaction. Finally, if patients feel more comfortable with PNs than doctors, they may be more willing to engage with nurses in systematic management of their chronic conditions.

Statement of Originality

I, Rosemary Mahomed, hereby certify that the work in this thesis has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

Signed…………………………………………………………………….

Date ………………

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List of Abbreviations

PN ………………………………………………………Practice Nurse

GP…………………………………………….…………General Practitioner

ARC...…...Australian Research Council

NHS……………………………………………National Health Service

IHD…………………………………………….Ischaemic heart disease

Acknowledgements

Chapter 1. Introduction

This study investigated the process of patient satisfaction with nurse-led chronic disease management in general practice. Patient satisfaction is a concept that has generally not been well developed, and no theoretical work has been conducted to investigate patient satisfaction in relation to care provision by PNs. Using a grounded theory approach, the study aimed to add to the theoretical understanding of the concept of patient satisfaction. It was nested within the Practice Nurse Project funded by the ARC, which trialled a new model of nurse-led care in three general practices. The model of care was trialled with patients suffering from diabetes type 2, IHD and hypertension. The research question posed for this study was 'How do patients arrive at their level of satisfaction with PN-led chronic disease management?'

The face of Australian general practice is changing. General practice workforce issues, an ageing population and an increasing prevalence of chronic diseases are putting Australian general practice under pressure (Australian Bureau of Statistics, 2008b; Charles, Britt, & Harrison, 2009a). As a result, the way in which general practice cares for those with chronic diseases is changing from the traditional model of episodic care by GPs to a more planned and multi-disciplinary approach. Innovative models of care have been introduced and proposed and PNs have been at the forefront of this change (Halcomb, Patterson, & Davidson, 2007; Pascoe, et al., 2005a; Tolhurst, Madjar, Schultz, & Schmidt, 2004a). In many places PNs are now involved in chronic disease management and are well placed to take up a more autonomous role (Halcomb, Davidson, Salamonson, Ollerton, &

Griffiths, 2008b; Kirby, 2005). Although this has been described as an expanded role for nurses in general practice (Halcomb, Patterson, & Davidson, 2006), it is actually more a case of PNs working to their full capacity, as nurses already undertake these roles in other areas of health care such as community nursing and hospitals. This has not happened to date because the role of Australian PNs has been constrained by factors specifically related to general practice in this country (Condon, Willis, & Litt, 2000a; Halcomb, et al., 2005; Halcomb, Davidson, Griffiths, & Daly, 2008a). These barriers include the way Australian general practice is funded, issues of legal liability and the extent to which GPs are willing to work collaboratively with PNs (Condon, et al., 2000a; Halcomb, et al., 2005; Halcomb, et al., 2008a).

Medicare funding for PNs is limited and most patient encounters require the patient to see the GP for a rebate to apply. This discourages general practices from utilising the skills of PNs to their full capacity as most general practices are privately owned businesses and PNs are employees (Condon, et al., 2000a; Halcomb, et al., 2005). Concerns about legal liability also constrain the full utilisation of PNs' skills (Condon, et al., 2000a; Halcomb, et al., 2005). GPs have reported wanting to keep control of care for which they could be legally liable (Condon, et al., 2000a). Also Halcomb et al. (2008a) identified that some GPs' attitudes toward PNs were a barrier to PNs working to their full capacity. Some GPs regarded PNs as subservient to GPs and were not willing to work in a collaborative relationship (Condon, et al., 2000a; Halcomb, et al., 2008a). If these barriers can be overcome, PN-led chronic disease management has the potential to help alleviate some of the pressure on care provided by general practice and contribute to optimal patient care.

However, while new models of care may be necessary, it is important that they are acceptable to the patients they are proposed to help. There has been a lack of research in Australia to evaluate patient satisfaction with new models of chronic disease management and the contribution that PNs can make in this area (Halcomb, Davidson, Yallop, Griffiths, & Daly, 2007; Halcomb, et al., 2006). In addition, the concept of patient satisfaction is not well understood and there has been a notable lack of theoretical research (Pascoe, 1983; Powell, Holloway, Lee, & Sitzia, 2004; Sitzia & Wood, 1997; Turris, 2005; Williams, 1994). This study used grounded theory to investigate the process of patient satisfaction with a completely new model of nurse-led chronic disease management in general practice. From the data a theory of Navigating Care was developed, which explains this process and adds to theoretical understanding of patient satisfaction.

This chapter will first present the context of the study and the workforce situation in general practice. The increased burden of chronic disease and the developing role of PNs in Australia will then be explained. The term PN as used in this study will be defined. Then the research problem and the significance of this patient satisfaction study will be presented. Finally, an outline of the structure of this thesis will be given.

The context of the study

Most nurses working in general practice will be involved with patients who suffer from a chronic disease. If PNs are to work to their full capacity, this will also involve them in the management of those patients. This section will describe the current situation in Australia in regards to chronic disease

and general practice in order to clarify why it is such a significant issue. This discussion will help to place the study in the context in which it was carried out. First, the current situation with regard to chronic diseases in Australia will be presented and the issues facing general practice will be explained. The development of practice nursing in Australia will then be described.

Chronic disease in Australia

Chronic diseases, not including cancer, are responsible for 61% of all deaths in Australia (World Health Organisation, 2005). The three chronic diseases found in this patient satisfaction study are diabetes type 2, IHD and hypertension. Cardiovascular disease was the leading cause of death, accounting for 35% of all deaths in 2005 and is the leading cause of the burden of disease in Australia (Australian Institute of Health and Welfare, 2008b). The most common form of cardiovascular disease in Australia is IHD, one of the chronic diseases included in the PN project (Australian Institute of Health and Welfare, 2008b). The prevalence of diabetes in Australia has more than doubled in the last 20 years and is particularly prevalent in those who are over 65 years of age (Australian Institute of Health and Welfare, 2008b). Diabetes type 2, another of the chronic diseases included in the PN project, is also a significant contributor to the burden of disease in Australia. It is a cause of other chronic diseases, such as chronic renal disease (Australian Institute of Health and Welfare, 2008b).

The situation with regard to chronic disease in Australia is influenced by the ageing of Australia's population with 13% of the population being over 65 years (Australian Bureau of Statistics, 2007). Chronic diseases become

more prevalent as people age and 25% of the Australian population over 75 years of age are reported to have diabetes, while 35% of those between the ages of 65 and 84 are diagnosed with cardiovascular disease (Australian Institute of Health and Welfare, 2006). The proportion of the Australian population over 50 years of age is projected to reach almost 50% of the total population by 2051, and those over 85 years are projected to increase from 1.5% of the population in 2004 to 6-8% of the population in 2051 (Australian Bureau of Statistics, 2005). Therefore, the increase in the prevalence of chronic diseases that has been seen in recent years is likely to continue or increase in the future. Adding to the problem of these chronic diseases is that being overweight or obese is a risk factor for both cardiovascular disease and diabetes, and Australia's population is increasingly overweight with 62% of Australian adults classed as overweight or obese in the 2004-05 National Health Survey (Australian Bureau of Statistics, 2006).

This rather dire picture of the health of Australians is one with which Australian general practice is now grappling and will need to address in the future. The Australian government has placed general practice firmly in the centre of its policy for tackling population health issues confronting Australians through its emphasis on primary health care (National Health and Hospitals Reform Commission, 2009). There needs to be changes in the way chronic diseases are managed in primary care if general practice is not to be overwhelmed by this increase in demand and complexity.

Issues in general practice

The general practice workforce is mainly a mix of doctors, nurses and support staff, although occasionally other allied health professionals may

work in close association with general practice. PNs work closely with GPs, although their working relationship may vary considerably from PNs being thought of as doctors' handmaidens to a collaborative partnership of health professionals (Halcomb, et al., 2008a). Issues with the medical workforce in general practice have implications for nurses working within general practice as well as for the doctors. Pressure placed on general practice by the growing burden of chronic disease in Australia and workforce shortages can result in more work for PNs as GPs, who are under pressure of time, delegate tasks. However, the situation can also present an opportunity for the skills of nurses to be better utilised in areas such as chronic disease management and health promotion.

Even a short perusal of Australian general practice journals reveals widespread claims of a shortage of GPs in Australia. The actual situation is complicated and several workforce issues, such as shorter working hours and more part-time GPs, a mal-distribution of GPs, and more consultations for chronic and complex problems, are contributing to the pressure under which general practice finds itself.

Although there has been an increase in the overall gross number of GPs in recent years, the number of full time equivalent (FTE) GPs has actually fallen. In 2002 there were 101 FTE GPs per 100,000 people and in 2006 this had fallen to 97 per 100,000. At the same time the relative numbers for all other medical specialities had gone up (Australian Institute of Health and Welfare, 2008a). This decrease may be partly explained by an increase in the number of female GPs who are more likely to work part-time than their male counterparts (Charles, et al., 2009a) and that GPs, generally, are working shorter hours than they used to, especially the younger ones

(Schofield & Beard, 2005). To add to the problem, the average age of GPs is increasing with approximately half being from the 'Baby Boomer' generation and, therefore, approaching retirement (Royal Australian College of General Practitioners, 2009; Schofield & Beard, 2005). It has also been found that many GPs intend to retire early (Brett, Arnold-Reed, Hince, Wood, & Moorhead, 2009). However, retiring GPs are not being replaced by younger doctors as fewer new graduates are choosing general practice as a speciality. In 2000 45% of graduates chose to specialise in general practice, but this fell to 24% in 2006 and was only marginally improved at 27% in 2008 (Royal Australian College of General Practitioners, 2009). Therefore, it appears that the number of FTE GPs may continue to fall over the coming years.

The problem with the number of GPs generally is exacerbated in some places because of their mal-distribution. Rural and remote areas are experiencing severe shortages of GPs and regional areas are also adversely affected (Royal Australian College of General Practitioners, 2009). Even though metropolitan areas generally have higher levels of GP numbers, there are areas of need within cities that are experiencing shortages. This means that general practice is often under more pressure just where community need is greatest (Royal Australian College of General Practitioners, 2009).

The nature of general practice is also changing, reflecting changes in the population and health patterns that have been discussed in the previous section. As the population of Australia ages, GPs are seeing older patients more often and children less often (Charles, et al., 2009a). Partly because of this and also because of the increased prevalence of chronic diseases, they are also using more of their time in managing chronic diseases and the

related risk factors than they used to, particularly hypertension, diabetes and lipid control. Chronic health problems account for 52% of all general practice encounters, with hypertension the most commonly managed chronic problem and diabetes the third most common (Britt & Harrison, 2009b). In addition, earlier discharge of patients from hospitals has also put increased pressure on general practice (Royal Australian College of General Practitioners, 2009).

All of the above issues have contributed to Australian general practice facing the challenge of how to provide the best possible care to patients where there is an increase in demand for chronic care, requiring longer consultations, and a decrease in the available medical workforce. This is a problem general practices are already facing and will continue to do so if changes to models of practice are not made. Traditional ways of practising that included episodic care and GPs being solely responsible for the management of patients and only delegating a limited number of tasks to PNs, are not going to be sufficient and are not going to provide the best care for the Australian population. New ways to address the situation are, therefore, needed to ensure that Australians receive the care they need. One such approach is to more effectively utilise the nursing workforce in general practice. PN-led chronic disease management, whereby PNs work collaboratively with GPs to manage patients with chronic disease, could help relieve the pressure on general practice provide optimal care for patients.

The role of the PN in Australia

Practice nursing is a relatively new discipline in Australia compared to the UK and New Zealand, where it has been established for many years (Dent

& Burtney, 1997; Watts, et al., 2004). However, practice nursing is now the fastest growing area within the health care sector. The number of PNs in Australia has grown quickly in recent years and, according to the Australian Practice Nurse Association (2009), there are now nearly 8000 PNs in 2009 - an increase of 3000 since 2005. Approximately 60% of general practices now employ at least one PN (Australian Practice Nurse Association, 2009).

Most research conducted into Australian practice nursing has been descriptive of the role of PNs (Bonawit & Watson, 1996; Condon, Willis, & Litt, 2000b; Pascoe, et al., 2005; Patterson, Del Mar, & Najman, 1999; Phillips, et al., 2009; Tolhurst, Madjar, Schultz, & Schmidt, 2004; Watts, et al., 2004). Until recently the role of PNs was essentially that of a GP's assistant (Patterson, et al., 1999) due to a number of factors: the way in which general practice and practice nursing has been funded in Australia, GPs' attitudes towards PNs, and educational issues (Halcomb, et al., 2005; Halcomb, et al., 2008a).   However, the role of PNs has changed recently with the majority involved, to varying extents, in health promotion and the assessment and management of chronic diseases which includes assuming a more autonomous role (Keleher, Joyce, Parker, & Piterman, 2007; Pascoe, et al., 2005; Phillips, et al., 2009; Tolhurst, et al., 2004).

Studies have shown that PNs contribute significantly to the quality of services provided by general practices and enhance the care provided (Phillips, et al., 2009; Watts, et al., 2004).   This move has been encouraged by the government and facilitated by changes in the funding of general practice: specifically the introduction of the Enhanced Primary Care and Chronic Disease Management Medicare item numbers, PN item numbers and the Nursing in General Practice initiative (Department of Health and

Ageing, 2005, 2007; Healthcare Management Advisors, 2005; Porritt, 2007; Walker, 2006; Wilkinson, et al., 2003).

Although PNs are increasingly being used to contribute to the care of general practice patients, they have the capacity to offer more, particularly in the area of chronic disease management (Halcomb, et al., 2008b; Halcomb, et al., 2007).   PNs working to their full capacity involves more autonomy for the PN, taking on more responsibility and not just extending the number of tasks undertaken (Halcomb, et al., 2008b). As far as chronic disease management is concerned, the role of the PN has been constrained by the Medicare funding arrangements, which only provide a small PN rebate for monitoring of chronic diseases. Other rebates for managing chronic disease are only payable if the patient also sees the GP. Therefore, the model of PN-led care that was trialled in the PN project, which will be described in Chapter Three, was quite new to Australia in allowing PNs more autonomy to manage patients in collaboration with the GP.

Definition of Practice Nurse

According to the Australian Practice Nurse Association, 'a practice nurse is a registered nurse or an enrolled nurse who is employed by, or whose services are otherwise retained by a General Practice' (Australian Practice Nurse Association, 2009). For the PN project all the nurses were registered nurses employed by the general practices. Enrolled nurses would not have been appropriate for this more autonomous role as they have to be supervised and work in association with a registered nurse (Royal College of Nursing Australia, 2005). The PNs in the PN project did not have any special extra training except the training provided by the project, which is

similar to staff development education available to most PNs. They were not trained as Nurse Practitioners.

The Practice Nurse Project

The study was nested within the PN project, which was funded by an ARC Discovery Grant. The purpose of the project was to trial a model of nurse-led chronic disease management in general practice to investigate the feasibility, acceptability and cost-effectiveness of this model of care. The chronic diseases managed within this model of care were diabetes type 2, IHD and hypertension. Diabetes type 2 and IHD fall within the National Health Priorities areas (Australian Institute of Health and Welfare, 2009). The model of care was trialled in three general practices, one in a small country town in Western Victoria and two in South East Queensland: a regional town and the Gold Coast.

Nurse-led care is a term that is increasingly being used in general practice circles to describe care that is organised by and contributed to by PNs. However, because of the 'fee for service' way Australian general practice is predominantly funded, most patients presently see the GP as well as the PN. There is a small Medicare rebate payable for services provided by a PN in relation to chronic disease management on behalf of and under the supervision of the doctor, where a patient has a GP management plan in place. However, when PNs contribute to GP management plans and reviews of those plans, for which a larger Medicare rebate applies, patients still have to be seen by a GP. In the PN project the PNs' role was different and more autonomous than the way in which PNs are involved in chronic disease management. In the PN project PNs were responsible for the on-

going management of the designated chronic diseases, working in collaboration with the GPs. The GPs saw the participants at the beginning of the 12 month intervention for preparation of a detailed care plan and at six months in order to review the plan. Apart from the six month review, the participants did not see their GP during the intervention period for the three specified conditions unless the PN or GP felt that it was necessary, or if the participant specifically requested to do so. For any other health issues the participants consulted with their GP as usual.

Chronic disease management provided by the PNs did not involve any cost to the participants. It was possible to bill Medicare directly, up to five times in a calendar year, for the PN item related to on-going management of chronic diseases for those patients with a GP management plan in place. However, some participants were seeing the PN very frequently and not all of the visits could be claimed from Medicare. Also, those patients who suffered from hypertension but no other chronic diseases did not qualify for a GP management plan and, therefore, the rebate did not apply to them. If participants had to see the doctor, they were billed in the way that they usually were.

This study investigated the process of patient satisfaction with those patients who experienced PN-led chronic disease management by being assigned to the PN-led arm of the larger PN project study and who had agreed to be interviewed.

The research problem

It is important for both ethical and pragmatic reasons that patients are satisfied with the care they receive. The Declaration of Alma Ata asserted

that health care should be socially acceptable (World Health Organisation, 1978). It has also long been emphasised that patients have a right to patient-centred care and to be involved in the development and evaluation of services (Australian Commission on Safety and Quality in Health Care, 2006; Australian Medical Association, 2004; Australian Nursing and Midwifery Council, 1993; Department of Health, 2000). The Federal Government of Australia has recently declared that the focus of reform of primary health care should be the patient rather than the processes of care (Roxon, 2008). The essence of health care should be a concern for the well being of patients. The responsibility of all health care workers to provide care that incorporates the ethical principles of beneficence and respect demands that the views of patients be considered when providing and evaluating services (Stevenson, 2002). Pragmatically, patient satisfaction is important because it has been linked to compliance with medical advice and treatment, and with improved clinical outcomes (Borras, et al., 2001; Gascon, Sanchez-Ortuno, Llor, Skidmore, & Saturno, 2004; Pascoe, 1983).

Patient satisfaction

Although the literature is replete with studies that measure patient satisfaction, the concept has not been well developed. From the early 1980s there has been repeated criticism of how satisfaction is measured on both methodological grounds and conceptual grounds, and calls for a better understanding of the concept. Methodological problems with the instruments used to measure patient satisfaction have repeatedly been identified (Pascoe, 1983; Sitzia, 1999). Sitzia (1999) undertook a meta-analysis of 195 patient satisfaction studies conducted in just one year, to assess the properties of validity and reliability of instruments used to

measure patient satisfaction. He found that very little attention had been given to the validity or reliability of satisfaction surveys with only 6% of the studies demonstrating any evidence for the validity or reliability of their instruments. However, studies focusing on instrument development were excluded from this analysis. Sitzia (1999) commented that as there were 20 such studies excluded, perhaps more attention was beginning to be focused on the proper development and psychometric testing of satisfaction instruments. In addition, surveys often reflect what management or health professionals consider to be important rather than being based on qualitative work that explored lay and patients' perceptions of care (Powell, Holloway, Lee, & Sitzia, 2004; Sitzia & Wood, 1997)

Even if more attention is now being paid to the validity and reliability of satisfaction surveys, they have rarely captured the complex nature of patient satisfaction and more work needs to be done to investigate the meaning of patient satisfaction to patients (Powell, et al., 2004; Sitzia, 1999; Turris, 2005; Williams, 1994). A repeated theme in the literature about patient satisfaction research is the lack of a sound theoretical basis (Pascoe, 1983; Powell, et al., 2004; Sitzia & Wood, 1997; Turris, 2005; Williams, 1994). Some theoretical work, seeking to understand how and why patients make the decisions they do regarding patient satisfaction in order to clarify the concept better, has been carried out with patients attending out-patient clinics, community mental health patients and general practice patients (Avis, Bond, & Arthur, 1997; Calnan, 1988; Collins & O'Cathain, 2003; Cromarty, 1996; Edwards, Staniszweska, & Crichton, 2004; Fitzpatrick & Hopkins, 1983; Linder-Pelz, 1982a, 1982b; Williams, Coyle, & Healy, 1998b). However, much more work is needed to develop the concept and explore the process by which patients evaluate health care

in terms of satisfaction. The theoretical foundations of patient satisfaction need to be understood: what individuals mean when they say they are satisfied, why they believe what they do, and how they arrive at that view (Sitzia & Wood, 1997; Williams, 1994). There is also a need to investigate the meaning of different aspects of health care to patients and why they are important to them, taking into account the context of patients' lives (Turris, 2005; Williams, 1994). No theory-building work has been conducted about satisfaction with PNs, either in a more traditional role or in a role that fully utilises PNs' capacity.

Many satisfaction studies have implicitly been based on discrepancy theory, which links satisfaction to fulfilment or non-fulfilment of expectations - although this theory has not been supported empirically (Pascoe, 1983). The results of satisfaction surveys are only of practical use if we understand why patients feel as they do and how they arrived at their opinion (Williams, 1994). Results of research with a sound theoretical base would be useful in informing practice to ensure that care is satisfactory to patients.

From the little research available regarding Australian patients' perceptions of PNs, it seems that PNs in Australia are well thought of by patients and that there is some support from patients for a more autonomous role for PNs (Cheek, et al., 2002; Hegney, et al., 2004a). These two studies found that there was widespread acceptance of PNs, although participants in both studies were adamant that they should have the right to choose whether they saw a PN or GP. Some participants in each study expressed an opinion that PNs should be able to do more in terms of dealing with minor illnesses and some thought that a role in chronic disease management would be appropriate. However, none of the participants in either study

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had experienced PNs working to their full capacity and some participants in each study had not had any experience of a PN at all.

A few studies have examined the role of PNs in the UK where they more fully utilise their capacity (Redsell, Stokes, Jackson, Hastings, & Baker, 2006; Wiles, 1997; Wright, Wiles, & Moher, 2001). One study specifically measured patient satisfaction with PNs and found high levels of satisfaction with visits to the nurse, regardless of whether the PN role was a traditional treatment room role or included chronic disease management and health promotion (Caldow, et al., 2006). A quantitative study was carried out by the Australian Practice Nurse Association in 2009 to investigate patient satisfaction with PNs in Australia. However, the results are not yet published. As PNs in Australia have not been able to practice to their full capacity because of the various constraints discussed earlier, there are no studies that examine patient satisfaction with PNs in Australia working to their full capacity.

Patient satisfaction is a concept that has been measured in numerous surveys over the last 25 years; however, it has rarely been explored in depth to understand the theoretical foundations of the concept. Research into patient satisfaction with PNs in the United Kingdom found participants were positive about their experiences with PNs. However, there has been no theoretical research carried out with PNs either overseas or in Australia.

Aims of the study and research question

To understand how patients determine their level of satisfaction with PN-led chronic disease management

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To elucidate the stages of the psycho-social process of patient satisfaction with PN-led chronic disease management

The research question for this study was 'How do patients arrive at their level of satisfaction with PN-led chronic disease management?'

Significance of the study

The concept of patient satisfaction is not well understood and there has been no theoretical work conducted to investigate patient satisfaction with PNs. This patient satisfaction study has extended the theoretical work that has been done to date on patient satisfaction and the knowledge generated will be useful in developing PN-led models of care that are responsive to patients' needs. The results of this study will also be useful in informing the development of more discerning and, therefore, more cost-effective instruments to measure patient satisfaction. More discerning instruments will enhance evaluation of patient satisfaction, making it more useful in informing practice.

A greater understanding of what satisfaction means to patients, what they believe about care, and how they arrive at their opinion can also be used to help identify those patients for whom PN-led chronic disease management would be most appropriate. This understanding of patient satisfaction can be useful when planning PN-led care so that it is satisfactory to patients. PNs can also utilise the results of the study to inform their practice. PN-led chronic disease management is a new model of care to Australia and understanding more about how patients arrive at their determination of satisfaction will help in providing care acceptable to patients.

The results of this study can also be used to inform policy regarding both practice nursing and the provision of chronic disease management that is acceptable to patients. Finally, those involved in planning nurse education can use the findings of this study to inform educational programs. This includes undergraduate and postgraduate programs provided by universities as well as professional development courses and workshops for PNs.

Structure of the thesis

This chapter has introduced the study and described the context within which it was conducted. It has also explained the rationale and significance of the study. Chapter Two will present a critical review of the available literature about patient satisfaction in relation to general practice and, in particular, nurse-led care. The methodology of the study will be explained in Chapter Three. An explanation for the choice of the methodology will be given and a detailed account of the PN project and how the study was conducted will be presented. Chapter Three will also include a discussion of the ethical considerations and how they were addressed as well as explaining how the trustworthiness of the study can be judged. The findings of the study are presented in Chapter Four including details of the participants and the participating practices. The theory, Navigating Care, will be explained in detail and illustrated with verbatim quotes from the participants. Finally, Chapter Five will discuss the findings of the study in the light of the available literature. Limitations of the study will be given and implications of the study discussed. Recommendations for practice and policy will then be made.

Chapter 2. Literature Review

The literature review and grounded theory

The place of the literature review in grounded theory is controversial. Traditionalists, who follow Glaser's approach to grounded theory, contended that any literature review should be delayed until after categories have emerged and begun to be integrated into a theory. Glaser (1992) contends that reviewing the literature on the research topic leads to researcher bias and the development of preconceived ideas. He stated that this can result in a theory being forced on to the data rather than a theory emerging from the data, as is the goal in grounded theory. Others, for instance Strauss and Corbin (1990), recommend using the literature to guide and enhance research methods as it can stimulate questions and theoretical sensitivity, and direct theoretical sampling.   The timing of the choice of grounded theory as the methodology for a research project can also be a deciding factor in when a literature review is conducted (McGhee, Marland, & Atkinson, 2007). If a researcher knows early on that they are going to use a grounded theory approach, then it might be appropriate to delay the literature review. On the other hand the suitability of grounded theory to the research may not become apparent until after a literature review has been conducted (McGhee, et al., 2007).

For this present study the researcher, at the beginning, had only a general idea of the area to be researched. Initially the literature was searched in order to find out what was already known about patient satisfaction and to ascertain if there was an appropriate instrument with which to measure satisfaction with PN-led chronic disease management. However, it soon

became clear from the literature that there was a paucity of theoretical research on patient satisfaction. This discovery then guided the direction of the research and the development of the research question. Grounded theory was subsequently chosen as the most appropriate methodology for investigating the process of patient satisfaction. The literature was then revisited as the theory of Navigating Care was developing and reviewed in the light of the concepts and categories found in the study.

Introduction

Patient satisfaction is a concept that has been measured in numerous surveys over the last 25 years and has increasingly been used as an outcome measure when evaluating quality of health care. It is generally accepted that patient satisfaction is a complex and multi-dimensional concept, and in measuring patient satisfaction many studies have identified different domains of care that affect satisfaction. Also, it has been suggested that some factors, which are separate from the process of care, influence satisfaction. However, little research has been undertaken to understand why the different domains of care are important and to understand the process that patients go through in evaluating their care. This chapter will present a critical review of the concepts associated with patient satisfaction and the different constructs arising from the literature that relate to patient satisfaction. As there are a multitude of studies measuring patient satisfaction in all areas of medicine, only those that add to a theoretical understanding of patient satisfaction and those that deal with general practice, practice nursing and nurse-led clinics are presented, as they are most relevant to the present patient satisfaction study.

Patient satisfaction as an outcome

Most studies of patient satisfaction have treated it as an outcome to be measured to determine how satisfied patients are with their care, and surveys routinely report very high levels of satisfaction (Fitzpatrick & Hopkins, 1983; Williams, 1998a). When investigating what impacts on patient satisfaction, researchers have concentrated on what domains of care or socio-demographic variables correlate with patient satisfaction. The only socio-demographic variable that has consistently been significantly associated with satisfaction is age, with satisfaction increasing with increased age (Like & Zyzanski, 1987; Locker & Dunt, 1978; Pascoe, 1983; Polit & Polit, 2006; Sitzia & Wood, 1997; Williams & Calnan, 1991). One possible explanation for this is that older people are a cohort, which are from a generation that was less critical of health care (Calnan, Almond, & Smith, 2003). If this is the case more recent studies would not show as strong an association between age and satisfaction. However, when Calnan et al. (2003) conducted a review of recent trends in patient satisfaction in relation to age they found that older people in the UK tended to be less critical and more satisfied with their health care than younger people. They concluded that there was little evidence that the association between age and satisfaction was changing or that older people were becoming more critical of health care. They suggested that as older people use the health system more than younger people they, therefore, may have a greater understanding of the system and what it is capable of delivering. Also, a more recent study in Norway, which had a large sample of participants, found that increased age was positively associated with satisfaction (Polit & Polit, 2006). However no reasons were posited for the association.

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The provider/patient relationship, communication, time, information giving, access and convenience, cost, continuity of care, professional competency and the physical environment have all been investigated in relation to patient satisfaction and found to be important to varying degrees (Alazri & Neal, 2003; Baker, 1996; Baker, Mainous Lii, Gray, & Love, 2003; Bikker & Thompson, 2006; Bower, et al., 2008; Fan, Burman, McDonell, & Fihn, 2005; Greco, Sweeny, Brownlea, & McGovern, 2001; Grol, et al., 1999; Infante, et al., 2004; Jung, Van Horne, Wensing, Hearnshaw, & Grol, 1998; Jung, Wensing, & Grol, 1997; McGaw, Jayasuriya, Bulsara, & Thompson, 2006; Pettigrew, Mizerski, & Donovan, 2004, 2005; Robertson, Dixon, & Le Grand, 2008; Tung & Chang, 2009; Ware, Davies-Avery, & Stewart, 1978; Wensing, Grol, & Smits, 1994; Williams & Calnan, 1991; Wong, Watson, Young, & Regan, 2008). For instance, Robertson, Dixon and Le Grand (2008) found that the patient/provider relationship was more important to patient satisfaction than access or the waiting room experience. Grol et al. (1999) found that time was the most important domain of care in terms of satisfaction, issues related to access ranked second and forth and issues related to information –giving ranked third and fifth. However, in Jung, Wensing and Grol's (1997) study of patients' and GPs' views on what makes a good GP, access for emergencies was most important, followed by time, confidentiality and information-giving. A concept analysis of 'bedside manner' by Person and Finch (2009) reported that although there were no concrete attributes of bedside manner found in the literature, empathy, friendliness, good listening and effective communication had positive associations for patients. On the contrary, providers being rude, arrogant, dismissive, uncaring or indifferent were experienced negatively.

Studies investigating satisfaction with nurse-led services have revealed similar findings to those investigating satisfaction with GPs, particularly with respect to the approachability of nurses, communication and time spent with the nurses (Burrows, 2006; Caldow, et al., 2006; Flynn, 2005; Haskard & DiMatteo, 2009; Koinberg, Holmberg, & Fridlund, 2002; Litaker, et al., 2003; Miles, Penny, Power, & Mercey, 2003; Wiles, 1997). In an investigation to understand more about the link between communication and patient satisfaction, Haskard and DiMatteo (2009) quantitatively examined the correlation between both verbal and non-verbal means of communication between nurses and patients. They found that communication that conveyed caring and sensitivity was positively correlated with patient satisfaction. Negative and rushed manner aspects of communication correlated with less patient satisfaction. DeFrino (2009) argued that although the relational skills of nurses are often taken-for-granted and under-valued, they are what give nurses their power and value. She developed a theory of the Relational Work of Nurses, derived from a parent theory by Fletcher, Jordan and Miller (2000) of the Relational Work of Women. Defrino's (2009) theory states that nurses use their relational skills to find out about patients and are therefore able to care for, encourage and teach them according to their needs and understanding. The knowledge nurses gain from the relationships they build with patients produce better outcomes for the patient.

There is some evidence that the importance of different domains of care, in terms of patient satisfaction, may vary for different age groups. In a study that sought the views of older people on what constitutes good general practice, Pettigrew, Mizerski and Donovan (2004, 2005) found that the three top areas were: prompt referrals to specialists, keeping up-to-date

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with medical developments, and being familiar with patients' medical history. The need for GPs to keep up to date with medical developments could be seen to be related to professional competency and the desire for GPs to be familiar with patients' medical histories is related to continuity of care. Professional competency and continuity have both been identified previously as being important to satisfaction (Alazri & Neal, 2003; Baker, et al., 2003; Bower, Roland, Campbell, & Mead, 2003; Fan, et al., 2005; Hall, Roter, & Katz, 1988; Infante, et al., 2004; Turner, et al., 2007; Wensing, et al., 1994; Wong, et al., 2008) although, not in the form identified by Pettigrew, Mizerski and Donovan (Pettigrew, et al., 2004, 2005). However, the desire for prompt and appropriate referrals to specialists has not been identified in other studies and demonstrates the importance of qualitative research with patients to ascertain what is important to them. The finding that older Australians may have different concerns about general practice from younger people is also particularly relevant to patient satisfaction with chronic disease management as chronic diseases are most prevalent in developed countries amongst older people.

The patient/patient relationship and interpersonal skills of the provider have consistently been shown to be related to patient satisfaction (Alazri & Neal, 2003; Baker, et al., 2003; Greco, et al., 2001; Infante, et al., 2004; Jung, et al., 1997; Pettigrew, et al., 2004, 2005; Wong, et al., 2008). However, when Mead, Bower and Hann (2002) investigated how the patient-centredness of a consultation affected satisfaction, they found, surprisingly, that there was only a weak correlation between patient-centred behaviour and satisfaction. They measured patient-centredness in terms of giving time for the patient to share, involving the patient in decision making, verbal and non-verbal caring and attending to the psycho-social aspects of

health. Their results indicated that the effect of domains of care such as the patient-doctor relationship and communication skills on satisfaction is not necessarily as straight forward as some surveys may indicate.

When examining the literature about the impact of different domains of care on patient satisfaction, one of the difficulties is that there is no consistent labelling of domains of care and sometimes two or more domains have been combined into one domain for analysis. For instance, interpersonal care and information-giving were combined into one category in one study (Bikker & Thompson, 2006) as were caring bedside manner, communication and adequate explanations in another (Pettigrew, et al., 2004), and time to listen and ability to book longer appointments in yet another (Pettigrew, et al., 2005). While it is probably true that these domains of care sometimes interact with each other (for example, good communication presumably helps with information-giving), when they are combined into one domain it is difficult to assess whether it is one domain alone or the combination that is important.

An example of how different domains of care, such as time and doctor-patient relationship, may interact but are not necessarily simple determinants of satisfaction, comes from the results of a study that investigated how different characteristics of general practices related to patient satisfaction (Baker, 1996). The study found that satisfaction with general practices that had trainee GPs was lower than those that did not, even though satisfaction with time in those practices was higher. This suggests that merely allowing more time for patients will not necessarily increase satisfaction. Other issues related to patient satisfaction such as the on-going provider/patient relationship, continuity of provider, and

confidence in the competency of the provider, which may be lacking with GP trainees, might be more important than time.

Qualitative studies have revealed that communication, time, continuity and the provider/patient relationship are closely tied together and interact to influence patient satisfaction (Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007; Chapple, 2001; Pooley, Gerrard, Hollis, Morton, & Astbury, 2001; Smith, Braunack-Mayer, Wittert, & Warin, 2008; Tarrant, Windridge, Boulton, Baker, & Freeman, 2003; Williams & Jones, 2006). Quality of time, rather than just amount of time, has been shown to be important to patients in order for them to feel that they are treated as individuals and to provide support as well as information (Chapple, 2001; Collins & Nicolson, 2002; Hornsten, Lundman, Selstam, & Sandstrom, 2005; Pooley, et al., 2001; Tarrant, et al., 2003; Williams & Jones, 2006). Studies evaluating nurse-led care have found that patients particularly appreciate the quality of time provided by nurses (Chapple, 2001; Flynn, 2005; Phillips & Brooks, 1998; Redsell, et al., 2006; Wiles, 1997; Williams & Jones, 2006; Wright, et al., 2001).

The way in which communication contributes to patient satisfaction has been explored to a limited extent.   Two studies found that the providers' style of communication was important, with some patients appreciating an open and friendly style of communication while some preferred a frank or directive approach (Smith, et al., 2008; Tarrant, et al., 2003). Being listened to, which is part of communication, has also been found to be important to patients (Pooley, et al., 2001). Qualitative investigation into the importance of continuity has shown that it helps in establishing the provider/patient relationship. Patients have also expressed that they want

to be seen by a provider who knows them and their circumstances and that continuity facilitates individualised care (Pooley, et al., 2001; Redsell, et al., 2006; Tarrant, et al., 2003).

Another aspect of the provider/patient relationship that has been shown to correlate positively with patient satisfaction is trust (Baker, et al., 2003; Platonova, Kennedy, & Shewchuk, 2008; Robertson, et al., 2008). Robertson, Dixon and Le Grand (2008) found that all their variables, such as communication, time spent waiting, time with the doctor, physical aspects of the surgery and access, were significantly associated with satisfaction. However, confidence and trust in the GP had the highest level of association with satisfaction, illustrating the importance of trust. The findings of a qualitative exploration of trust in a GP showed that many aspects of the provider/patient relationship including communication, empathy, knowing the patient and partnership, contributed either positively or negatively to trust being established (Thom & Campbell, 1997). In contrast, Baker et al.'s study (2003) found that continuity did not improve satisfaction unless the patient trusted the doctor. This illustrates the complex nature of the provider/patient relationship and how different domains of care can be interrelated.

While it is clear that different domains of care are important to patient satisfaction, treating it purely as single measurable response to care reduces patient care to a check list of domains without understanding why they are important or how patients arrive at a decision of satisfaction (Turris, 2005; Williams, 1994) or how they may be related to and affect each other. Measuring satisfaction with different domains of care without understanding the meaning they have for patients is too simplistic and risks

masking real problems with patient care, because the concept is not being fully understood and addressed. Rather than being a single response to care, patient satisfaction is better viewed as a process, developing over time, especially in the case of on-going care such as with chronic diseases. Understanding the process of patient satisfaction would provide a deeper and more thorough understanding of the concept and help to explain how and why certain domains of care are important to patient satisfaction. It would also enable instruments to be more discerning and give a more accurate picture of patient satisfaction.

Patient satisfaction as a process

As well as satisfaction being viewed as an outcome or product of care, patient satisfaction is a complex psycho-social process involving both a cognitive evaluation of and an affective response to care (Newsome & Wright, 1999; Pascoe, 1983). Research from the marketing field into customer satisfaction has produced various theories about the process of satisfaction, the most dominant of which is discrepancy theory from which the expectation/disconfirmation theory was developed (Newsome & Wright, 1999; Parker & Mathews, 2001). According to the expectation/disconfirmation theory, customers compare their perception of what they receive (service or product) with a pre-purchase standard. The degree and direction of dissonance between the perceived result and the pre-purchase standard determines the level of satisfaction (Newsome & Wright, 1999; Parker & Mathews, 2001).

Parker and Matthews (2001) investigated whether consumers' definitions of satisfaction correlated with academic interpretations of satisfaction as

both a process and a response or outcome. In a qualitative study participants were asked to record a situation in which they had felt satisfied with a product or service and then write a definition for satisfaction in the context of the situation. The researchers found that satisfaction meant different things to different people, but that the majority of definitions fell into one of two categories: an evaluative process and a feeling, giving support to the definition of satisfaction as not just an outcome but also a process. The participants came from a wide geographical area of England and a wide range of occupational groups. However, they were all managers within those occupations and relatively well qualified and, thus, may well have been familiar with the academic theories of satisfaction and may not have responded in the same way as would the majority of consumers.

The expectation/discrepancy theory has been carried over into patient satisfaction research and assumed to be theoretically relevant (Pascoe, 1983). However, although it seems clear that there is a process of satisfaction, there are difficulties associated with imposing marketing theories directly onto the concept of patient satisfaction. Patients, while being consumers of health care, are unlikely to respond to health care in a purely consumerist way (Leavey, Wilkin, & Metcalfe, 1989; Lupton, 1997; Lupton, Donaldson, & Lloyd, 1991; Wiles & Higgins, 1996).

A study in the UK by Wiles and Higgins (1996) found that even though their participants were private patients paying to see a doctor, they still did not act in a purely consumerist way in their relationships with doctors. While relationships in the private sector were less paternalistic than between patients and doctors within the free National Health Service, there was still a power differential in favour of doctors that constrained a totally

consumerist approach. Lupton et al. (1991) in their research with patients in Sydney, Australia found that none of the participants responded as consumers and most did not want to view health care as a commodity at all. Participants did not actively 'shop around' or try to compare the services offered by different doctors as would be consistent with a consumerist approach to health care. However, all participants felt that they were able to evaluate the health care they received. While a large sample of 330 participants from six different general practices in Sydney was used, nearly half the sample was over 55 years of age. This group may be more reliant on their doctor's opinion and less likely to take a consumer approach to health care as it has been found that older people tend to be less cynical about health care (Lupton, 1997).

Very little research has been carried out to develop a better understanding of the process of satisfaction in relation to health care. Evidence that patients do evaluate the health care they receive was found in a qualitative study conducted in the Netherlands with general practice patients (Jung, et al., 1998). Both task-orientated and affective-orientated domains of care were evaluated. Patients were able to identify which domains of care they used in their evaluations, but how they used them was not explored. Qualitative studies have revealed that very often patients have negative experiences of health care, but that these negative evaluations undergo a process of transformation when they complete satisfaction questionnaires, which results in reports of satisfaction (Avis, et al., 1997; Dougall, Russell, Rubin, & Ling, 2000; Edwards, et al., 2004; Fitzpatrick & Hopkins, 1983; Williams, et al., 1998b).

A study by Williams, Coyle and Healy (1998b) set out to explain why reports of satisfaction with health care are consistently very high. They

explored the meaning of satisfaction with patients of a community mental health service and found that patient satisfaction is a complex process of evaluation that often resulted in negative experiences being rated as satisfactory. They proposed an explanation for this process of negative experiences being transformed into positive reports of satisfaction. A theory of duty and culpability was developed from their study to explain this transformation.

The process identified by Williams et al. (1998b) involved two stages, first, an evaluation of whether the health care provider or service agency had a duty with respect to the particular domain of care being evaluated and, second, whether the provider or service could be held responsible if this duty was breached. For instance, a participant may feel that they did not get a chance to express themselves and were not really listened to during a consultation with a consultant psychiatrist, but if they perceived that the psychiatrist was there to prescribe and not to listen to them (no duty) they still rated the encounter as satisfactory. Even when they perceived that there was a duty to provide a particular type of care they did not necessary hold the provider or service culpable. For instance, if they thought they should be seen in a timely manner but they could see mitigating circumstances as to why this did not occur, such as there being a lot of people to see (not culpable), then they could still rate a poor experience as satisfactory. It was only if patients perceived both a clear duty in relation to a domain of care and they considered the provider or service culpable in failing to provide it that they rated their experience as unsatisfactory.

Although the study by Williams et al. (1998b) was not directly related to general practice patients, mental health services do share some characteristics with general practice in that mental illness is usually a long

term condition and the interpersonal nature of the provider/patient relationship is very important. Another similarity is that rather than being in a hospital with a one-off encounter, this study took place in a community setting where an on-going relationship between patient and provider would be established.

Edwards, Staniszweska and Crichton (2004) also found that patients went through a transformational process in reporting their level of satisfaction. They conducted a study to extend Williams et al.'s (1998b) work in a very different health care setting. Their participants were drawn from elective orthopaedic surgical patients and were, thus, very different from community mental health patients. They identified three pressures that influenced the process of evaluation: the dominance of the health care system, interpersonal care, and intrapersonal care. These will be discussed in detail in the next section.

In summary, there is evidence that patient satisfaction is a complex psycho-social process that is poorly understood. Different researchers over the last 30 years have highlighted the need for a better understanding of this process (Locker & Dunt, 1978; Pascoe, 1983; Turris, 2005; Williams, 1994). Imposing customer satisfaction theories from the marketing field on to patient satisfaction is inappropriate, as individuals rarely behave as consumers in relation to health care. Unfortunately, because this concept has not been thoroughly explored in health settings, patient satisfaction surveys often lack a sound theoretical base, which limits the usefulness of their findings. No studies were found that explored the process of satisfaction with nurses and it is possible that the process used by patients to evaluate the care they receive from nurses is different from that used when evaluating care from doctors. Therefore, there is a need to

investigate the process of satisfaction with nurse-led models of care directed at chronic disease management in general practice.

Other factors influencing patient satisfaction

Several factors that possibly exert an influence on patients during evaluation of health care have been identified (Calnan, 1988; Edwards, et al., 2004). Edwards et al. (2004) identified three pressures that influence the process of satisfaction, the dominance of the health care system, interpersonal care and intrapersonal care. Calnan (1988) developed a framework of four factors that may impact on patient satisfaction: the specific goals of the patient, previous experience with health care, the socio-political values of the system, and lay images of health. These four factors are external to the actual process of care but may have an influence on the process of patient satisfaction.

Specific goals of the patient

According to Calnan (1988) patients have different goals for their care, depending on what their problem is and, thus, different domains of care, such as access, continuity, or communication, will be important in different situations depending on the presenting problem. This is supported by the findings of other studies (Cheraghi-Sohi, et al., 2008; Kearley, Freeman, & Heath, 2001; Rubin, Bate, George, Shackley, & Hall, 2006; Turner, et al., 2007) that have found that the presenting problem affected what value patients put on different domains of care. For instance, patients with an urgent physical problem wanted a same day appointment more than a warm and friendly doctor or a doctor who knew them well (Cheraghi-Sohi, et al.,

2008; Rubin, et al., 2006), while those who considered that their problems were serious preferred to wait to see a familiar doctor (Kearley, et al., 2001; Rubin, et al., 2006). Cromarty (1996) also found that the specific aims of the patient were important in determining satisfaction. In a qualitative study he investigated what general practice patients think about during consultations and found that all participants had specific aims related to their problem. How well these aims were addressed determined their level of satisfaction. However, the work by Williams et al. (1998b), detailed earlier, suggests that the effect of having specific aims may be lessened by an individual's perceptions of duty and/or culpability of the service or provider. Patients may have desired aims in relation to their treatment or care but make allowances when they are not met because they do not consider the provider or service has a duty to provide that care or because of mitigating circumstances, which make it impossible to provide care in the way they would like.

Previous experience with health care

Previous experience, either personal or from others, can inform expectations that individuals may have of health care (Calnan, 1988). Another study found that a lack of experience with an area of health care meant that patients did not know what to expect when encountering that area for the first time (Avis, et al., 1997). However, the role of expectations in patient satisfaction, although a factor that is often considered to be significant, is debateable and will be discussed later. Although Calnan only related previous experience to expectations of care, it can also be important in relation to the level of trust a patient has in doctors or nurses, individually or as a professional group. Trust is very

important to the provider/patient relationship (Baker, 1996). It has also been found that previous experience or lack of it can affect the level of confidence in PNs working to their full capacity (Cheek, et al., 2002; Redsell, et al., 2006). This could have implications for the introduction of new models of care provided by nurses in general practice. Confidence in the knowledge and skills of the provider is another concept related to satisfaction and will be discussed later.

The Socio-political values of the health system

In addition to the patient-specific factors discussed, a general influential factor suggested by Calnan (1988) is the socio-political values on which the health system is based. A totally private health system has a consumerist approach and the emphasis is on individual choice. In a fully state-funded health system distribution of resources is decided on by the government and may be rationed according to need. Although health care systems are rarely purely one type or the other, Calnan (1988) proposed that the different approaches could have an effect on the expectations of patients. Williams et al.'s (1998b) theory of duty and culpability could have relevance in this regard as patients could have different perceptions as to what sort of care it is the duty of a state funded or a private system to provide. The type of system might also influence whether or not patients perceive the provider to be culpable if the desired care is not provided. Australian general practice is funded through a mixture of public and private payments and so the process of satisfaction may be influenced by how patients are billed for their consultations. This could have implications for the satisfaction with PN-led models of care for chronic disease

management as consultations with the PN will be free, although some patients will be private patients who still pay for consultations with a GP.

Lay images of health

The final element in Calnan's (1988) framework relates to the images of health held by lay people. This element can have an effect on expectations as well as what domains of care are valued by patients. Those who see health as the absence of disease may want different things from a health service and a different approach from providers than someone who sees health in terms of physical and emotional well-being. The latter group are more likely to value such things as preventative health advice and screening procedures. This influential element also relates to the specific goals of patients, because the individual's goals will sometimes be affected by their view of health and well being.

Dominance of the health care system

Edwards et al. (2004) identified that the health care system will exert a pressure on the process of evaluation. They suggested that the dominance of the system is influential in producing positive reports of satisfaction. Participants in their study were very aware of the unequal relationship between doctor and patient. They often felt that they were not in a position to question health care providers or the system because of their inferior status and, therefore, were not willing to say they were dissatisfied. Participants also recognised the limitations of the health care system and the realities of providing health care, making allowances for deficiencies they experienced. This process of patients dissipating blame and even self-appropriating blame for negative experiences has been shown in several

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other studies (Avis, et al., 1997; Dougall, et al., 2000; Fitzpatrick & Hopkins, 1983; Williams, et al., 1998b). All of these studies were conducted in the UK within the National Health Service (NHS). Therefore, attitudes may have been subjected to the socio-political values of the health care system identified by Calnan (1988) as the NHS is fully state-funded and resources limited. Patients may have felt that they could not expect as much in a publicly-funded system. However, the Australian system is different from the NHS in being only partly state-funded and also partly funded privately. No available studies have investigated how the socio-political values of the Australian system might affect the process of satisfaction. Therefore, it is not known whether Australian patients would react in the same way.

Interpersonal and intrapersonal care

Edwards et al. (2004) identified two other pressures on the process of satisfaction that originated with the participants themselves. The first of these, identified as interpersonal care, was a need to maintain good social relationships with those caring for them. Making allowances for shortcomings was very evident in respect to maintaining good interpersonal relationships with providers of health care as participants felt blaming care providers for unsatisfactory care could damage their relationship with them. The influence of interpersonal care could be very relevant in a situation of on-going care such as in nurse-led chronic disease management, although general practice patients may not feel as vulnerable as surgical in-patients.

The second pressure identified by Edwards et al. (2004) was a need to maintain a positive outlook, referred to in the study as intrapersonal care.

Participants felt that their recovery or well-being would benefit from a positive outlook. Responses, in terms of satisfaction, to the care they received were manipulated in order to provide a more positive impression of care. The element of intrapersonal care could potentially be very relevant to the care of patients with a chronic disease as much of their care is assisting them to self-manage which requires a positive attitude on behalf of the patient.

Edwards et al.'s (2004) study was conducted in a setting very different from general practice and in the UK where the health system is somewhat different from that in Australia. However, it supports findings about the transformational process identified by Williams et al. (1998b) that were derived from a community setting. Calnan's (1988) work was also developed from studies conducted in the UK but his framework of influences is a general one that could be applicable to any health care setting. However, he does conclude that there could be other elements that influence satisfaction and that further research is needed.

It is clear that the process of determining a level of satisfaction with health care may be subject to several different influences that will vary in type and extent for individual patients. Simple surveys or feedback forms that ask for satisfaction ratings cannot capture these influences and the resulting high reports of satisfaction can lead to misplaced confidence in the acceptability of care provided.

Expectations

The role of expectations in patient satisfaction has been assumed to be of significant importance because research into customer satisfaction has

identified expectations as a major antecedent to satisfaction (Newsome & Wright, 1999). However, it appears from the little research that has been done to specifically explore the concept of expectations in relation to patient satisfaction that, although they have some effect, they are by no means the major driver of satisfaction that most research assumes.

Linder-Pelz (1982a, 1982b) was the first person to try and develop a theory of patient satisfaction. From a review of the satisfaction literature in the field of psychology, she identified expectations as an antecedent to satisfaction along with three other variables: value placed on domains of care, sense of entitlement to care, and interpersonal comparisons. Expectations were defined as an individual's beliefs about the perceived probability of a particular outcome or occurrence. This definition would correspond to 'anticipated outcome' as described by Newsom and Wright (1999).

Linder-Pelz (1982b) developed five hypotheses to quantitatively test her theory that the four variables she had identified, plus perceived occurrence (the patient's perception of the encounter), were related to patient satisfaction. Expectations were found to be significantly associated with satisfaction with doctor conduct (p=0.001) and general satisfaction. Of the three independent variables that had an effect on satisfaction, expectations was the most important antecedent to satisfaction. It was also found that expectations had an independent effect on satisfaction, that is, irrespective of the fulfilment of those expectations. Satisfaction was greater among those who had favourable expectations and encounters than those who had favourable expectations and negative encounters. However, satisfaction was least among those who had negative expectations and negative outcomes. This result calls into question the simple use of discrepancy

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theory in relation to patient satisfaction. If satisfaction is only related to the extent to which expectations are met, then those with low expectations should be easily satisfied. From the results of Linder-Pelz's (1982b) study, this does not appear to be the case.

Newsome and Wright (1999), in their review of the concept of satisfaction in relation to patient satisfaction, described three levels of expectations, which could help to explain why those with low expectations are not automatically satisfied by fulfilment of their low expectations. The three levels described are: desired or ideal outcome, which could be considered to be similar to high expectations; adequate outcome (the minimum acceptable outcome); and anticipated outcome. Rather than expectations being an individual's belief about the perceived probability of a particular outcome, as defined by Linder-Pelz (1982a, 1982b), low expectations could be considered to be similar to anticipated outcome. An outcome may be anticipated but not desired, in which case fulfilment of that outcome will not lead to satisfaction.

Linder-Pelz's (Linder-Pelz, 1982b) study found that expectations accounted for less than 10% of the variation in satisfaction, which calls into questions the importance of expectations and suggests that there are other factors involved. Linder-Pelz's (Linder-Pelz, 1982a, 1982b) study was carried out with general practice patients; however, only two domains of care, conduct of the doctor and convenience plus general satisfaction, were tested in her study and some of the hypotheses were only tested against one of these. Additionally, the domains of care were those that were considered to be important by the researchers rather than being identified by the patients.

Another study (Like & Zyzanski, 1987) examined the effect of fulfilment of requests on patient satisfaction. Request fulfilment can be equated to desired outcome, one of the levels of expectation defined by Newsome and Wright (1999). Participants were asked to complete a pre-visit questionnaire about what they wanted from the consultation. They then completed a post-visit questionnaire about the outcome of the consultation and gave a single rating of satisfaction with the consultation as the dependent variable. It was found that whether or not requests were met accounted for 19% of the variance in satisfaction, a higher percentage than in Linder-Pelz's (1982b) study. However, a 19% effect is still low and the authors concluded that there must be other factors playing a role in satisfaction.

The generalisability of the work of Like and Zyzanski (1987) is limited because they used a convenience sample in only one general practice clinic in the United States. They also noted that the use of the pre-visit questionnaire may have had an effect on satisfaction, as some of the doctors reported that those patients participating in the study seemed more organised in their approach to the consultation. Possibly completing the questionnaire made the patients more aware of what they really wanted to achieve from the consultation and, therefore, more focused on achieving a desired outcome. This would have made met or unmet requests seem more influential than they might otherwise have been and the finding that they explained 19% of the variance in satisfaction might have been overstated.

Comprehensive investigations into the role of expectations in relation to patient satisfaction were carried out in two studies of hospital outpatient clinics (Avis, et al., 1997; Fitzpatrick & Hopkins, 1983). Participants were specifically asked about expectations and the researchers found that many

participants were unable to express any expectations at all. Those participants who did were very hesitant and if they did express expectations they were very tentative. Fitzpatrick and Hopkins (1983) found that where expectations were expressed they were based more on ideas of their illness and what tests they might have rather than on prior experience with health care. This finding suggests that previous experience of health care, an influence on satisfaction identified by Calnan (1988), may not be a strong influence in previously unexperienced health care settings. Avis, Bond and Arthur (1997) found that participants were able to express what they hoped would happen but were unsure about what would happen in the consultation and, therefore, did not feel qualified to express an expectation.

A strength of these studies (Avis, et al., 1997; Fitzpatrick & Hopkins, 1983) was that they were conducted using in-depth interviews, which allowed researcher to gain an insight into the complex decision-making process and ideas of patients. Both the studies were conducted with patients of out-patient clinics who were referred for the first time and, therefore, the participants had not had any prior experience on which to base expectations. A lack of experience with care provision and context is quite different from most general practice situations.

Pascoe (1983) and Williams (1994), in extensive reviews of the patient satisfaction literature, both found that researchers assume that expectations are a significant determinant of satisfaction. Most studies measuring patient satisfaction do not identify a theoretical basis for their investigations. However, most studies are implicitly based on discrepancy theory, that is, the difference between expectations and perceived outcome (Pascoe, 1983). However, from the work done to specifically investigate the role of expectations (Avis, et al., 1997; Fitzpatrick & Hopkins, 1983;

Linder-Pelz, 1982a, 1982b), it seems that, although they may play a part in patient satisfaction, they do not fully explain the concept and, therefore, there must be other factors that have an impact on patient satisfaction.

The need for meaning and understanding

The findings of many studies have shown that patients have an overwhelming need from their health care encounters, to better understand their condition or what is happening to them (Anden, Andersson, & Rudebeck, 2005; Avis, et al., 1997; Collins & Nicolson, 2002; Edwards, et al., 2004; Fitzpatrick & Hopkins, 1983; Flynn, 2005; Koinberg, et al., 2002; Shaw, Williams, & Assassa, 2000). This is the outcome in which they are most interested, rather than the process of care, which is what researchers have mostly concentrated. The importance to patients of finding meaning or understanding about their condition or situation could explain why domains of care such as communication, the provider/patient relationship, time spent with the provider and information giving are repeatedly found to be correlated to patient satisfaction.

Fitzpatrick and Hopkins' (1983) qualitative investigation found that participants were more concerned with the outcome of their visit in regard to their symptoms than the behaviour of the doctor, in terms of attitude or technical competence. They were not always looking for a cure, but for reassurance or understanding of the significance of their symptoms. Another study (Avis, et al., 1997) also found that patients had an underlying yearning for certainty, to find out more about what was happening to them and to gain more understanding of their condition. Both of these studies (Avis, et al., 1997; Fitzpatrick & Hopkins, 1983) were

conducted using in-depth interviews before a consultation and several weeks after, giving time for outcomes of the consultation to become apparent. Participants were able to reflect on their situation rather than just react to an isolated health care encounter. During follow-up interviews Avis et al.'s (1997) study participants, who expressed satisfaction, felt that they had gained some certainty about their condition and treatment or lack of treatment. Those who were still unclear about their situation found it difficult to separate their satisfaction with care from the progress of their treatment. T hose who expressed dissatisfaction did so in terms of lack of understanding of what was happening to them. Praise or criticism of the process of the consultation focused on those aspects of the consultation that helped or hindered the participants' understanding.

When Edwards et al. (2004) investigated the process of satisfaction they found that the 'patient's need to know' and 'making sense of their situation' were part of the process of reflection in evaluating their care. Unfortunately, although the authors identified these themes, suggesting the importance of understanding in relation to patient satisfaction, they were not elaborated on in their report.

The importance of understanding in relation to patient satisfaction is demonstrated in another study that investigated the meaning of satisfaction with dermatology patients (Collins & Nicolson, 2002). Collins and Nicolson (2002) found explanations and understanding were more important to some participants, when explaining the meaning of satisfaction, than receiving a diagnosis or cure. To achieve understanding, information exchange was important rather than just receiving information. Patients needed to be able to express their concerns and ask questions in

order to be able to understand and, therefore, they valued time spent with providers to be able to do this. Participants in Collins and Nicolson's (2002) study also wanted to be given sufficient explanations and information to understand what was happening to them. If this was not forthcoming they were left feeling uncertain and less satisfied. These findings perhaps explain why domains of care such as communication and time are important to patient satisfaction.

Collins and Nicolson's (2002) study captured an in-depth view of the meaning of satisfaction to patients by taking a phenomenological approach and using in-depth interviews to explore the meaning of satisfaction with participants. The sample was drawn from patients suffering from dermatological problems who had either had a traditional encounter with a dermatologist or a telemedicine consultation as part of a trial of telemedicine in dermatology. The authors do not distinguish between the two groups in their analysis so it is not known if the type of consultation made a difference to participants in terms of satisfaction.

Understanding was also found to be an important outcome of general practice consultation to patients in a Swedish study by Anden, Andersson and Rudebeck (2005). Their phenomenological study also found that understanding was more important than knowing the name of the diagnosis and was important to satisfaction, even if patients had experienced a cure. This study was conducted with general practice patients from five different health centres who had a wide range of conditions including some chronic conditions. Understanding was found to be important to all of the participants.

The importance of facilitating understanding with respect to satisfaction may have implications for PN-led care as several studies have reported that patients find PNs approachable and easy to talk to (Caldow, et al., 2006; Flynn, 2005; Shaw, et al., 2000; Wiles, 1997; Wright, et al., 2001). Participants in a study to evaluate a nurse-led orthopaedic joint replacement review clinic reported that one of the advantages of the clinic was that the nurse gave them plenty of time, gave good explanations in ways that they could understand, and helped them to understand and be reassured (Flynn, 2005). The nurse running the clinic was a nurse practitioner, which is a more advanced level nurse than a PN. However, the ability to facilitate understanding may be similar for PNs.

Wright, Wiles and Moher (2001) evaluated a PN-led secondary prevention clinic for patients with IHD. Participants reported that the unrushed consultations and more relaxed style of the PNs enabled discussion of issues. PNs were able to listen and give easily understood explanations to participants. These qualities were identified by participants as the primary advantage of the clinic.

Shaw, Williams and Assassa (2000) conducted an investigation into patients' views of a nurse-led continence service. Two of the three themes to emerge from the analysis were the interpersonal skills of the nurse and information giving. They delved deeper with participants to elicit why good communication, the provider/patient relationship and information giving were important. They found that the interpersonal skills of the nurses enabled patients to feel more at ease, more relaxed and therefore, better able to engage in good communication which, led to good understanding and satisfaction. The second theme of communication and

information giving was also related to good understanding and satisfaction by allowing sufficient amount and depth of explanations, good listening and appropriate ways of explaining. It was felt by participants that this was more likely to occur in the informal and relaxed relationship established with the nurses. The nurses who provided this continence service were not nurse practitioners, but had received extra training in the theory and practice of care and treatment of urinary symptoms.

Facilitating the understanding that patients need is not just about providing sufficient information. There is a need to be sensitive to the amount and type of information that patients can take in at particular times, for instance when first diagnosed with a condition or being given bad news. Koinberg, Holmberg and Fridlund (2002) found that participants in their study wanted information as they needed it and not necessarily at other times. The appropriate time could vary from patient to patient. These participants were patients recovering from surgery for breast cancer and some expressed that too much information could be overwhelming when they were coping with so many emotions. This finding could be particularly relevant in the present study as a chronic disease involves many stages of adjustment.   Patients may experience many emotions as they are diagnosed and then learn to manage a chronic disease. The amount and type of information they want/or can take in will vary at different times in the progress of a chronic disease and with each individual.

The literature indicates that patients are more concerned with the outcome of their health care encounters rather than the process of care. In particular they are concerned with finding meaning and understanding about their condition or situation. It could be that the different domains of care are

only important to satisfaction to the extent that they facilitate this understanding. This might explain why the domains of care such as communication, time, information giving and the provider/patient relationship have repeatedly been found to be related to satisfaction as they can all be important in facilitating understanding. Research that focuses only on the process of care, as an end in itself, rather than also examining the outcome of consultations from the patients' perspective, risks missing the real concerns of the patient with regard to their health care.

Confidence in the competency of the provider

Confidence in the provider's professional ability appears to be an important concept in relation to patient satisfaction, particularly when nurses are working more autonomously than has previously been experienced by patients. Two Australian studies that investigated what patients felt were important in general practice identified GP competence (McGaw, et al., 2006; Pettigrew, et al., 2004, 2005). McGaw, Jayasuriya, Bulsara and Thompson's (2006) study conducted a telephone survey to investigate trends in usage of, and reasons for, satisfaction with general practice. Although the sample was drawn from a very low socio-economic area of Perth, only 3.8% stated that being bulk-billed (the government paying the GP on behalf of the patient) for a visit was the reason for being satisfied. In contrast, over a third of participants gave the GP being competent or well qualified as their reason for satisfaction. This was the second most reported reason for satisfaction with a GP after good communication.

Pettigrew et al. (2004, 2005) found in both the focus groups and a national telephone survey that older Australians thought keeping up-to-date with

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medical developments, especially with respect to seniors, was the second most important feature of a good GP. In the survey 99% of the respondents (n=505) thought this was important and 79% indicated that it was relevant to themselves. Both of these studies had large samples and, although McGaw et al.'s (2006) was restricted to one area of Perth, Pettigrew et al.'s (2004, 2005) was a representative national sample of Australians over 50 years. They had also conducted a qualitative study first so that patients' perspectives were captured for the questionnaire items.

The concept of confidence in the professional skills of the provider has been found to be specifically relevant in the management of chronic diseases and so could be specifically relevant in the present study. Infante et al. (2004) undertook a qualitative investigation of what was important to patients in the care of their chronic disease. Using focus groups in New South Wales and South Australia to elicit participants' views, they found that it was important to participants that their GP was undertaking some form of continuing professional development in order to stay up-to-date with medical knowledge and treatments. Participants also thought that it was a good thing when GPs consulted guidelines during consultations.

Confidence with the provider may be especially important to satisfaction when PNs are assuming more autonomy and providing care previously provided by the GP. Caldow et al. (2006) found that one of the most important factors in relation to satisfaction was that patients had confidence in whoever provided care whether it be a doctor or a nurse. Evaluations of nurse-led services and investigations into patients' perceptions regarding larger roles for PNs than previously experienced, found that there were sometimes concerns among patients about the knowledge and skills of nurses working in autonomous roles (Flynn, 2005; Hegney, et al., 2004a;

Phillips & Brooks, 1998; Redsell, et al., 2006; Wiles, 1997; Wright, et al., 2001). PNs tended not to be regarded as medical experts in comparison to GPs (Redsell, et al., 2006; Wiles, 1997). Conversely, nurses who specialised in one area of practice were sometimes viewed as experts in their field, in some instances, even more than GPs. This was because they were working in only one area and, therefore, were able to concentrate on, and gain extensive experience in that particular speciality (Shaw, et al., 2000; Wiles, 1997).

Confidence in nurse-led care has often rested on the assumptions made by patients that nurses would only be allowed to work in areas for which they are appropriately qualified (Cheek, et al., 2002; Flynn, 2005; Wiles, 1997; Wright, et al., 2001). In other instances patients felt that a nurse had proved themselves competent to them through previous experience with the nurses (Shaw, et al., 2000; Wiles, 1997). In Shaw et al.'s (2000) qualitative exploration of patients' views about a nurse-led continence service, they found that it was through the good interpersonal and communication skills of the nurses that professional competence was conveyed, thus inspiring confidence. This link between good communication and confidence may be another reason why the interpersonal domains of consultations and the communications skills of providers have repeatedly been found to correlate with satisfaction.

There is some evidence available that the extent to which a patient perceives their condition as serious affects their confidence in nurses (Redsell, et al., 2006; Wiles, 1997). Studies have found that patients were generally happy to see a nurse for routine monitoring and assessment but wanted to reserve the right to return to the doctor for care if they felt there was a problem or if their condition was perceived as serious (Flynn, 2005;

Hegney, et al., 2004a; Phillips & Brooks, 1998; Wiles, 1997; Wright, et al., 2001). Confidence was bolstered by nurses being willing to consult with doctors when they were unsure of a situation or a problem arose (Wiles, 1997). Participants of an investigation into Australians' perceptions of PNs found that patients generally expressed confidence that nurses knew and would work within their scope of competency (Cheek, et al., 2002).

Patients need to feel confident that a provider, be it doctor or nurse, can fulfil their role competently. Their level of confidence in the provider affects their evaluation of health care in terms of patient satisfaction. There is evidence that nurses are able to demonstrate their competency to patients who experience nurse-led care (Shaw, et al., 2000; Wiles, 1997). However, as nurses take up the full capacity of their role in general practice, there is some uncertainty on the part of patients as to what that role should look like and whether PNs are competent to take on a more autonomous role (Cheek, et al., 2002; Hegney, et al., 2004a; Redsell, et al., 2006). PNs working to their full capacity are new to Australian general practice and the extent to which patients will feel confident in the skills and knowledge of PNs in this role is not known.

Conclusion

The literature demonstrates that patient satisfaction is a complex and multi-dimensional concept that has not been adequately examined and is therefore, not fully understood. A plethora of surveys have measured patient satisfaction as an outcome of service delivery and have routinely returned very high levels of satisfaction. However, the methodological and theoretical insufficiencies of these studies call into question the results,

which could produce a false sense of security and complacency on the part of service providers. Qualitative investigation often reveals that negative and unpleasant experiences with health care are masked by high levels of reported satisfaction. There may be many different factors that account for this discrepancy between experience and reported level of satisfaction. Some factors that influence this process of transformation from negative experience to positive report of satisfaction, such as the socio-political values of the health system, the need for good interpersonal and intrapersonal care and the dominance of the health care system, have been identified.

Many studies have shown that different domains of the consultation process are important to satisfaction, for instance, communication, time, information-giving, the provider/patient relationship and continuity. However, very little work has been done to explain why this is so. There has also been a concentration in the research literature on the interpersonal domains of consultations leaving those domains, such as outcomes of care or continuity of care, largely ignored. Also, patients have rarely been asked what they feel is important to them in terms of satisfaction with health care. Rather they are often being presented with a list of different domains of care to rate. When items on surveys are not derived from qualitative studies that capture the complexity of the patients' perspective and what they consider to be most important to satisfaction, researchers risk missing things that are important and trivialising patients' concerns.

It appears that patients are particularly concerned about the outcomes of care, in terms of understanding what is happening to them. This could explain why domains of care that facilitate or hinder understanding such as communication, time, interpersonal skills and information giving are

repeatedly shown to be correlated with satisfaction. However, this has not been investigated and the connections may not be simple and straight forward. Another feature that is important to satisfaction appears to be the patient's confidence in the professional competence of the provider. It has been found that patients are generally confident with nurses providing on-going monitoring and assessment but feel that a doctor is needed for diagnosis and treatment. However, nurses are sometimes viewed as experts when they have specialised in one particular area of practice. The relationship between confidence in the provider and patient satisfaction has specific implications for nurse-led care as PNs may not be as highly regarded as GPs in terms of their ability to provide proficient management.

Even though there is a plethora of surveys of patient satisfaction, the theoretical concept of patient satisfaction still needs to be developed, especially in relation to nurse-led management of chronic diseases in general practice. In particular, very little research has examined patient satisfaction in Australian general practice and there are no published studies in relation to satisfaction with Australian PNs. As PNs in Australia have not been able to work to their full capacity to date, there have been no studies to investigate patient satisfaction with this role. An area of patient satisfaction that has attracted very little investigation is the process that patients go through, consciously or sub-consciously, to arrive at their determination of satisfaction. A better understanding of this process would allow more insight into why and how different domains of care facilitate satisfaction enabling practitioners to improve the provision of care. It would also help in the development of more discerning and appropriate surveys to measure patient satisfaction so that results more accurately

reflect the experience of patients and can be of more use in evaluating services and guiding practice.

Methodology

Methodology can be defined as "a way of thinking about and studying social reality" (Strauss & Corbin, 1998, p. 3). As such, the choice of which methodology to use is guided by the researcher's world view with respect to reality (ontology) and their belief as to the way in which reality (or realities) can be discovered or understood (epistemology) (Guba & Lincoln, 1994). This chapter will explain and justify the use of grounded theory, the methodology chosen for this study. It will also describe the development of grounded theory in order to show where this study sits within the array of grounded theory approaches. The ontological and epistemological perspectives that underpin the particular form of grounded theory chosen for this study will also be made clear. A description of the Practice Nurse Project will be given and the grounded theory methods employed by the researcher will be explained in detail. Ethical considerations for this study will be detailed and finally strategies that were used to ensure the trustworthiness of the study will be explained.

Grounded theory

Grounded theory aims to generate theory inductively from the data resulting in theory that is firmly rooted in data and, therefore, more likely to reflect the situation being studied (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Rather than producing a study that is only descriptive, an explanation for the particular situation being studied is produced by examining the data conceptually (Glaser, 1978; Glaser & Strauss, 1967). The grounded theory approach has been widely used in nursing from the 1970s onwards (Benoliel, 1996). The interpersonal

process between nurses and patients is foundational to nursing and so the emphasis on searching for processes in grounded theory makes it valuable to nursing research (McCann & Clarke, 2003a). Also, nurses take a holistic approach to health and their patients. They are concerned about the social context and the way in which it impacts on the health, health-related decisions and daily lives of individuals, families and communities. Grounded theory focuses on discerning social processes and contextual features of a situation in order to explain how participants deal with a given situation (Benoliel, 1996). It is also useful in investigating issues and situations that have not been explored before or to give greater insight into the different aspects of previously studied areas (Stern, 1980). As a result of these characteristics grounded theory was considered to be the most appropriate approach for this study as patient satisfaction is not an area that has been fully explored theoretically and not at all with PNs. Also, the emphasis on psycho-social processes in grounded theory made it particularly appropriate, as the aims of this study were to understand the social processes involved in patients determining their level of satisfaction with nurse-led chronic disease management.

The evolution of grounded theory

Grounded theory is an approach to research that was developed in the 1960s by Barney Glaser and Anselm Strauss while they were working on a project about dying (Glaser & Strauss, 1967). It provides a systematic though flexible way of collecting and analysing many different forms of data (Charmaz, 2006; Glaser & Strauss, 1967). Since Glaser and Strauss' 'classical' grounded theory was developed, others have adapted and modified the methodology (Annells, 1997a; McCann & Clarke, 2003a;

Mills, Chapman, Bonner, & Francis, 2007), most notably Strauss and Corbin (1990) and Charmaz (1990, 2006). These changes have caused some controversy and much debate as proponents of the different approaches have defended their stances (Charmaz, 2006; Clarke, 2003; Cutcliffe, 2005; Glaser, 1992, 2002; Mills, Bonner, & Francis, 2006a).

Although Glaser and Strauss stated in their book *The Discovery of grounded theory* (Glaser & Strauss, 1967) that others should and would develop the methodology further, it seems that Glaser has taken exception to anything other than the original approach (Glaser, 1992, 2002). Glaser's approach, which is usually labelled classical or traditional grounded theory in the literature, is a product of its time, being developed in the 1960s and, thus, has modernist and positivist underpinnings, despite its interpretive heritage (Annells, 1997a; Guba & Lincoln, 1994). The emphasis is on a reality to be discovered by a researcher who, though immersed in the data, remains objective and detached (Glaser & Strauss, 1967).

Strauss and Corbin (1998) do not make their ontological and epistemological position explicit, although they seem to have adopted a more relativist position as to reality, perhaps returning to the interpretive tradition of symbolic interactionism from which grounded theory evolved (Charmaz, 2000). Their epistemological position, however, is more ambiguous. They show constructivist leanings in asserting that "analysis is the interplay between researcher and data" (Strauss & Corbin, 1998, p. 13), that theory is constructed from data, and that the researcher shapes data as they are sensitive to the issues and problems of the participants. At the same time they claim that objectivity on the part of the researcher is needed to arrive at impartial and accurate interpretations of events, a positivist approach (Strauss & Corbin, 1998). Strauss and Corbin (1998), while

maintaining the methods of the classical approach, have made some additions to the analysis techniques, in particular the conditional/consequential matrix. Glaser (1992) claims that this 'forces' the analysis instead of letting concepts and categories emerge from the data. Strauss and Corbin (1998), however, argued that the methods they present should not be taken as 'hard and fast' rules, but as flexible guidelines to assist the researcher.

In a further move away from positivism, Charmaz (1990, 2006) developed what she calls constructivist grounded theory. While using essentially the same methods as classical grounded theory, she takes a relativist position ontologically and a constructivist epistemological stance. From this perspective the researcher is firmly situated as a co-constructor of data with the participants, as well as an interpreter of meaning, particularly taken-for-granted meanings.

Other authors have proposed that grounded theory can also be useful for research with a postmodern perspective (Clarke, 2003; Mills, et al., 2007). Clarke (2003) claimed that a grounded theory approach is suited to the postmodern emphasis on context and historical, economic and political situatedness. She aimed to "renovate and rejuvenate" (2003, p. 571) grounded theory by using a new method of analysis, that she calls situational analysis, to supplement traditional grounded theory methods.

As different world views have evolved and beliefs about our ways of knowing have changed, grounded theory has been modified to reflect these different ontological and epistemological views (Annells, 1997a; Clarke, 2003). Rather than insisting on one grounded theory approach that is the 'right' one, the methods can be used for a variety of approaches, provided

that the ontological and epistemological positions of the researcher are made clear (Annells, 1996; McCann & Clarke, 2003a).

Common ground within grounded theory

While there has been much debate regarding the correct ontological and epistemological basis for grounded theory approaches, there is general agreement about the methods fundamental to grounded theory (Annells, 1997b; Glaser & Strauss, 1967; McCann & Clarke, 2003b; Strauss & Corbin, 1998). These are: theoretical sampling, constant comparative analysis, theoretical sensitivity, memo writing, identification of a core category (usually a basic social pr psycho-social process), theoretical saturation, and development of an abstract theory firmly grounded in the data.

These methods provide a means of generating theory, rather than just description, from the systematic collection and analysis of data (Glaser & Strauss, 1967). The resulting theory has fit and relevance to the situation being studied because it is inductively derived from the data (Glaser & Strauss, 1967). Grounded theory is particularly useful for identifying processes. The core conceptual category, which should explain most of what is going on in the substantive area and be related to all the other identified categories, is usually a basic social or psycho-social process (Glaser & Strauss, 1967; Morse, 2001; Strauss & Corbin, 1998). This focus on psycho-social processes made grounded theory an appropriate choice for this study, which sought to discover the processes by which patients determine their satisfaction with PN-led care. Grounded theory methods and how they were used for this study will be explained in detail later in this chapter.

Ontological and epistemological perspectives of this study

This study was underpinned by a constructivist understanding of the social world. Constructivism is ontologically relativist, taking the view that there is no one, objective reality but rather multiple and varied realities, which are constructed by individuals and are socially and experientially based (Guba & Lincoln, 1994; Schwandt, 1994). The historical and cultural contexts of an individual, family, group of people or community influence their constructions of reality and so meanings are culturally and temporally relative. Therefore, these realities can and do change with new experiences and as circumstances are incorporated into an understanding of reality (Guba & Lincoln, 1994; Schwandt, 1994).

Constructivism is not a single world view, rather it is a continuum of approaches with radical constructivism and social constructionism at each end. Radical constructivism takes the view that reality is constructed by individuals, although many meanings will be shared, while social constructionism emphasises the collective generation of meaning shaped by social pressures (Schwandt, 1994). This researcher takes a midpoint view that while some realities are individually constructed, there are also realities that are collectively constructed and influenced by social structures and processes, particularly in terms of cultural reality.

This relativist ontological position informed the epistemological approach to the patient satisfaction study, because if there is no objective reality then there can be no objective observer to discover the 'truth' (Guba & Lincoln, 1994). Rather than seeking to discover truth, a relativist understanding of reality requires an interpretation of meaning to understand a given situation and to develop a more informed and sophisticated reconstruction of reality

(Guba & Lincoln, 1994; Schwandt, 1994). With an interpretive approach the researcher is not an objective observer but interacts with the participants and the data to create an impression of reality (Charmaz, 1990).

Glaser's (1978, 1992) insistence that theory should be allowed to emerge from the data by patiently applying a process of constant comparison of the data is epistemologically objective. Strauss and Corbin take a more interpretive stance epistemologically, interacting more with the data by means of their multiple tools, questioning and analytical frameworks (Duchscher & Morgan, 2004). It is this way of dealing with the data that Glaser contends to be forcing the data into preconceived ideas (Glaser, 1992). Although Strauss and Corbin's approach is more interpretive, in considering options for this study, the tools they use seemed cumbersome and possibly, as argued by Glaser, could 'force' the data. Charmaz (2006), argued that constructivist approaches could be used together with grounded theory. While constructivist principles were useful in examining the socially constructed world of patient and nurse and in exploring the meaning doctors, nurses and care provision had for participants, the methods used in this study were underpinned by an interpretive understanding of epistemology.

While not religiously following one particular form of grounded theory, the essential elements of theoretical sampling, constant comparative analysis, theoretical sensitivity, memo writing, identification of a core category and the development of an abstract theory firmly grounded in the data were adhered to. The theory resulting from this study is the author's interpretation of the data. However, the process of constant comparison kept the researcher close to the data and every effort was made to ensure

that interpretations made by the researcher were fully supported by and reflected the data.

The PN-led arm of the project

Those participants in the PN-led group had a detailed care plan prepared for them by their GP, which laid out the clinical targets such as blood pressure, weight, blood glucose levels and cholesterol. Participants then commenced seeing the PN for management of their diabetes type 2, IHD and hypertension. Management protocols, written especially for the project in conjunction with the GPs and following best practice guidelines, were provided for the PNs to follow at each consultation (see Appendix A). There were three sets of protocols, one generic protocol that applied to all the participants in the PN-led group and additional ones specifically for those with diabetes type 2 and/or IHD. These protocols guided the PNs in monitoring and managing the participants and assisted the PNs in deciding if patients needed to return to usual care, at least temporarily, or could continue with PN-led care. PNs communicated with the GPs on a regular basis about the participants' management. How this was done and whether on a daily or weekly basis was decided by the PNs and GPs to fit in with the demands of the individual general practices. In addition to providing the PNs with the protocols, a one day intensive training workshop was provided by the PN project team before the intervention commenced. Further training opportunities were made available during the intervention period.

Methods

Grounded theory provides a set of flexible tools that, when used with discernment and creativity, can bring the researcher closer to the subject or situation being studied and enhance the gaze of the researcher (Charmaz, 2006; Strauss & Corbin, 1998). Rather than being prescriptive, both Charmaz (2006) and Strauss and Corbin (1998) emphasise that grounded theory methods are guidelines to assist the researcher in developing their theory. Sampling, data collection, analysis and writing in grounded theory are not discrete stages of a linear process as they are in other types of research. Instead, they form a cyclical process with analysis starting immediately the first data have been collected and the results guiding the next round of sampling and data collection, as ideas arising from the data are pursued, developed and refined (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). The researcher spirals through multiple rounds of sampling, data collection and analysis becoming more focused as the study progresses. Although each of these methods will be discussed separately it should be kept in mind that they actually occurred concurrently.

Sampling

Recruitment into the PN project

Patients from each of the practices involved in the PN project were invited by a letter from their GP to be part of the study (see Appendix B). Criteria for inclusion in the study were that patients be over 18, able to read and speak English, have attended the practice for at least 12 months and have diabetes type 2 and/or IHD and/or hypertension. Patients who had had a

myocardial infarction or cardiac surgical intervention in the last six months or who had unstable angina were excluded from the study as their medical condition may not have been stable enough to be managed by a PN. Recruitment into the study was staggered over several months in order to accommodate the work flows of busy general practices.

Letters from the GP were sent out to eligible patients inviting them to participate in the project. These were accompanied by an information sheet and consent form explaining the project and their involvement if they chose to take part (see Appendix C). Patients who responded to the invitation to participate visited their GP to discuss the project and their possible involvement in more detail. If they were happy to continue they then signed the consent form. Once patients had consented to participate, they were asked if they would be willing to be interviewed about their experience and if so to provide their contact details for the interviewer (see Appendix D). Once admitted to the project, participants were randomly assigned to either the PN-led arm of the study or the usual-care arm.

Sampling for qualitative research is by nature purposive as participants are chosen who have the necessary experience and insights to inform the topic of investigation (Strauss & Corbin, 1990). Therefore, the participants for this study were drawn from those people who had consented to be involved in the ARC-Discovery PN project and who had been randomised to the PN-led arm of the study, as they had experienced PN-led care for their chronic diseases.

Choosing participants for the patient satisfaction study

Criteria for initial sampling of participants are different from later in a grounded theory project (Charmaz, 2006). At the beginning the broad area

of study directs the sampling as participants or situations are sought who can provide relevant material (Charmaz, 2006). Initially, participants for the patient satisfaction study were chosen purposively on the basis of their gender, age and disease type so that both men and women with a range of ages and suffering from each of the disease types were interviewed. Individuals who were randomised to the PN-led arm of the PN project and who had indicated that they were willing to be interviewed were contacted by telephone. After ascertaining that they were willing to be interviewed, a suitable time and place was arranged for either a focus group or individual interview.

It was originally planned that participants who commenced PN-led care but returned to usual care would also be chosen, provided that they had consented to be interviewed and had not withdrawn from the project entirely. This was in order to capture possibly negative perceptions or experiences of PN-led care. However, although several participants did return to usual care, most did so before they had started the intervention. The sole participant who had consented to be interviewed and then returned to usual care after having experienced PN-led care was interviewed for the study.

Theoretical sampling

Theoretical sampling is one of the defining elements of grounded theory (Annells, 1997b; McCann & Clarke, 2003b). Sampling is not predetermined, but controlled by the emerging theory. Sampling is based on the concepts and categories that have relevance to the theory being developed and to fill in gaps in the theory that become apparent as analysis progresses (Charmaz, 2006; Glaser, 1978; Strauss & Corbin, 1990).

Participants are sampled widely to begin with in order to find as many categories as possible. Then, as a study progresses and the theory develops, theoretical sampling becomes more and more focused in order to saturate and integrate categories (Charmaz, 2006; Glaser, 1978; Strauss & Corbin, 1990). It is used inductively as participants, events or situations are sought that can provide further insight into particular concepts that appear relevant to the developing theory. It is also used deductively to test out theoretical concepts that have already been developed (Stern, 1980). Theoretical sampling is based on sampling of incidents or events rather than participants per se and so may involve sampling the same participants in different situations, different participants who may have a different experience or perspective or asking particularly focused questions of the participants (Strauss & Corbin, 1998). Theoretical sampling can begin as soon as preliminary categories have emerged from initial data (Charmaz, 2006).

In the present study, theoretical sampling was used as soon as conceptual ideas began to emerge from the data. For instance, as the idea of 'assessing their condition' became apparent, participants were sought who had different conditions, more than one condition/s or only one condition in order to explore if their condition/s were important to every day living and/or made a difference to how the conditions were assessed by patients. As the category of 'Working Together' emerged from the data, participants were chosen who had seen the PN several times and, therefore, had the opportunity to develop a working relationship with the PN. Also, the importance of continuity in 'Forming a Relationship' became apparent and so participants who had seen more than one PN during the intervention were interviewed. Some participants were interviewed more than once, at

different stages of the intervention in order to investigate how relationships with and confidence in the PN developed over time. In addition, as the analysis progressed, interview questions were added that explored the emerging categories in order to develop and integrate categories into a theory.

Theoretical saturation

Sampling continued until theoretical saturation was achieved, which was after one focus group interview and 46 individual interviews. Theoretical saturation is reached through the joint collection and analysis of data (Glaser & Strauss, 1967). In grounded theory theoretical saturation refers to all the properties of the identified categories being fully developed and the categories being satisfactorily related to each other and to the core category or process. When this is achieved the resulting theory is dense and precise, explaining what is going on in the area being investigated (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1998). This requires careful and thorough analysis and theoretical sensitivity, which will be discussed later in this chapter.

Data Collection

Individual interviews and a focus group interview were the means of collecting data for this study. It has been stated that grounded theory should use data from multiple sources, not just interviewing (Benoliel, 1996). However, there are some situations that are only available to the researcher via interviews (Lofland & Lofland, 1995) and understanding the psycho-social process of patient satisfaction is such a situation. It was only

possible to discover how patients arrived at their level of satisfaction with PN-led care by asking them about it.

It was the researcher's original intention to collect initial data through a focus group at each research site, to widely explore the process of patient satisfaction, and then to use individual interviews for a deeper and more focused exploration as concepts and categories developed. Focus groups can stimulate debate, helping participants to recall events and to think about their experiences in new ways. Hearing the stories of other people can also assist participants to be more explicit about their own experience and may bring up points of view that they had not previously considered (Frey & Fontana, 1993; Morgan, 1997; Morgan & Krueger, 1993). However, very few participants indicated that they were willing to be part of a focus group in the early stages of the intervention. Therefore, only one focus group was held, with participants in the regional town, and individual interviews were substituted at the other two research sites. All subsequent data collection was by individual interviews.

The interviews were unstructured, which allowed the participant's perspective to guide the interview and allowed for in-depth exploration of experiences and meanings (Taylor, 2005). Interview guides were used as an aide memoire for the researcher during the interviews. However, the progress of each interview was guided by participants' answers as the researcher explored ideas arising from what the participants said. This enables exploration of information generated by participants rather than being restricted to areas identified by the researcher. Although grounded theory can be undertaken with any type of data (Glaser, 1978; Glaser & Strauss, 1967), unstructured interviews are particularly suited to grounded theory as they facilitate the development of ideas and, through prolonged

engagement, the identification of processes over time (Charmaz, 2006; Morse, 2001). Returning to interview some of the participants more than once, at different stages of the intervention assisted in identifying the processes involved in patient satisfaction with PN-led management.

In-depth interviews have often been described as guided conversations (Holstein & Gubrium, 1997; Lofland & Lofland, 1995), which perhaps reflects the informal and congenial milieu that the researcher aims for in order to facilitate generation of rich data. However, an in-depth interview is more reflective but also more intrusive than a conversation, as the interviewer probes and seeks clarification, which in everyday conversation would probably be considered impolite (Charmaz, 2006). Through the use of probes, such as 'Why do you think that is?' or 'In what way?' the researcher often sought clarification or expansion of answers that participants gave, or requested examples of what they meant. This usually gave participants pause for thought and was quite difficult for some but ensured that it was the participants' meaning that was captured and not the researcher's assumptions.

There is some evidence in the literature that patient satisfaction is influenced by expectations (Linder-Pelz, 1982a, 1982b) and so the focus group and some interviews were conducted prior to the intervention to capture any expectations participants might have had about PN-led care. General questions were asked such as, 'What sort of experience have you had with the PN so far?' and 'How do you think this will be different?' These questions aimed to elicit what experience the participants had with PNs and what expectations, if any, of how or if the PN-led model of care would be different. The responses of the participants guided follow-up questions during the interviews. As it was the purpose of this study to

discover the psycho-social process of patient satisfaction, it was decided that interviews should also be conducted with participants during the intervention as well as post intervention. The table below summarises the number of interviews in each location at different times during the project.

	Pre-intervention	Mid-intervention	Late/post-intervention
Metropolitan	5	5	3
Regional	1 (Focus Group)	9	5
Rural	5	8	6
Total	*11*	*22*	*14*

Table 1 Number of Interviews by Stage of Intervention

Although both focus group and individual interviews were unstructured, considerable thought was given to the opening questions, prompts and general themes that would be explored and these formed interview guides (see Appendix E). For interviews conducted in the early stages of the intervention the questions started out as very general, such as 'When you first got the letter inviting you take part in the project what did you think?' and 'What did you like about seeing the PN?' or 'What didn't you like about seeing the PN?' These were followed up with probes and questions based on the answers given by participants. As interviewing and analysis progressed, the interview guides were reviewed and revised and the questions or areas to be covered became more focused on the emerging categories and theory. For example, questions such as 'What things make it easier to relate to the PN?' were asked to inform development of the category 'Forming a Relationship'. Also, 'Do you have any goals in relation to your diabetes/heart disease/ blood pressure?' and 'Who decides

what those goals are?' were some of the questions asked to investigate the category of 'Working Together'.

It is important that participants are happy with the location of an interview so that they feel comfortable and safe and it should also, preferably, be a quiet environment without disturbances (Hansen, 2006). The focus group was held at the general practice in Toowoomba in a separate and private room. It was considered that the participants were already familiar and comfortable with this location and that it provided adequate parking facilities. For the individual interviews, it was considered that the participants would feel more comfortable in their own homes and that it would be more convenient for them and, therefore, that it would be a more appropriate place to meet. Private homes also provided a quiet environment for the interview so that the interview could be successfully recorded. In addition, many of the participants were elderly and could find travelling to another location difficult and inconvenient. However, when participants were contacted by telephone to arrange a time for the interview they were offered the choice of being interviewed at home or at another location of their choosing if they preferred. The length of interviews varied from approximately 30 minutes to an hour with the length of interviews increasing as the data collection progressed.

All the interviews were recorded and then transcribed verbatim. Glaser (1992) strongly advocated that interviews should not be recorded as it was intrusive in the interview and the essence of a conversation should be captured in interview notes. Strauss and Corbin (1998) also thought that recording interviews was unnecessary. However, making notes during an interview can be very distracting for the interviewer and disconcerting for

the participant. Having the interview recorded allowed the researcher to concentrate on what the participants were saying, maintain eye contact and to follow up ideas as they arose from the interview. Also, many ideas were covered in each interview and it would have been impossible for the researcher to remember in detail all that had been discussed. A very small Olympus digital recorder was used for the interviews. This was unobtrusive but provided good quality voice recordings. Notes were made about the context of the interview as soon as possible after the interview and these formed an additional source of data.

Data management

Although transcribing is a time consuming task, it was decided that the interviews would be transcribed by the researcher. Analysis of qualitative data requires the researcher to become immersed in the data (Hesse-Biber & Leavey, 2006). The careful listening that transcribing requires facilitated this familiarity with the data early in the process of analysis. Transcribing was carried out as soon as possible after the interviews, while interviews were still fresh in the researcher's mind. This helped in capturing the interviews accurately and informed questions for subsequent interviews. All transcripts were given numbers and no identifying information was included in order to maintain participant confidentiality.

The computer program NVivo version 8 was used to assist in organising and managing the data. The use of computer programs for qualitative analysis can help to save time and improve efficiency when analysing large amounts of qualitative data. It also allows for codes to be developed, merged or deleted as analysis progresses and for the easy retrieval of data related to different codes (St John & Johnson, 2000). Computer programs

do not, however, replace analytical thought, which is still the essence of qualitative analysis and the responsibility of the researcher (Liamputtong, 2009). Using a computer program for analysis runs the risk of losing recorded data if there are technical difficulties with the program or the computer. In order to avoid this difficulty if such problems were encountered, back-up copies of the NVivo file were kept on different computers and on a USB memory stick so that a back-up copy could easily be restored. As soon as interviews were transcribed the transcripts were imported into NVivo for analysis.

NVivo was invaluable in managing the large volume of data generated for this study and in being able to sort and find all pieces of data assigned to particular codes easily and quickly. However, as the theory began to develop the researcher found that a more visual process for identifying how codes and categories were linked was useful. To facilitate this, categories were mapped on a white board in order to demonstrate and develop the connections between them. As the theory began to take shape, these were developed into the diagrams that illustrate the findings in the following chapter.

Data analysis

In grounded theory, data analysis starts immediately the first data are obtained and it controls further sampling and data collection. The system of constant comparison continues throughout the stages of analysis. First comparisons are made between incidents to develop codes and categories. Then, as analysis progresses, incidents are compared to the emerging categories and their properties (Glaser & Strauss, 1967; Strauss & Corbin, 1990).

Memoing

Memoing is another essential element of grounded theory (Annells, 1997b; Charmaz, 2006; Glaser, 1978). Memoing begins early in the research process and continues throughout (Charmaz, 2006; Glaser, 1978; Strauss & Corbin, 1998). As soon as the first data were analysed in this study the researcher started to write memos. They were used to record and explore analytical ideas as they occurred to the researcher. These were sometimes short and revisited later to develop them further. As analysis progressed the memos became longer pieces of analysis. When sorted, memos become the basis of the final report (Charmaz, 2006; Glaser, 1978), and in this study they were used to form the basis of the findings given in Chapter Four.

Writing memos helped the researcher to examine codes and categories, they were used to make comparisons and to grapple with analytical ideas, revealing areas that need further investigation (Charmaz, 2006). Glaser (1978) suggests that to assist with sorting at a later date, memos should be dated, given a title related to the category it refers to and be referenced to the data to which it applies. However, as the researcher used NVivo to manage study data, it was possible to link memos, titled and dated, directly to the related codes, categories and related data. Field notes, made after each interview to capture the context of the interviews, were also a form of memo. They were used to record the researcher's first thoughts about the data and helped in illuminating areas that needed to be explored further.

Coding

Coding is central to grounded theory analysis (Walker & Myrick, 2006). It is the process of assigning conceptual names to parts of the data to define

what is happening in the data (Charmaz, 2006). Codes provide the 'bones' of the analysis that are later theoretically integrated to become the explanatory theory. Coding allows researchers to turn concrete events and descriptions into theoretical understandings (Charmaz, 2006).

Different proponents of grounded theory suggest different ways of coding and use different terms. Glaser's emphasis is intuitive and that of Strauss and Corbin is more prescriptive (Walker & Myrick, 2006). Glaser (1978, 2005) calls his coding procedures open coding, selective coding and theoretical coding. Strauss and Corbin (1998) describe open, axial and selective coding plus they use a conditional/consequential matrix for analysis. Charmaz (2006) divides coding into two stages, initial coding and focused coding. All three approaches include being immersed in the data and asking questions of the data in order to develop the codes and categories (Charmaz, 2000, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). However, there is a difference in the type of questions recommended. The questions Glaser (1978) and Charmaz (2006) suggest are general in nature, while those suggested by Strauss and Corbin (1998) are more specific and prescribed and focus on finding the properties and dimensions of categories.

The approach to coding taken for this study was closest to that of the approaches described by Charmaz (2006), which is an intuitive way of coding while acknowledging the place of the researcher in interpreting the data and not as an independent observer. However, some aspects of Strauss and Corbin's (1998) methods were used to identify the contextual and intervening conditions when it was deemed appropriate for developing the theory.

Initial coding involves fracturing the data by a careful line by line or incident by incident analysis, comparing data to data and assigning codes to each small section (Charmaz, 2006; Strauss & Corbin, 1998). These codes are provisional at this stage as the researcher remains open analytically to what best fits the data (Charmaz, 2006). As analysis progresses codes may be renamed to better conceptualise the data, subsumed into another code or category or dropped as not being relevant to the emerging theory (Charmaz, 2006; Stern, 1980). A line by line analysis of the data in this study was conducted and codes such as 'Doctor back-up' and 'Being listened to' were assigned to small sections of the data. These codes were classified as 'free nodes' within NVivo. Some of these early codes, for instance 'Time', later became a category to be further developed. Sometimes 'in vivo' codes were used, where participants' own words are used for the name of a code. In vivo codes help to preserve the participants' meaning and voice. However, to remain in the theory they have to 'earn' their place by having theoretical relevance (Charmaz, 2006). For instance 'Personal trainer' was an initial in vivo code used to describe how some participants related to the PN. It alerted the researcher to one aspect of the relationship with the PN. It was later subsumed into the category of 'Being accountable'.

As analysis progressed, more focussed coding occurred where the most significant codes and/or frequent codes were compared to the data and to other codes to find the best conceptual explanation of what was occurring in the data (Charmaz, 2006). At this stage codes were integrated into categories, which were more conceptual than codes and often subsumed several codes into one category (Charmaz, 2006). As grounded theory methods are not used in a linear fashion, but in cycles of sampling, data

collection and analysis, these stages of coding do not occur discretely one after the other. Although focused coding only begins after initial coding, there is a back and forth process between the two types of coding at times (Charmaz, 2006).

In the patient satisfaction study, an examination of the codes developed during initial coding revealed several categories to which groups of codes were linked. These categories became 'tree nodes' in NVivo and related codes were linked under them as 'child nodes' or the branches of the category. For instance, 'Relationship with the PN' became a tree node (later becoming 'Forming a Relationship) and the codes linked to this category included 'Feeling comfortable', 'Being listened to', and 'Receiving explanations'. Categories were further developed by asking questions of the data such as 'What does this mean?', 'What facilitates this?', 'How is this happening?' and 'Why is this happening/important?' Data were continually revisited and compared with new data and emerging categories until all the categories were fully developed and related and a core category, Navigating Care, emerged that was related to the other categories and explained most of what was going on in the substantive area of the process of patient satisfaction with PN-led chronic disease management.

Theoretical sensitivity

Theoretical sensitivity is an essential feature of grounded theory that is necessary at all stages of the research process to ensure that a well integrated theory, firmly grounded in the data is constructed (Charmaz, 2006; Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1998). Theoretical sensitivity is a creative aspect of grounded theory that enables

researchers to understand the data in new ways, giving meaning to it in conceptual rather than concrete ways (Strauss & Corbin, 1990). A researcher's professional experience can be a source of theoretical sensitivity if the research area is closely related to their professional background. Familiarity with a research context can provide intuitive understanding and insights into events and situations talked about by participants (Strauss & Corbin, 1990).

The researcher has worked as a nurse in general practice for nine years. In that time she has had constant contact with patients in this setting and has become increasingly involved in chronic disease management. During the nine years of working in the same general practice she has developed on-going relationships with the patients and has come to know many of them very well. This professional experience contributed to theoretical sensitivity that helped to interpret data in meaningful ways. As the researcher is so professionally close to the area of research she is also aware that personal assumptions could bias the analysis. Therefore, care was taken to maintain an open and receptive attitude towards the data. The use of a personal journal also helped the researcher to challenge any pre-conceived ideas that may have clouded the analysis. Discussions with supervisors throughout the research process also served to help in considering other points of view.

Theoretical sensitivity increases during the research process and can also be fostered by extensive reading of a wide range of related literature (Glaser, 1978; Strauss & Corbin, 1990). The literature review that was conducted prior to the research sensitised the researcher to concepts that might be related to patient satisfaction. It also raised awareness of the lack

of theoretical understanding of the area. Keeping this in mind helped the researcher to keep an open mind and look for answers in the data.

Ethical considerations

Permission to undertake this study was provided by Griffith University Human Ethics Research Committee. The National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council, 2007) states that the principles of respect for human beings, research merit and integrity, justice and beneficence should guide all aspects of research planning and process. These principles were considered when planning each stage of this research and were kept in mind throughout the research process.

Respect for human beings

Respect for human beings is central to ethical considerations and is the principle that underpins the other three principles (National Health and Medical Research Council, 2007). Respect for human beings includes respect for individuals' autonomy, their right to make their own decisions; having regard for individuals' welfare, beliefs, perceptions, customs and culture; respecting their privacy; and maintaining confidentiality (National Health and Medical Research Council, 2007)

The first area in which participants' autonomy was considered was in respect to consenting to take part in the project. Consent to be a participant in research must be voluntary, be based on adequate information and understanding about the project and what is required of participants (National Health and Medical Research Council, 2007). Every effort was

made by the researcher and the PN project research team to respect the individuals' autonomy and to provide information as a basis for informed consent. Prospective participants for the PN project were sent an information sheet with the invitation to participate. This information sheet was reviewed by the research team prior to being sent out to make sure that it was in language that could be easily understood by prospective participants. This was particularly important as most prospective participants were elderly and it is common for older people to experience significant literacy problems, especially if they have a chronic disease (Brownson, 1998; Cohen, 2002).

If patients expressed an interest in taking part in the PN project they were then able to meet with their GP to discuss the project further and what would be involved for them. This gave participants an opportunity to ask any questions they might have and to really understand the project and what was involved. If they still wanted to participate they then signed the consent form. At this interview they were also given a form explaining why the researcher needed to interview people about their experience with PN-led care. If they were happy to be interviewed they then provided their contact details on the form and indicated if they were willing to take part in a focus group and/or individual interview. Only those who had provided their contact details specifically to be interviewed were contacted for an interview. Participants were reminded of the reasons for the research before the interviews. Respect for autonomy also extended to the participants having the choice of where and when the interviews took place and to whether they consented to the interview being recorded.

Respect for participants' welfare, beliefs, customs and culture was kept in mind throughout the research process. Times for interviews were arranged

that best suited the participants and they and their opinions were treated with care and respect during the interviews. It was emphasised to them that there were no right or wrong answers, but that the researcher wanted to hear their thoughts and opinions about PN-led care.

It is also important that participants know that all information given by them is confidential and that they are free to withdraw from the study at any time if they change their mind and without having to give a reason (National Health and Medical Research Council, 2007). It was made clear to prospective participants in the information sheet and by the GP that they could withdraw from the project at any time. In addition, when telephoning the participants to arrange an interview, it was first ascertained that they were still willing to be interviewed. Before each interview the purpose of the interview was explained to the participant and they were asked if they were still happy for the interview to be recorded.

To ensure that participants understood that confidentiality would be maintained, they were assured that the transcript of the interview would not contain any identifying information and that recordings would be erased once the study was completed. Only the researcher had access to the raw data, which was kept on a password protected computer. The participants' contact detail forms were kept in a locked filing cabinet in the researcher's office. The de-identified transcripts of the interviews were imported into NVivo and also kept in Word documents on the password protected computer and in back up copies. Once the study is complete and any journal articles are published, the raw material will be erased and the transcripts transferred to a compact disc and stored in the repository of the Research Centre for Clinical and Community Practice Innovation at

Griffith University, along with the contact detail forms. Electronic copies of the raw data and transcripts will then be deleted.

Participants were also assured that the researcher would not repeat anything they had said to any of the members of the general practices and that there would no identifying information included in the final report or any publications resulting from the study. Pseudonyms for both participants and PNs have been used when using verbatim quotes in this report. Only the title of the GPs is used where participants have referred to their doctor in the quotes. This ensures that participants cannot be identified through identification of the participating practice.

Research merit and integrity

Research merit and integrity is another ethical principle to be considered. This principle encompasses the study being justified by its potential benefits, using methods appropriate to achieving the aims of the research, being based on a thorough study of the current literature and previous studies, being designed in a way respectful to the participants and conducted or supervised by people with appropriate qualifications and experience (National Health and Medical Research Council, 2007). The need for this study and the benefit that may be derived from it has been demonstrated elsewhere in this report. The researcher has endeavoured to demonstrate previously in this chapter that the methodology and methods chosen were appropriate in order to answer the research question. A comprehensive literature review, presented in Chapter Two of this report, was conducted on the subject of patient satisfaction. It presented theoretical work already carried out in relation to patient satisfaction as well as reviewing studies conducted to measure patient satisfaction, which

demonstrated the need for this study. The researcher, who already had some experience in qualitative research and interviewing, had two supervisors both appropriately qualified and with extensive qualitative research experience.

Justice

The third ethical principle is justice and attention to this principle ensures that all aspects of the research are fair and just (Holloway & Wheeler, 2002). The selection and recruitment of participants should be accurately described in the report to enable readers to ascertain that fair procedures and criteria for inclusion and exclusion were utilised (National Health and Medical Research Council, 2007). A description of the recruitment process and inclusion and exclusion criteria has been given earlier in this chapter.

There should also be no exploitation of participants, no unfair burden on particular participants and there should be a fair distribution of any benefits from the research (National Health and Medical Research Council, 2007). The researcher treated participants with respect and courtesy at all times during the research process, respecting their individuality and autonomy. The researcher also endeavoured to spread the burden of participating fairly, interviewing different groups of participants. However, theoretical sampling sometimes made it necessary to return to the same participant to follow up on specific areas of interest. The participants were always given the choice of participating in extra interviews. This study will contribute to PN-led chronic disease management that is acceptable to a broad range of patients and from which the participants may eventually benefit. A more immediate benefit was that all participants were able to have their say on their own PN-led care, if they so wished, enabling their voice to be heard.

Beneficence

Beneficence is the final ethical principle to be considered and requires that potential risks are assessed and that benefits of the research justify any potential risks. Every effort should be made to minimise them and the welfare of the participants given precedence at all times (National Health and Medical Research Council, 2007). A risk is "a potential for harm, discomfort or inconvenience" (National Health and Medical Research Council, 2007, p. 15). Before the research is carried out a comprehensive assessment needs to be made as to the likelihood of harm, discomfort or inconvenience occurring, the likely severity of harm, whether they are justified by the potential benefits and how the risks can be managed (National Health and Medical Research Council, 2007).

Risks of harm include those that could result in physical or psychological harm, which extends to feelings of worthlessness, distress, anger, guilt and fear. Social, economic and legal risks also need to be considered (National Health and Medical Research Council, 2007). Discomfort, while less serious than a risk of harm, still needs to be considered and can include anxiety produced as a result of an interview. A third type of risk is that of inconvenience and, while not as serious as the other types, should still be considered in order to make the research experience as un-intrusive as possible for participants (National Health and Medical Research Council, 2007).

When the risks attached to this study were considered, it was determined that only minimal physical risks to participants were likely, that is, only those risks that may be encountered in everyday life (Polit & Beck, 2004). Some physical risk and inconvenience could have been associated with

travelling to the focus group interview. However, it was decided to hold this at the GPs' surgery that participants already frequently visited and were, therefore, familiar with the journey and parking was provided. All other interviews were held in participants' own homes and so presented no extra physical risk to them. Any inconvenience to the participants was minimised by ensuring that they were happy to be interviewed in their own home at a time that they suggested.

Psychological risks were also considered to be minimal as it was not anticipated that the interviews would cover any issues of a particularly sensitive or intimate nature. Also, participants were informed prior to the interview that they would be discussing their experience with PN-led care.

A potential social risk to participants was that their care could be adversely affected if they made negative comments. The researcher was not involved in the care of any of the participants and so negative comments made to her by the participants could not affect their care. In addition, participants were assured that nothing would be repeated to any of the staff at the general practice to eliminate potential embarrassment or adverse impact on their care from what they might say. Current clinicians involved in the PN Project only had access to the findings of the study in an aggregate form so that individual practices or PNs could not be identified. It was considered that the opportunity to have a voice about PN-led care and to contribute to a study that can be used to provide acceptable care to patients outweighed the potential minimal risks.

There was also a potential social risk to the reputations and or employment of clinicians and practices involved in the PN project if there were negative findings. This risk was addressed by only presenting the findings in an

aggregate form and by removing any identifying information from quotes used to illustrate findings. By doing this no individual PNs, doctors or practices could be identified.

Trustworthiness of the study

Measuring the trustworthiness of qualitative research is a contentious issue and there is much debate about what criteria can be used to determine the quality of a qualitative study (Guba & Lincoln, 1985, 1986; Seale, 1999; Strauss & Corbin, 1998). Validity and reliability are the traditional concepts, originating from a positivist paradigm of inquiry, which are used to demonstrate quality (Guba & Lincoln, 1985). However, these are inappropriate criteria to apply to qualitative research, particularly research underpinned by constructivist ontology which takes the view that reality is relative and multiple and socially constructed (Guba & Lincoln, 1986, 1994; Schwandt, 1994). Guba and Lincoln (1985) suggest four different criteria by which qualitative research can be judged; these are credibility, transferability, dependability and confirmability.

Credibility

Credibility is defined as "worthy of belief" (1995, p. 316) and there are various techniques that can be used to demonstrate that the findings of a study are worthy of belief. These include prolonged engagement, persistent observation, triangulation, negative case analysis, and peer review (Guba & Lincoln, 1985). Methodological triangulation was not possible in this study as the only possible means of collecting data was interviewing. However, data triangulation in the form of collecting data

from different sites and at different times was achieved. Participants were interviewed at the three different practices that represented three different geographical areas and at different time in the intervention and occurred over time.

The focus group and individual, unstructured interviews provided the opportunity for engagement with participants on a deep level with sufficient time to establish trust and to fully explore the issues surrounding the research question and those that arose as a result of analysis. In addition several participants were interviewed more than once, which allowed for extra engagement with participants. Negative case analysis is a feature of grounded theory analysis as differences are deliberately looked for to fully develop the evolving theory (Charmaz, 2006; Glaser & Strauss, 1967) and were included in this study's analysis. Peer review was accomplished through the presentation of the study at two conferences. Early in the study the author presented at the Royal College of Nursing Australia's PN conference in Hobart, Australia in October 2007. The findings of the study were presented at the GP and Primary Health Care conference in Melbourne, Australia in July 2009. Regular discussions throughout the course of the research with supervisors experienced in qualitative research also provided another form peer review.

Chiovitti and Piran (2003) add other strategies for ensuring credibility. These are letting participants guide the inquiry process, making sure that participants' perspective and meaning is reflected in the theory and articulating the researcher's personal views and insights. When interviewing participants for this study their responses to initial questions were used to guide subsequent lines of questioning and in this way interviews were guided by the participants. In addition, codes that arose

from analysis of data were used to guide subsequent interviews by adding questions about the codes to the interview guides. Checking theoretical interpretations against participants' own meanings is part of grounded theory through the use of theoretical sampling and the constant comparative system of data analysis and so was part of the way this study was conducted.

The researcher's personal views and insights were articulated by means of a reflexive attitude throughout the research process. Reflexivity is an integral part of qualitative research as the researcher considers their own preconceptions and relationships with the participants and the data. At the very beginning of the project the researcher reflected on her ontological and epistemological stances towards the research topic and the conclusions arrived at guided the overall approach to the study. These stances have been elucidated earlier in this chapter.

A research journal was also kept as a way of reflecting on the research process and the position of the researcher in relation to the participants and the data. The use of a research journal facilitates reflexivity by recording the content of and reactions to the interactions between the researcher and the participants, increasing self-awareness and providing the material for reflection (Koch, 1994). During the present study the researcher recorded her thoughts in a journal following interviews with participants, including her reactions to the participants and what they had said and how the participants reacted to her. This enabled the researcher to reflect on her approach to the participants and how this might be affecting the data. It also enabled the researcher to reflect on and critique her position in respect to the data and the analysis. As the researcher was also a nurse working in general practice she took care to consider whether preconceptions from her

professional role were influencing the way in which she collected and interpreted the data. Discussions with experienced supervisors throughout the research process also encouraged a reflexive attitude.

Transferability

Transferability refers to the degree to which a study's findings can be transferred to a similar situation or group of people. The reader needs sufficient information in the report to enable them to make a judgement about the transferability of findings (Guba & Lincoln, 1985). A detailed and complete description of the context of this research has been provided earlier in this chapter and Chapter Four will present a picture of the participants and participating practices. This will assist readers in making decisions regarding whether the findings of this study could be applicable to other settings and inform their practice.

Dependability

Dependability refers to whether the approach and methods used in a study were appropriate and could be repeated in similar circumstances (Holloway & Wheeler, 2002). Guba and Lincoln (1985) borrow the term 'audit' from accounting as a means of establishing dependability. An audit or decision trail is provided by a detailed description of and rationale for the entire research process, thus allowing the reader to assess the suitability of the methods and their application. The background to this study has been made clear and this chapter has provided a detailed description of and justification for all the methods used in this study. The author has provided explicit reasons for many of the decisions made at each stage of the research process and examples have been given to demonstrate these

decisions. The extensive use of verbatim quotations, in the results in Chapter Four, also helps to illustrate findings and how concepts and categories were derived.

Confirmability

The fourth criteria for trustworthiness is confirmability, which attests to the degree to which the findings are supported by the data (Guba & Lincoln, 1985). The audit trail, in addition to demonstrating dependability, can also be used to demonstrate confirmability by providing the reader with the rationale for decisions made in the research process and in the interpretation of the data. By nature grounded theory stays close to the data to ensure that the resulting theory is thoroughly 'grounded' (Charmaz, 2006; Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1998). A detailed account of how the analysis was conducted has been provided to help readers judge the confirmability of the findings. In addition, verbatim quotations have been used extensively to illustrate the processes that emerged from the data and to demonstrate that the theory was developed from analysis of the data.

Summary

This study sought to answer the question 'What is the process patients go through when determining their level of satisfaction with PN-led care'. This chapter has made explicit the author's philosophical understanding of reality that underpins the study. It has also presented a detailed account of how the methods specific to grounded theory were applied in order to answer the research question. The essential elements of grounded theory

that were followed in this study were outlined: theoretical sampling, constant comparative analysis, theoretical sensitivity, memo writing, identification of a core category, theoretical saturation, and development of an abstract theory firmly grounded in the data. These inductive-deductive methods enabled the researcher to elucidate the process of patient satisfaction with PN-led care and develop the theory Navigating Care. Data collection was by unstructured interviews in participants' homes and one focus group interview. Analysis was conducted by a process of constant comparison, employing theoretical sensitivity and coding. Initial coding was followed by more focused coding and the development and integration of categories. Developing categories were tested and further developed by the use of theoretical sampling and continually revisiting the data.

The ethical considerations of this research have been discussed and details of how ethical issues were addressed have been outlined. Finally the criteria by which this study can be judged as trustworthy have been examined and details given as to how the criteria have been met. The following chapter will present in detail the finding of the study and the substantive theory 'Navigating Care'.

Chapter 3. Results

This chapter will present a summary of the participants in this study so that an overall picture of the sample can be seen. It will also describe the three practices that trialled the PN-led model of care in the PN project. The theory of patient satisfaction with PN-led chronic disease management, which emerged from the data, will then be presented and explained. Verbatim quotes from the participants will be used to illustrate the findings. When presenting the quotes from participants 'sic' has not been used to indicate incorrect use of grammar and/or syntax as conversational speech is rarely completely grammatically correct. All the participants have been given pseudonyms for the verbatim quotes and any information that could identify participants has been removed. All the PNs will be referred to as 'Sally' to help maintain the anonymity of the participants.

When writing this thesis consideration was given to whether or not to use the term 'chronic disease management'. Although this is a term in common usage in the medical world, patients do not generally refer to or understand their conditions as chronic diseases. Therefore, when writing from the perspective of the participants, 'on-going condition/s' has been used instead of chronic disease/s. When writing from a more clinical or professional perspective the term chronic disease management has been used.

The participants

There were 38 participants in this study, 21 women and 17 men. A focus group interview was conducted with eight participants, four men and four

women. This was followed by forty-six individual interviews with 34 participants, four of whom had also been members of the focus group. Of the total number of participants and including the focus group interview, 22 were interviewed once, 14 twice and one, three times. Table 2, below summarises the number of times participants were interviewed.   Of the four members of the focus group who were also interviewed individually, three participants were interviewed once individually and one female participant was interviewed individually on two occasions.

NB. Data about participants have been aggregated by condition and location to maintain confidentiality.

	Metropolitan participants	*No of interviews*	Regional participants	*No of interviews(incl. focus group)*	Rural participants	*No of interviews*
Men	**2** **2**	*x1* *x2*	**3** **3**	*x1* *x2*	**6** **1**	*x1* *x2*
Women	**3** **2**	*x1* *x2*	**6** **2** **1**	*x1* *x2* *x3*	**3** **4**	*x1* *x2*
Total	**9**	*15*	**15**	*22*	**14**	*19*

Table 2: Number of interviews by location

The majority of participants were over 65 years, which was expected as the three chronic diseases in the study are more common among older people. However, 11 participants were under 65 years including four who were younger than 50 years. Table 3, below, gives a summary of participants' ages and the locations they came from. There was a fairly even representation of participants in terms of location and age. The slightly lower number of participants from the metropolitan practice reflects the smaller size of that practice.

	Age <50	Age 50-65	Age 66-75	Age > 75	Metropolitan	Regional	Rural
Men n=15	2	4	4	7	4	6	7
Women n=20	2	4	6	9	5	9	7

Table 3: Participants by Age and Location

Approximately one third of the participants had more than one of the chronic diseases included in the study. Seven participants had two of the three conditions and three participants had all three conditions. Hypertension was by far the most common of the three conditions with 23 out of the 38 participants having hypertension either alone or in addition to the other conditions. Of the 26 participants who had only one of the conditions, hypertension accounted for 14, IHD for seven and diabetes type 2 for five. A summary of the participants by condition is provided in Table 4.

	Hyper-tension	Diabetes Type 2	IHD	Hypertension & Diabetes Type 2	Hypertension & IHD	Diabetes Type 2 & IHD	Diabetes Type 2 Hypertension & CVD
Men n=15	3	3	4	1	1	2	3
Women n=20	11	2	3	2	0	1	2

Table 4: Participants by disease type

Navigating care – An overview

In this study of patient satisfaction with PN-led chronic disease management a basic social process, conceptualised as *Navigating Care*, emerged. This section will present an overview of the process of Navigating Care and introduce the three sub-processes involved. These

sub-processes will then be described in detail in later sections. Diagrams to illustrate the process are also provided to assist in demonstrating how the three sub-processes relate to the main process of Navigating Care.

Navigating Care is the basic social process that emerged from the study into the process of patient satisfaction with PN-led chronic disease management. It is the response by patients to the question "Is PN-led care right for me"? and is an on-going and cyclical process comprised of three separate but inter-related processes, *Determining Care Needs, Forming a Relationship* and *Having Confidence*. Navigating Care is represented by the diagram in Figure 1.

"Is Practice Nurse-led care right for me?"
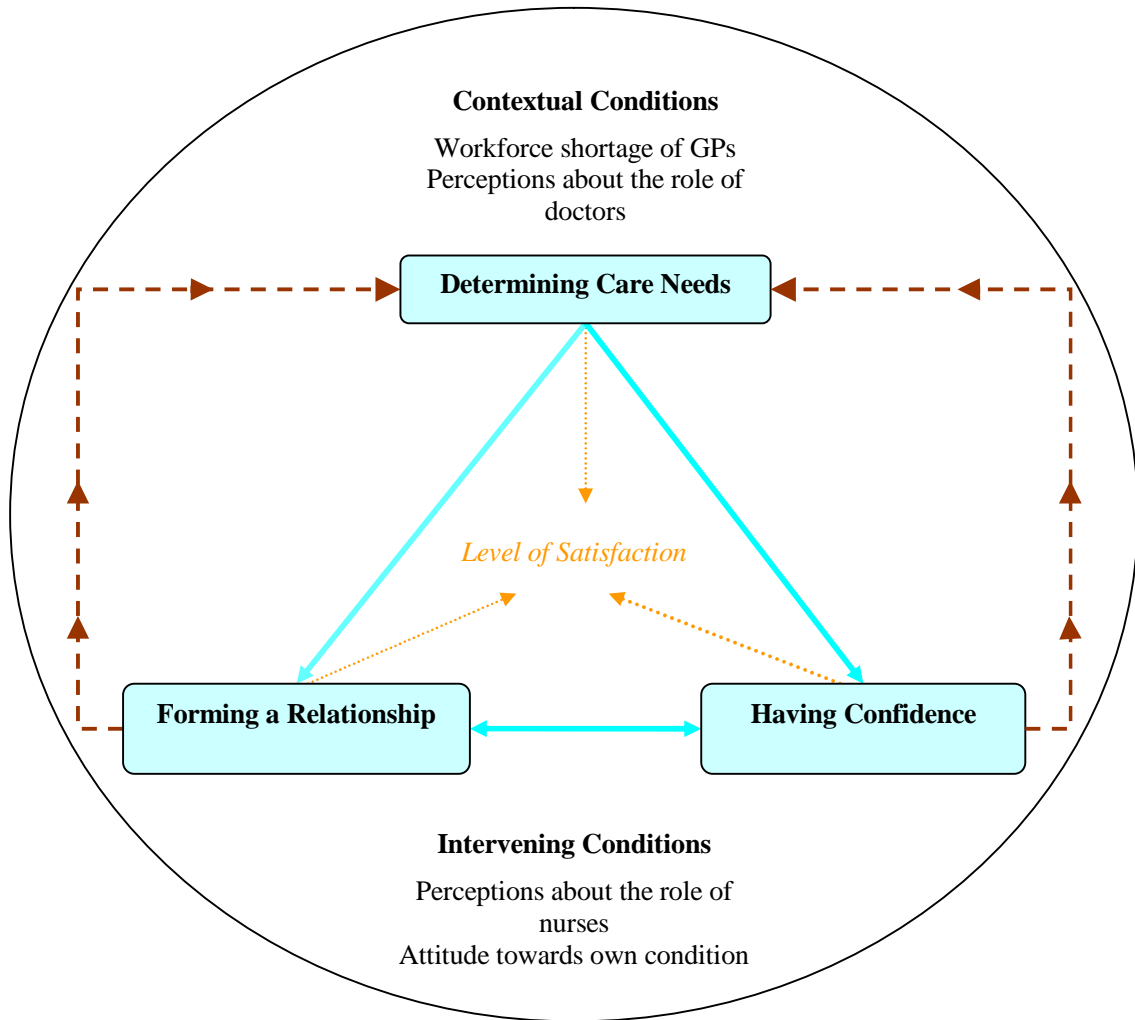
Figure 1 Navigating Care

Determining Care Needs is the first process involved in Navigating Care. Patients assess their condition/s to determine what sort of care they feel is required. If they determine that their care needs are such that can be met by the PN they proceed to Forming a Relationship with and Having Confidence in the PN. These two latter processes are interdependent and

there is a feedback loop from them to inform subsequent cycles of Determining Care Needs. Satisfaction is dependent on all three processes and an issue with any of the three processes can lead to decreased satisfaction and may result in a patient opting out of the model of care and returning to usual care. This process of Navigating Care is situated within the contextual conditions of the *Workforce shortage of GPs* and patients' *Perceptions about the role of doctors*. Intervening conditions affecting the process are patients' *Perceptions of nurses* and patients' *Attitude towards own condition/s*.

When Determining Care Needs, patients need to decide what their care needs are in order to determine whether PN-led care is appropriate for them. They do this by *Self-Monitoring* their condition/s subjectively and, sometimes, objectively as well as *Relying on Health Professionals* for monitoring. The type and extent of monitoring undertaken is influenced by a patient's attitude towards their health, their understanding of their condition/s and the impact their condition/s has on everyday living.

Once patients have decided that their care needs are appropriate to PN-led care they begin to form a relationship with the PN. The two stages of Forming a Relationship are *Building Rapport* and *Working Together*. *Time*, both in amount and quality, *Communication* and *Continuity* are all important properties of Building Rapport. Once rapport has been established between the patient and the PN they can then go on to Working Together which includes the elements *Receiving Advice, Receiving Encouragement* and *Being Accountable*. Here again, Communication and Continuity are important properties that influence the working relationship between the patient and PN. As patients develop a relationship with the PN and experience Working Together they are more aware of the type of care

offered by the PN and this provides a feedback loop to further determination of their care needs.

Trusting the Model, Trusting Nurses, Trusting their doctor and *Evaluating the PN* are all elements of Having Confidence, the third process in Navigating Care. The extent to which each of these elements influence the level of confidence depends on the individual patient. The processes of Having Confidence and Forming a Relationship are dependent on each other, because a good relationship with the PN will engender trust and thus confidence and, in turn, developing confidence enhances the relationship between the PN and the patient. The level of confidence patients have in the PN also feeds back to Determining Care Needs as they decide whether the care provided by the PN can fulfil their care needs.

These three processes, Determining Care Needs, Forming a Relationship and Having Confidence are the stages patients go through when determining their level of satisfaction with PN-led chronic disease management. The processes are cyclical and interrelated and together form the overall process of satisfaction which has been called Navigating Care.

Contextual and intervening conditions

In grounded theory contextual and intervening conditions have an influence on the basic social process that emerges from the data. The conditions that have an impact on the process of patient satisfaction with PN-led care, Navigating Care, will be explained and described in the following sections.

Contextual Conditions

 Contextual conditions arise from the overall situation within which a psycho-social process occurs. They have an impact on the overall process that emerges from the data. The context in which the Practice Nurse Project was conducted was one of a shortage of GPs and an increasing prevalence of chronic disease in the community, leading to GPs being under pressure of time to adequately care for their patients. This situation gave rise to the contextual conditions where participants perceived that there was a workforce shortage of GPs and contributed to their perceptions about the role of doctors. How these conditions impact on the overall process of Navigating Care will now be explained.

Workforce shortage of GPs

The workforce shortage of GPs in Australia is both a macro-level and micro-level contextual condition of Navigating Care. Participants were aware of the national shortage of GPs from the media, but also experienced the effects of this shortage at a personal, micro level through long waiting times to get an appointment with a GP and also experiencing long waits in the waiting room. Not only did participants feel that they could relieve the pressure on the doctor by consenting to PN-led care, but also that there was less waiting time for consultations with the PNs both for appointments and in the waiting room.

Perceptions about the role of doctors

Participants' perceptions about the role of doctors also influenced how they decided which sort of care best matched their needs. Participants perceived the doctor to be the 'expert', 'the boss' and the one who should make the decisions regarding changes in management of their condition. They felt

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that doctors should be free to deal with acute, severe or urgent medical problems, rather than on-going monitoring and management of stable conditions. Doctors' time was considered to be more important than the PNs' time and that doctors' time should not to be taken up with what participants considered to be unimportant matters. This was especially so as they perceived that a shortage of GPs placed doctors under increased pressure of time. Participants' awareness of how busy doctors are and the time constraints they work under resulted in them being reluctant to impose on the doctor's time by asking questions or sharing concerns that they felt were trivial. They felt it would be more appropriate to discuss such matters with a PN. These 'trivial matters' included such things as family responsibilities leading to increased stress, emotional upheavals and weight concerns, which could all have a significant impact on their health. Many participants with hypertension felt that it was a minor condition that did not merit the attention of a busy doctor as long as it remained under control. The following comments, made by Wendy, Jill and Beth respectively, illustrate the contextual conditions:

> *Well it saves doctor and it's easier on me because with the times, [Sally] says a time and you're in on that time whereas with [Doctor] we could be sat there for 30 mins, 40 mins waiting for him, to get in to see him.*

> Wendy

> *I know what it's like, doctors are getting fewer and fewer and their demand is getting more and more so just from that I realise how valuable their time is, how precious. So probably yes. I'd feel more inclined to discuss little minor details with the PN because I'd think that they're not important enough to be bothering the doctor with because their time is so precious.*

I just don't mind them doing it because I think it's freeing the doctor to see a more urgent or sicker person. Where this is, yeah, it's important but it's only something minor to have it checked where somebody could be really ill and feel that the doctor needs to see them more.

Beth

Intervening conditions

Intervening conditions are those features within the study population that have an influence on the overall process. In this study the intervening conditions that influenced the processes of Navigating Care were participants' perceptions about the role of nurses and their attitude towards their own condition/s. These intervening conditions and how they affected the processes involved in Navigating Care will now be described.

Perceptions about the role of nurses

Participants' perceptions about the role of nurses and what they were qualified to do varied considerably. At one end of the continuum some participants still held the view that nurses were doctors' assistants, working for them to save them time and without the training, experience or authority for autonomous practice. At the other end of the continuum there were those participants who saw nurses as highly trained professionals and considered that nurses had expanded their role and expertise in recent years and proved themselves to be capable of taking on more responsibility.

Audrey's and Fred's comments illustrate the two ends of the spectrum:

I mean they're lovely the nurses and she give (sic) you a needle they're really good. But I don't think they've got the experience to say to you um "oh look go home and do this or do that". I don't think so. I think doctor must do that, you know, because it's too much responsibility on their part and it's not fair on my side you know.

Audrey

We are also recognising the tremendous experience and knowledge of the nursing profession, which like all others has moved on.

Fred

These different perceptions of the role of nurses affected all three of the major processes involved in Navigating Care. A patient's view of nurses as doctors' assistants or competent health professionals affected whether, and to what extent, they regarded a PN as an appropriate person to manage their chronic condition. It also influenced the type of relationship they formed with the PN, in particular Working Together with the PN, as it affected whether or not they were willing to accept advice from a nurse. Having Confidence in the PN is also affected by Perceptions of the Role of Nurses as it impinges on their level of trust in nurses.

Attitude towards own condition/s

Participants also had different attitudes towards how their condition/s should be managed and how involved they should be in that management. These attitudes were shaped by their understanding of their condition/s and whether they considered that they needed active management, just

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monitoring, or that there was nothing much to be done. The degree of responsibility participants felt for their own health varied. Some participants were very proactive and wanted to be involved with their own management whereas others did not worry about their condition at all or were fatalistic, accepting limitations caused by heart disease as a normal part of ageing and inevitable. While it might be expected that some older people might feel this way, not all of the older participants did. Some participants were very proactive, even though they were over 80 years of age.   In the middle of this continuum were those who were concerned about their condition and wanted it to be monitored regularly, but relied totally on the doctor and nurse to do this and to manage their condition. Elizabeth wanted to have her blood pressure checked regularly:

> *No, as long as they check my blood pressure, that's all I worry about.*

However, Dorothy was very fatalistic about her health:

> *That's what I say, I take one step at a time now because* [at] *82* [years]*, you don't know how long you're going to last. And I just live for each day. I don't let anything worry me. I can't see any sense in it.*

Alice and Sarah, respectively, were both more proactive in their approach to their condition though Alice was in her eighties and Sarah was 30 years younger:

> *How do I manage it? I exercise as much as I can with the leg magic and swing and so forth and I'm going to gym now which is psychologically it's good for me I think.*

Alice

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Well really it's up to me to manage my own blood pressure. Because I'm the person who's got it so it's up to me.

Sarah

Those participants who considered that their condition only needed routine monitoring considered PN-led care adequate for them and often appreciated the more regular monitoring provided by the PN, which increased their level of confidence. How much responsibility participants took in managing their health affected the extent to which they formed a working relationship with the PN. At times the interaction of these intervening conditions increased or decreased the effect they had on the processes of Navigating Care. For instance, someone may perceive nurses to be knowledgeable and able to give advice, but not want to work together with the PN because they are fatalistic about their health and do not see a need to self-manage.

Both contextual and intervening conditions affected the process of Navigating Care. Contextually the workforce shortage of GPs and patients' perceptions about the role of doctors contributed to participants considering that a PN was an appropriate person to manage their chronic condition/s. The intervening conditions of Perceptions about the role Nurses and Attitude Towards their Own Health influenced the three processes involved in Navigating Care. At times the intervening conditions combined to have a stronger influence on one or all of the processes. Alternatively, one intervening condition could cancel out or mitigate the effect of the other condition on part of the process.

Navigating Care: An explanation

The three processes that comprise Navigating Care - Determining Care Needs, Forming a Relationship and Having Confidence will now be described. Diagrams will be provided to assist in illustrating the process and showing the relationships between the categories and properties of each process.

Determining Care Needs

The first process in Navigating Care is Determining Care Needs. This process will now be explained and how patients arrive at their decision regarding what their care needs are will be described. Figure 2 gives a diagrammatical representation of the process Determining Care Needs.
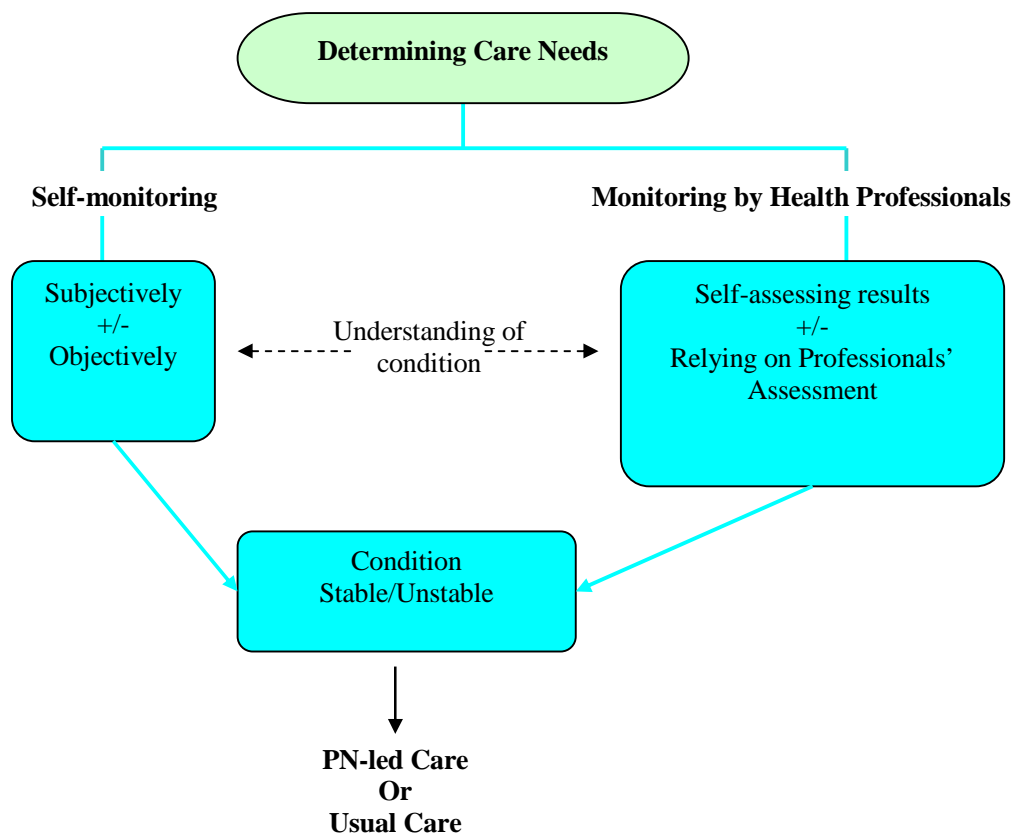
Figure 2 Determining Care Needs

Participants needed to determine what sort of care they considered necessary so that they could decide if PN-led care was the most appropriate for them at any particular time. At first they did this by assessing their condition and making a decision based on this assessment. Once they had experienced the sort of care that the PN could provide and started Forming a Relationship with and Having Confidence in the PN there was a feedback loop from these processes which informed further cycles of Determining Care Needs.

The way participants thought about the three conditions included in the study, diabetes type 2, HD and hypertension, was primarily in terms of stability and control. For stable conditions they considered their care needs to be on-going monitoring. If participants thought their condition was unstable or uncontrolled they considered that they would need monitoring and medical intervention. Therefore, if they perceived their condition to be stable or under control and that they only required monitoring, participants identified that the PN was an appropriate person to manage their condition. A higher level of medical expertise was thought to be necessary to manage conditions that were unstable or uncontrolled. In this case a doctor was the preferred practitioner to manage their chronic disease. Adam's comment was typical of this thinking:

> *If it's an ongoing thing and it's stable at the time I'm going "there's no real need to see the doctor". Um if it was bouncing up and down and I was getting sick from it or whatever I'd say "yeah go"* [to the doctor].

As participants experienced PN-led care they became more aware that the PN offered more than just routine monitoring, in particular lifestyle advice and support. This informed their decision about whether PN-led care was best suited to their needs as this type of care offered by PNs was not always available from the doctors. As Wendy pointed out:

> *Also, she talks about you, what you're eating with your weight problem, she talks about that. Whereas before* [the] *doctor would say I've got to lose weight. With the nurse she talks about how to lose it and what to give up, and things like that.*

As participants developed a relationship with and confidence in the PN they trusted her to refer them back to the doctor if necessary, although they

still held firmly to their right to make that decision for themselves if they wanted to, as Tom said:

> *Well I think it should be up to me. If I feel that I need to see him I'll say so. And I don't think there would be any problem. With the experience that we've had there so far, if there's anything at all, she'll soon refer us into the doctor.*

To summarise, in order to make decisions about their care needs patients self-assessed their condition. This involved both *Self-Monitoring* their condition and *Monitoring by Health Professionals*. The type and frequency of monitoring was influenced not only by the patients' attitude to their condition/s but also their understanding of their condition and the extent to which they perceived it to intrude into their everyday life. Once participants had assessed their condition as stable or unstable they decided what sort of care they felt was needed and whether the PN was the appropriate person to provide it.

Self-monitoring

Participants used both objective and subjective means of Self-Monitoring. Objective measurements of blood pressure were taken with automatic sphygmomanometers at home and blood glucose levels were measured with home glucometers. The extent to which participants used these means of monitoring of their condition appeared to be influenced by their attitude towards and understanding of their condition, and also the impact it had on their every day living. Those who were proactive about their health were more likely to undertake objective monitoring of their condition. For example, those with diabetes tended to monitor their condition more often and more closely than those who were hypertensive, as diabetes affects many aspects of every day living. Having to adjust their diet to help

glycaemic control and particularly if they already had complications attributed to diabetes meant that their condition was obvious to them. Hypertension, on the other hand is largely silent and less intrusive in the lives of patients and, although most participants were aware of potential complications from uncontrolled hypertension such as strokes, it mostly had no effect on their day-to-day lives.

> *Blood pressure I don't really think about. I'm on medication. I think it's pretty stable. The diabetes I'm getting a little concerned [about] because I'm having more and more feet trouble. I don't know what's down the track for me there.*
>
> Tom

Some participants were very proactive in their approach to their condition and would take blood pressure recordings frequently even though they were asymptomatic, because they were aware of possible complications from hypertension. Adam was one such participant:

> *Well my mother's in a home with vascular dementia. She can't remember, oh honestly 5 – 10 seconds. And they've attributed some of that to dementia and, as I mentioned, vascular dementia as a result of long term high blood pressure....*
>
> *And if I do it [take my blood pressure] 4 or 5 times in a row at different times, like getting up in the morning, after going for a walk down the beach or getting home from work and it's all within scope, it's been under 130/70 or whatever it is 70 or 75 or whatever, that's fine.*

In addition to or instead of these objective measures, participants subjectively monitored their condition by how well they felt, not just physically but also emotionally. They assumed that if they felt well, then

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all was well with their chronic condition. This was sometimes the main way in which participants assessed how stable their condition was, and is demonstrated by the following quotes from three different participants.

> *I'm one of these people that I just go from one day to the other. And if I'm feeling OK well that's OK. And if I'm not feeling all right well I know there's something wrong.*

Dorothy

> *Yeah, I tend to get symptomatic. I get tired very easily if my blood pressure is too high.*

Elaine

> *Well I think you know* [how your blood sugar is] *by your mood swings with diabetes.*

Alice

Participants used Self-monitoring to assess how controlled their condition was. They did this both subjectively, by how well they felt, and objectively, by measuring blood pressure and blood glucose levels at home. Their understanding of their condition and their Attitude towards their Own Health influenced how much they relied on subjective Self-Monitoring and the extent to which they objectively self-monitored.

Monitoring by health professionals

Participants also relied on health professionals to monitor their health, in particular when they had conditions that required regular blood tests. Health professionals interpreted blood tests for participants, and participants used test results as an additional way in which to judge the

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stability of their condition. Many also relied on the doctor or nurse for
blood pressure measurements. Many participants were very concerned that
their blood pressure was measured regularly and wanted to know the
reading in order to assess if their blood pressure was well controlled or not.

> *I have the yearly urine checks which I have regularly and my*
> *blood checks every three months. And I think if they're right*
> *you're pretty well.*

> Alice

> *Well I want to know. When I go there I want to know how my*
> *weight is, my blood pressure, what the blood tests are all*
> *about, and all things like that.*

> Charles

Not all participants needed to know the results of their monitoring. Some
were content to be told that their condition was satisfactory and relied on
the doctor or nurse to tell them that there was a problem. They assumed
that everything was all right if nothing was said to the contrary.

> *Well they know what's dangerous on blood pressure and I*
> *don't even know. I don't know. They just say it's higher than*
> *last time or I say "is that all right?"*

> Karen

Having assessed their condition, if participants determined that their care
needs could be met by the PN, they continued on to the next part of the
process: that of Forming a Relationship with and Having Confidence in the
PN.

Forming a relationship

The process of Forming a Relationship will now be described. Although it is dealt with first, it has to be remembered that this process happens concurrently with Having Confidence in the PN and is interdependent on that process. Diagrams are provided to help illustrate Forming a Relationship and how the properties of Time, Communication and Continuity relate to the sub-processes of Building Rapport and Working Together.
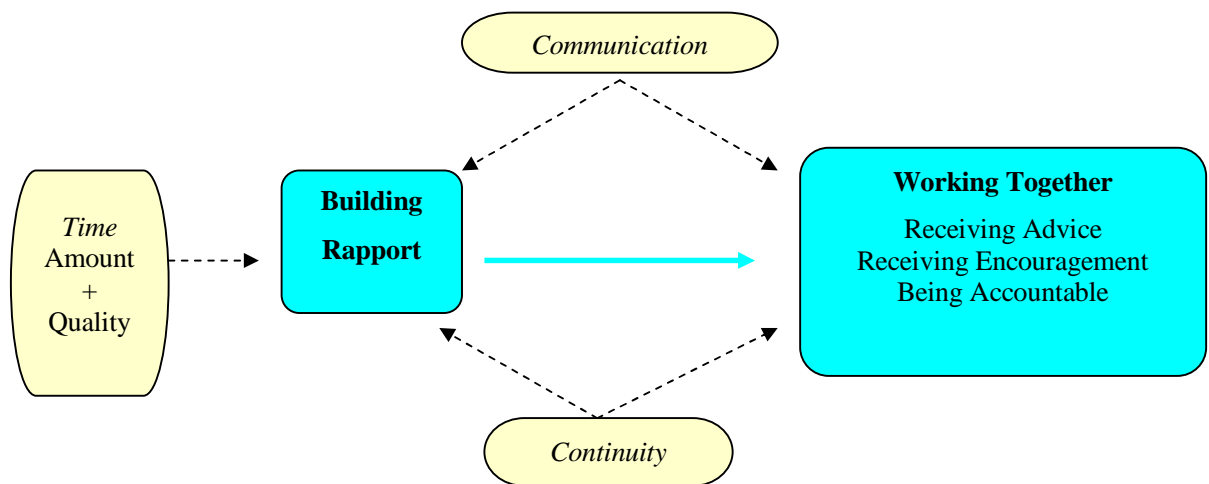
Figure 3 Forming a Relationship

There are two stages of Forming a Relationship, *Building Rapport* and *Working Together* and it is an on-going process. Once rapport is established between the PN and the patient, it facilitates them working together to manage the patient's chronic condition. Time, both in amount and quality, is an important property of Building Rapport. Communication

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and Continuity are properties of both Building Rapport and Working Together. Working Together encompasses Receiving Advice, Receiving Encouragement and Being Accountable. Although the different properties of Forming a Relationship are discussed here separately they are inter-related; for instance, Quality of Time is inter-related to Communication in that the way in which a PN communicates with a patient can enhance or detract from the Quality of Time, and Continuity is inter-related with Being Accountable as patients feel more accountable to a PN if they are seeing the same one at each visit.

Building rapport
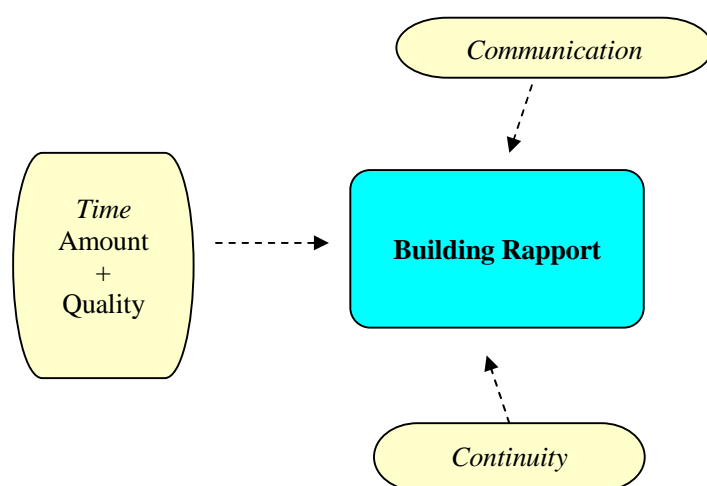
Figure 4 Building Rapport

Building Rapport is the first step in the process of Forming a Relationship with the PN. Time, Communication and Continuity all contribute to how well and how quickly rapport is built between patients and PN. This section will deal with how Time, Communication and Continuity affect the

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establishment of rapport and will be illustrated by what the participants had to say.

The word rapport encompasses the sense of understanding and empathy that develops in the relationship, an affinity between the PN and the patient. When a good rapport existed between a participant and the PN the participant felt comfortable, able to discuss issues that may be concerning them, and ask questions. This was foundational in forming a good relationship with the PN, as Fred expressed it:

> *Because first I can relate to her, that's very important because no matter what the qualifications or experience is if you don't relate to that person you don't get anywhere. So, I can relate to that person and knowing that if I have a problem I can mention that early.*

Good rapport between the PN and patient was established by means of good communication. However, rapport also provided the foundation for continuing communication between the PN and participant, especially with respect to the patient being able to ask questions and raise issues with the PN. Time was an essential element in Building Rapport as is Continuity. These properties will now be discussed.

Time

Time was a concept that emerged as very important in relation to building a satisfactory relationship with the PN. The first dimension of Time is *Amount of Time*. This refers both to the passage of time over several consultations and episodic time, the amount of time spent at each consultation. The second dimension of time is Q*uality of Time* and this

included participants feeling that they were the focus of the PN's attention and that the PN cared about them.

The passage of time was important in building the rapport between the participants and the PN. For some participants this happened quickly with rapport being established almost immediately, even when there had been some apprehension beforehand about seeing the PN. Others were a bit shy or reserved and took a couple of consultations to relax, whereas some felt that only multiple visits would allow them to feel that they had built a relationship with the PN. Jill was one of those that felt comfortable with the PN straight away:

> *But from the first time I met [Sally] we were right. Or I should say I was right.*

Marion, however, took a little longer:

> *Not long, two or three visits. She's very easy to get along with.*

And Janet felt that a relationship with the PN would only grow over multiple visits:

> *The more you see them like anybody else. The more you see them and you talk about a few things and get to know them better, they get to know you better.*

The Amount of Time at each encounter was also important in Building Rapport. Participants reported that not feeling rushed enabled them to relax more and indulge in an informal and sometimes light-hearted exchange that facilitated the establishment of good rapport. Some participants also felt that not being rushed helped their condition by taking away some of the

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stress related to the consultation. Having enough time and not feeling rushed, therefore, produced better clinical readings, particularly for blood pressure, but also blood glucose. There was a very strong awareness amongst participants of how busy the doctors were and of full waiting rooms. They often felt under pressure of time when consulting with the doctor because of this. In addition participants generally perceived that the PN had more available time than the doctors and were not responsible for seriously ill patients. Therefore, participants did not feel that they were imposing by taking up more of her time. Participants who felt they had been rushed through their consultation with the PN left feeling dissatisfied. Sarah explained how she felt under pressure of time when seeing the doctor and that not being rushed helped her to feel more comfortable:

> *I think it's a good idea having the nurses as in they seem to have a little bit more time to spend with you. Whereas the doctor, from the time you walk in, at least I do, I always feel that doctor is a really busy doctor so when you go you feel like you're always rushed. So I mean with the nurse you've got that little bit of extra time, because she's not as busy as the doctor.*

> *Well it makes you more comfortable, you know. Before you even get there you know that you're not going to be rushed through.*

David, however, expressed his dissatisfaction when feeling rushed by the PN:

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> *The last time* [Sally] *was a bit rushed. I felt as if I was just rushed through, because I came back and said to my son that was a waste of time.*

However, there was one participant who felt that the time spent with the PN was too long and that it was unnecessary. Audrey did not appreciate the longer consultation with the PN, even though she was retired and not constrained by time. She felt that the length of time was unnecessary:

> *It's a long thing, different things that they don't need to do. But she's been told that, probably* [the] *the doctor, I want this done and that done. But I think it's* [the PN's consultation] *just a lot of waste of time. Like if you go up there - right fair enough take me blood pressure and whatever little things she does, weight and that, but not go on.*

The second dimension of Time that was significant in Building Rapport between the PN and the participants was Quality of Time. The Quality of Time spent with the PN was high when participants felt that they were important to the PN: the number one priority, and that the PN was interested in them and their concerns. This was facilitated by the PN focusing on the patient without distractions. Participants reported that they would feel unimportant and insignificant if this quality of time was lacking, for instance, by the PN spending much of the consultation attending to the computer instead of them.

Annie expressed it this way:

> *I think it's her behaviour. Yes, it's I've got time for you. You are my patient right now and you're whom I'm concentrating*

on. Yeah and that's great, you don't ever feel she's distracted by anything else.

And Alice:

Well she really listens to you, which is important. Quite often now people look at computers and you feel like saying "hey I'm over here". But no, she's not like that. She gives you good quality time.

David said that he'd felt 'insignificant' because:

Well the last time I was there, maybe I got her on a bad day, but I just felt as if she couldn't have cared less. Get the thing filled out, put it through to doctor on his computer.

The Amount of Time spent with the PN, both in terms of repeated visits and at each consultation, as well as the Quality of Time at those consultations affected Building Rapport between patient and PN. Not feeling rushed and feeling that the PN was interested in them as a person and cared about them enabled participants to relax and share their concerns and questions, which helped to build rapport. When participants felt rushed or not the focus of attention during their consultation with the PN, this had a negative effect on Building of Rapport between them and the PN.

Communication

Communication was another property of Building Rapport. The types of Communication that were important in Building Rapport were *Communication Style, Communicating-Self* and *Communicating-With*. Participants found that when the PN had a friendly and open style of communication it helped them to relax and get to know the PN. They

repeatedly referred to the PNs as *'friendly'* and *'easy to talk to'*. Tom's comment was typical of many:

> *Oh just their attitude, they're, they know what they're doing but I wouldn't say casual, business-like but friendly. And it just makes it a pleasure to be there.   Oh I think so. I think if you can be on a friendly basis and someone's not stand-offish, you're more inclined to open up and talk about things.*

Another important part of Communication Style is the ability to communicate on the same level as the patient, so as they do not feel inferior, which helps to build rapport. Jill was one of the participants who voiced the importance of this:

> *I think if I didn't feel that I could just talk to her as if it was my very best friend or my mother or somebody who didn't think they were just above everybody else you know? I don't know, but do you know what I mean?...She's just on the same level sort of thing.*

If a PN's style of communication was not friendly then this could seriously impede the development of rapport and even lead to patients dropping out of PN-led care and returning to usual care. Comments by Trevor and Rose made this clear:

> *Oh because I'm fairly amiable sort of a fellow and* [if] *anybody went off crook at me, well I might feel, you know, how do you say it nicely? 'Bother you'.*

<div align="right">Trevor</div>

> *If they* [the PNs] *were stroppy and I've never seen one yet, you wouldn't like to go back because you'd get your back up.*

<div align="right">120</div>

In addition to a friendly and open style of communication, Communicating-Self helps reveal the person behind the role of the PN and facilitates rapport. Participants found that PNs who were willing to be self-disclosing and share something of their own lives helped in getting to know them and establish rapport. Sometimes this was personal events such as a wedding in the family or chat about children.

> *She just made me feel really, really comfortable. You know she just talked about her family, my family, things like that that put you at ease.*

Sarah

The third important type of Communication as regards Building Rapport is Communicating-With and this relates closely to the previous property of Quality of Time. Communicating-with is two-way communication that involves the PN listening to and hearing the patient as well as talking. Participants felt that the PN was interested in them when she listened to them. Asking appropriate questions of the patient and listening carefully to the reply also helped the patient feel that the PN cared, knew them and understood their condition, as David and Marion, respectively indicated.

> *No, as I said she just gives the impression that she's interested, that she's listening.*

David

> *Well I just feel as if they're interested in what's going on with me and they do know. Because by the questions they ask me, I know that they know what my condition is and what's happening.*

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Continuity

The importance of Continuity to the process of Building Rapport will now be explained and illustrated with verbatim quotes from the participants.

Continuity contributes to Building Rapport between the PN and the patient by providing the opportunity for patients to get to know the PN, allowing the relationship to develop over time. If this relationship is good then continuing to see the same PN adds to the patient's sense of satisfaction. Seeing different PNs can disrupt the relationship and the patient would have to start again in Forming a Relationship with a new PN. If there is more than one PN in the practice and the patient does not see the same PN each time, the formation of a relationship can be fragmented and a sense of uncertainty introduced. Participants appreciated the sense of certainty that seeing the same PN gave them. They knew what to expect at each consultation and that the PN knew all about them and their medical history.

Participants in this study expressed that they preferred to see the same PN each time especially as they had already started to form a relationship with her and given her all their medical information. Sarah explained why she preferred seeing the same PN each time and how she felt when she saw a different PN on one of her visits:

> *Yes I think so. Because I think you both get to know each other. The more you see them, the better you will get, the more information will be exchanged, I suppose, between two people.*
>
> *As I said, you know the first one I felt, great and she was the type of person... I was a little bit, the second time I went and*

walked in and it wasn't her, I kind of arhh! Do you know what I mean? There's a little bit of a shock because I thought that the first person would be the person I was going to see, continue to see. But it just didn't work out that way.

In summary, Time, Communication and Continuity are all vital properties of Building Rapport between the PN and the patient. Not feeling rushed and having a good Quality of Time with the PN help the patient to relax, feel comfortable with the PN and thus able to share concerns and ask any questions that they may have. Good Communication includes a friendly and open Communication Style as well as Communication-Self, a willingness on the part of PNs to be self- disclosing so that they can relate to the patient on a personal level and not just a professional level. Communicating-With, listening to the patient and hearing their situation and concerns is also important. Continuity enables the process of Building Rapport to continue uninterrupted and gives patients a sense of certainty about their encounters with the PN. As rapport is established, patients move toward working together with the PN.

Working Together

The second stage in the process of Forming a Relationship is Working Together which is comprised of Receiving Advice, Receiving Encouragement and Being Accountable (Figure 5). This section will explain how Communication and Continuity contribute to Receiving Advice, Receiving Encouragement and Being Accountable and, in doing so, contribute to a satisfactory working relationship. This will be demonstrated with verbatim quotes from the participants.
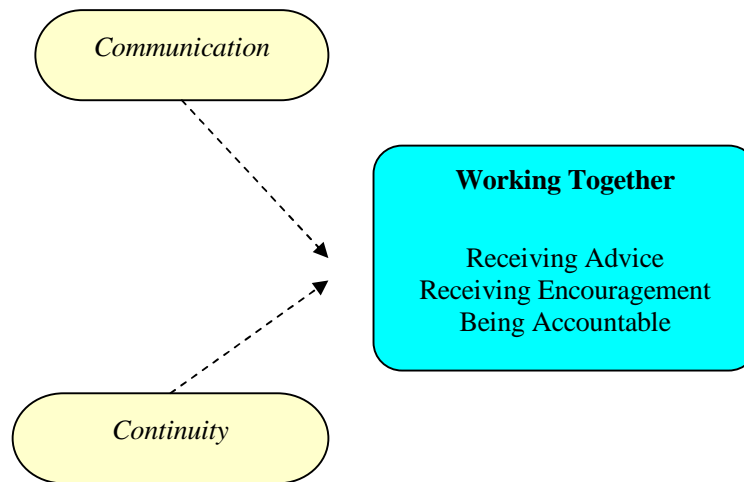
Figure 5 Working Together

Once rapport has been established between the PN and the patient they are
able to move forward to Working Together. This part of the relationship
includes Receiving Advice, Receiving Encouragement and Being
Accountable.   Communication and Continuity are important influences on
this stage of Forming a Relationship. The extent to which participants
wished to work together with the PN depended on the attitude of
individuals toward their condition. Some wanted to negotiate goals with
the PN and be involved in how to achieve them, whereas at the other end of
the continuum, there were those that were content to 'do as they were told'
because they viewed the PN as the person trained to know what is best to
do. Finally there were also patients who just wanted the PN to check on
their condition. Different ways of communicating suited different patients
and contributed to the individual working relationships.

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Marion and Elaine were both participants who wanted to be involved in setting their goals and planning how to achieve them:

> *Yes, well the first goal we made was for me to get my waist measurement down, which I'm really trying* [to do].

<div align="right">Marion</div>

> *Yeah we're definitely working together and that is one thing that I feel good about. I don't feel as though I'm being pushed in any one direction or the other. I'm still given choices and I think that's so important.*

<div align="right">Elaine</div>

However, at the other end of the continuum there are those who were content to let the PN set the goals, for example Des:

> *Well if* [Sally] *gives you the information then the advice well she can't make you take it can she. But she does the best she can. If I'm stupid enough not to take her advice well that's my problem. But I'm not that stupid. If she tells me that something's not quite right, I should be doing this and doing that well I just go ahead and do it...You see* [Sally] *has been trained for her job. I haven't. So I can't see the sense in me trying to argue about something that I know nothing about.*

The third group, who wanted the PN to just keep a check on their condition, was represented by Beverley who said:

<div align="right">125</div>

*No. I haven't had anything to really talk to her about really,
you know. It's only more or less questions that she asks me…*

*And she asks straight forward questions and examines me
blood pressure and so it's over and done with [quickly].*

Receiving advice

Receiving advice is the first part of Working Together with the PN. Most

participants valued receiving advice from the PN especially as they

considered that advice to usually be more detailed, specific and tailored to

their own individual situation than the information given to them by their

GP. However the way in which advice is communicated is important in

terms of satisfaction and in developing a working relationship with the PN.

Participants did not appreciate advice given in a dictatorial or critical way.

They wanted to be respected as autonomous individuals and be given

advice that was personalised to their particular situation. Explanations

about why advice was given were also helpful to participants, so that they

understood the need for whatever action they were being advised to take.

The importance of a friendly communication style was emphasised by the

participants in this study. They frequently referred to the importance of a

friendly approach when working with the PN. Marion made the comment:

*Well I just think, you know, you can't work with somebody's
who's bossy and domineering.*

Wendy explained how a dictatorial style could actually deter her from following advice, and that she appreciated a gentler approach:

> *That's important because I think the more people nag at me the worse I get. I dig my heels in. …….But [Sally's] a lot easier to talk to with that and she doesn't push you.*

This way of communicating advice reassured participants that they were respected as individuals and allowed them to make up their own minds about the management of their condition. The following remark made by Elaine illustrates this point:

> *I feel comfortable with the advice. It's not something she forces on me, but she suggests things… And so she's not treating me like an idiot. She respects my knowledge at the same time and respects my decision-making abilities.*

Communication was also important for providing explanations that participants could understand. Having advice explained to them was another way in which participants felt respected and involved in their management. As Annie said:

> *Well it's your life. It's your body. You have a right to know why someone says you're overweight. You know, what have they based that on? You know, where has that comment come from? What information and what study and what research, you know?...She takes the time to make sure you understand.*

Finally, as far as Receiving Advice is concerned, participants liked advice that was personalised to their situation. Jill commented:

> *Well I think it's good because you can't treat them all [the same], everybody's an individual and everybody has different likes and dislikes.*

And Annie stated:

> *She understands that we've got small kids and my husband's a shift worker, so we don't really have a normal Monday to Friday lifestyle like a lot of people have. And so she can personalise it [her advice] for me.*

Receiving encouragement

Part of Working Together with the PN is the encouragement that patients receive from the PN to achieve or continue working toward their goals. This is very important to their on-going relationship with the PN, as patients feel that they are not alone but have someone to help them in managing their condition. Communication-style was important in encouraging participants, and they responded well to the gentle style of encouragement provided by the PNs. Elaine was one participant who responded well to this style of encouragement:

> *She's not pushing you all the time to just keep those figures down just with the insulin you know. She'll encourage you with exercise and make suggestions with what you can do with exercise….You know, yeah, she's, she helps you with alternatives that you're not seeing for whatever reason at that time.*

Des explained the importance of the PN providing encouragement:

> *Well if she keeps knocking you, you're not going to go back are you? Like, if she gives encouragement well you'll do what she wants and then you'll look forward to the next time.*

Continuity also affects Receiving Encouragement. Seeing the same PN each time meant that they knew what had been talked about in previous consultations, the advice that had been given and that they understood the

goals that has been set. Participants did not want to have to keep explaining their situation to different people. If participants had been having difficulties with following advice, seeing the same nurse each time meant that the PN was more likely to know and understand this. Jill was one of the participants in this study who expressed this point of view:

> *Follow through. They know. They know your story and I think it's continuity, sort of thing…But no I just think, I think it's just continuity because they know exactly what you've said.*

Receiving Encouragement is also closely tied to Being Accountable as PNs encourage patients in their efforts to achieve their goals.

Being Accountable

Being Accountable is also important to Working Together with the PN. Participants explained that seeing the PN regularly made them feel accountable to her and, therefore, they were more likely to try and follow her advice and achieve goals. This accountability helped to motivate them to take responsibility for their health and lifestyle factors that affected their condition. Participants seeing a PN also felt that they were not alone, but had someone working with them to help them achieve their goals. Communication was important in making Being Accountable acceptable, as different participants responded to different communication styles. While some participants felt they were motivated by a firm approach to accountability, most thought that a censorious approach would make them withdraw from a working relationship with the PN. Participants preferred a more encouraging style that did not make them feel guilty but helped them to keep working towards their goal and recognised any difficulties or setbacks they faced. Continuity also had an effect on Being Accountable,

as participants were more likely to feel accountable to the person that they have been working with and with whom they had already developed a relationship.

Those participants who wanted to follow the PN's advice found that going back regularly to see her helped to keep them focused and to keep trying to achieve their goals instead of giving up. Beth was one participant who expressed it this way:

> *It's practical advice and things to do… I probably wouldn't do just off my own back, where if you have somebody else keeping an eye on you it's umm and you have to report back to them, it makes a bit of a difference,*

Karen also found that a sense of accountability made a difference:

> *I find the backup like of the nurses and this dietician lass and the physio we were seeing that gives you that incentive to do that extra, because you're going to see her again and you're going to have to answer for what you're doing. So I rather like that. Because otherwise you can just slacko right off and forget the whole lot.*

Some participants felt that they benefited from a firm approach by the PN to Being Accountable. They mentioned the PN 'going crook' or 'rousing' on them, but were not put off by this. In fact, they found it helpful in keeping them accountable. Adam expressed it this way:

> *Go up and see the PN. And the last one I went and saw was pretty good, because she gave me a little bit of a, a bit of curry. She said 'you said you'd do this last time and you didn't do it and you've actually put weight on instead of taking it off' you know. So I found that was probably more, in my case, more of an advantage to me.*

However, not everyone wanted this approach and remarked that they appreciated the gentler way in which the PN would deal with lack of progress towards individual goals. Elaine said:

> *I don't feel as though I'm going to get revved and that if I do have a bad month or something like that so you know.*

And Sarah remarked,

> *It's just I was aware of it so as soon as I walked in I said I know I've put on weight. Yes she didn't make a big deal out of it....I mean because, if you're managing someone, the way I see it if they have put on weight, then give them the advice they need, which is OK. Don't be critical.*

Being Accountable was also affected by Continuity. Participants felt that it would be beneficial to see the same PN with whom they had set goals. This helped in following their progress. Adam put it this way:

> *If I was having some issues and we'd agreed to do something, I'd like to see the same nurse again to see what her opinion was on if I was actually improving or not improving as such.*

Continuity also mattered to participants because, having formed a relationship with one PN, they felt a personal commitment to her not to let her down when it came to working towards goals they had set together. This is what Jill had to say:

> *I always felt I didn't want to sort of go to* [Sally] *and get on those scales and find out that I'd gone up. It would have been embarrassing for me and I felt I didn't want to disappoint* [Sally].

This section has explained the sub-process of Working Together with the PN and described the second stage of the process of Forming a Relationship with the PN. It has also demonstrated how Communication and Continuity have an effect on Working Together by impacting on Receiving Advice, Receiving Encouragement and Being Accountable. The final major process in Navigating Care is Having Confidence. This will now be explained.

Having confidence

This section will deal with the process of Having Confidence. As can be seen from the diagram (Figure 6) *Trusting the Model of Care, Trusting the Role of Nurse, Trusting their Doctor and Evaluating the PN* are all related to this process. These four areas will be explained, as well as how they contribute to a patient's overall level of confidence in the PN.

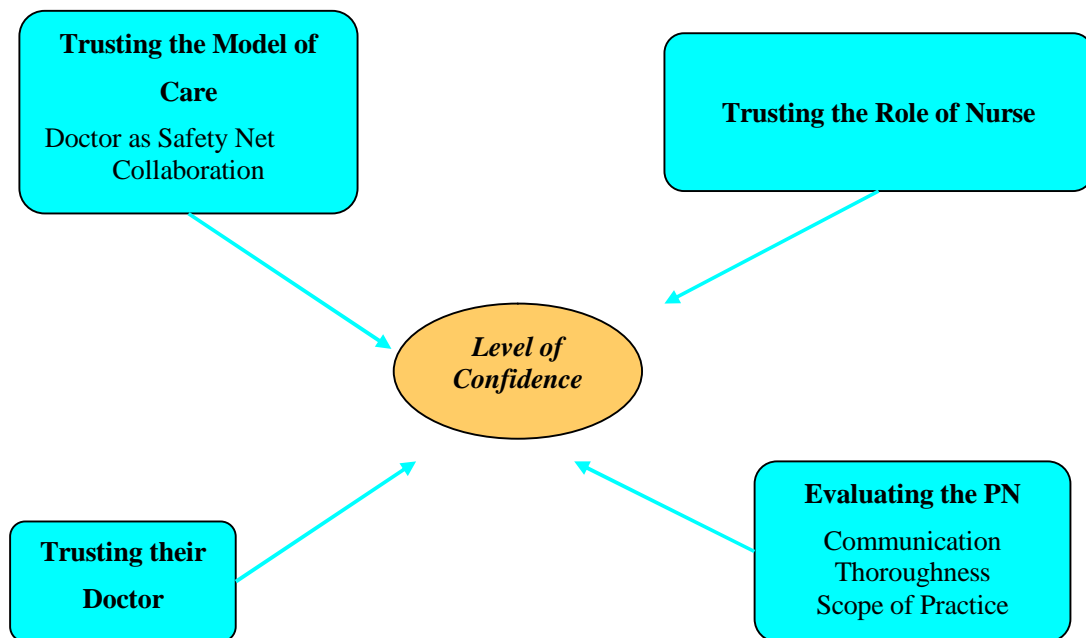**Trusting the Model of Care**
Doctor as Safety Net
Collaboration

Trusting the Role of Nurse

Level of Confidence

Trusting their Doctor

Evaluating the PN
Communication
Thoroughness
Scope of Practice

Figure 6 Having Confidence

Having confidence is the third major process in Navigating Care. As with the other two processes, Determining Care Needs and Forming a Relationship, it is an on-going process. It has an effect on the process of Forming a Relationship and also feeds back into the re-determination of care needs by patients once they have experienced PN-led care. The confidence that patients have in the PN-led model is situated in four areas, Trusting the Model of Care, Trusting the Role of Nurse, Trusting Their Doctor and Evaluating the PN. The extent to which each of these influence the overall level of confidence will vary from individual to individual.

Trusting the Model of Care

Doctor as Safety Net and *Collaboration* both contribute to Trusting the Model of Care. Patients found it reassuring to have the doctor as a back up and working in collaboration with the PN. They held firmly to their right to consult with the GP although, as their confidence in the PN grew, they were more willing to trust the PN to refer back to the GP if she considered it necessary. The trust patients had in the model of care was strongly underpinned by the knowledge that they could return to their doctor at any time and would be referred back to the doctor if their condition gave any cause for concern. Some patients were content to allow the nurse to make this decision, but most held strongly to their right to choose for themself who they should be seeing and would initiate a consultation with the doctor if they thought it was necessary.

Patients also gained confidence from the knowledge that the PN is working in collaboration with the GP and that the doctor would be kept informed about their condition and know what was happening with them. There was an expectation that the nurse would confer regularly with the GP. As well

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as keeping the doctor informed about what was happening with patients' conditions, patients felt this collaboration was useful when nurses needed to find out information they did not have or had questions they could not answer. Patients did not expect PNs to know all the answers to their questions and were happy for them find out the answers for them and let them know later.

As participants talked about their experience of PN-led care they made it very clear that they were reassured by the fact that the doctor was always available if they needed or wanted to see him. As Tom stated:

> *I'm quite happy with it. And I know that if I've got a problem I can always see doctor.*

Rachel also said:

> *Oh yes I mean, as I said, perhaps the nicest part of it was that if at anytime you were perhaps a little unhappy or any reason to be, you could always speak to doctor.*

Participants were generally confident that the PN would refer back to the doctor if there was a problem, as Beverly expressed:

> *Yes, just talk it out with her and naturally she'd refer to me, you know, refer doctor to me if necessary. I'm sure about that.*

However, most participants also reserved the right to make their own appointment with him/her if they wanted to as Janet stated:

> *If I want to see the doctor I make an appointment to go and see the doctor and go and see him.*

As the intervention progressed there was a sense that participants were more inclined to leave it to the PN to decide if a consultation with the doctor was necessary. Charles indicated this:

> *I'd go to her first. Just like [a] chain of command in the army. You don't go to the top; you go down and then go up. Instead of worrying the doctor straight away you go and see [Sally] and if she can't do nothing (sic) about it. Well she'll have a talk to me. And then she'll go and see, or she'll ring doctor and doctor will come out.*

Participants also talked about the importance to them of knowing that the PN was working in collaboration with the GP and that their doctor would be kept up-to-date with their condition.

> *Well this is the only reason why I wanted to do this program, if they kept in touch with my doctor and they promised me they would and they have.*

> Marion

> *Well if it's just a general check up it's fine. And I can alert her to anything that's wrong and she will pass it on to doctor instead of him having to sit there and listen to me talking for half an hour when he could be seeing someone else.*

> Les

Collaboration was also a means of the doctor giving the PN advice about how to manage a patient's condition and access to information that she might not have.

> *Well I just feel as if they're interested in what's going on with me and they do know, because by the questions they ask me I know that they know what my condition is and what's happening. I think they talk a lot to* [the doctor].

<div align="right">Marion</div>

> *If she doesn't know something that I want well she'll ask doctor … Yes, well there's never anything that she doesn't know that I've asked. But if there was she'd just go and see* [the] *doctor.*

<div align="right">Charles</div>

Trusting the Role of the Nurse

Trusting the Role of the Nurse is also part of the process of Having Confidence and is greatly influenced by the view of nurses that patients hold. Patients tended to have an implicit trust in nurses in general. They assumed that a person holding the position of PN must be capable of doing the job required of them because of their training and qualifications. Some people have come into contact with nurses in hospitals and having experienced what nurses can do they are confident that nurses in general practice can also care for them. Participants assumed that the PN had been assessed and deemed them capable of the job of managing their chronic disease. There was also a confidence in the qualifications of nurses, that nurses in general are well trained. Therefore, there was a perception that PNs have good training and experience to rely on when undertaking the management of the patients' chronic diseases. An awareness that the role

and training of nurses have advanced over the years gave patients confidence that nurses are capable of taking on more responsibility.

When asked about confidence in the PN, participants revealed their trust in nurses in general and in their training and qualifications. Karen and Mike put it this way:

> *I presume they've all got the same training, they all know what they're doing and they know what they've got to do for me.*

<div align="right">Karen</div>

> *Well she's had the training and I think if you can't trust someone who's trained in a profession, then she shouldn't be there doing her job.*

<div align="right">Mike</div>

Adam recognised that nurses are now highly trained professionals:

> *I used to think that they were [a] doctor's PA, an assistant to the doctor, a personal assistant, a helper type thing. But now we have a few friends who are nurses and I've realised that it's quite a high qualification and I respect the amount of study that they have to do to become a nurse.*

Some participants referred to previous experience with hospital nurses on which they based this opinion as was the case with Sarah:

> *If you ever think of going to hospital it's always the nurses, they're doing your blood pressure, they're doing everything um and you see the doctor the next morning or something. So to me I mean in a nurse situation, especially this situation um she wouldn't be doing the job unless someone thought that nurses are, had the ability to handle these situations.*

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There were those, however, who viewed the role of nurses differently and did not have as much confidence in a nurse's role. They saw nurses as an assistant to the doctor with little autonomy. Participants who viewed nurses in this way felt that they did not have the training to allow them to make assessments and decisions regarding the management of chronic disease. Janet took this view:

> *Because she's not qualified to tell you more than the doctor, sort of thing, or as much as the doctor... I don't think they're qualified to assess.*

Trusting their doctor

A patient's relationship with their individual doctor is very important in the process of Having Confidence. When patients have an established and trusting relationship with their doctors, they have confidence in the nurses that are employed by the doctors. There is an assumption that their care will only be entrusted to nurses that are capable of undertaking the role. Annie's comment is typical of this attitude:

> *Well I have a lot of respect for the doctors down there. And I think if they've given her the responsibility they trust her and so I should.*

Evaluating the PN

Evaluating the PN is the final way in which Having Confidence is developed, and this is an on-going process. Communication, *Thoroughness* and *Scope of Practice* are influential in how patients evaluate the PN's competency as they experience PN-led care. Patients' assessment of the competence of the nurse to manage their chronic condition tended to be subjective and Communication was very important in inspiring confidence

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in the PN's competency. PNs communicated their competence when they interacted with the participants confidently, inspiring confidence. Giving clear and understandable explanations and considered answers to questions (or finding out the answers) also helped participants evaluate the competency of the PN. Participants appreciated it when the PN explained why she was doing things. Being able to explain about their condition, why the advice is important and how to manage their condition indicated to patients that the PN knew what she was talking about. Participants' evaluation was also influenced by their perception of the Thoroughness of the PN. Patients found it very reassuring to have comprehensive checks done at every visit, particularly as these were not necessarily always done at every visit with the doctor. They felt that their condition was being meticulously monitored, which increased their level of confidence.

Finally participants evaluated whether PNs worked within their scope of practice. They felt more confident when they knew that PNs would refer them back to the doctor if something required an intervention outside of her scope of practice.

When asked what gave them confidence in the PN's ability, participants repeatedly talked about how easy the PN was to talk to and that she seemed to know what she was talking about. The following two quotes from Marion illustrate this,

> *Well she's confident. When she's speaking she knows what she is talking about……But there's no hesitation with what they're saying or doing so it gives you a fair indication they know what they're doing.*

They explain things and you don't have to ask and that's what I like… it just gives you confidence that they know what they're doing.

And Albert and Alice said,

Oh she was very good. She explained everything, what was going on and everything. No she was very good.

<div align="right">Albert</div>

And she's not quick to give an answer without thinking.

<div align="right">Alice</div>

Participants also repeatedly commented on how thorough the PNs were in monitoring their conditions and recording the readings, even if this was only blood pressure readings at every visit for those with hypertension alone. Elizabeth felt this way,

I mean she, some nurses you have to ask to take your blood pressure but [Sally] takes it.

As did Des,

She does more checking up than the doctor does. Like you go to the doctor and say I feel this and feel that. That's all he worries about. Whereas you go to [Sally] *and she does it all. Takes your blood pressure and your ears and everything, your height, your weight.*

In evaluating whether the PN worked within her scope of practice, Jill and Des said,

> *I just feel that if there was anything that she thought was out of her area she would not hesitate to say.*

<div align="right">Jill</div>

> *Yeah, see if [Sally] finds something that's not quite right she'll get in touch with the doctor. She doesn't say 'oh well your blood pressure's too high, that's all right'. If there's something not quite satisfactory she gives the doctor a ring to come and see me.*

<div align="right">Des</div>

Trusting the Model of Care, Trusting the Role of Nurse, Trusting their Doctor and Evaluating the PN all contribute to the process of Having Confidence in the PN. The effect that each of these four areas have on the overall level of confidence will vary depending on the individual patient and can either diminish or increase the level of confidence. It is a process that is heavily influenced by patients' Perceptions of Nurses.

Conclusion

Navigating Care is the overall process patients go through to arrive at a level of satisfaction with PN-led care. There are three processes involved in Navigating Care: Determining Care Needs, Forming a Relationship and Having Confidence. These are on-going and inter-related processes. Forming a Relationship and Having Confidence inform each other as a good developing relationship helps in building confidence in the PN and Having Confidence in the PN enhances the PN-patient relationship. Once

patients experience PN-led care they become more aware of what PN-led care offers them. This, as well as the developing relationship and their confidence in the PN, affects how patients determine what their care needs are. How patients view nurses and the attitude they have towards their own health are intervening conditions that affect the three processes of Navigating Care.

Chapter 4. Discussion

This chapter will first present a synopsis of the theory Navigating Care and the processes that relate to it. The detail of the theory will then be discussed in the light of the literature that relates to the concepts identified. The next section will consider the limitations of the study, the implications of the findings will be discussed and finally recommendations will be made.

Navigating Care – A synopsis

Navigating Care is the basic social process that emerged from the study into the process of patient satisfaction with PN-led chronic disease management. It is comprised of three separate but interrelated processes, Determining Care Needs, Forming a Relationship and Having Confidence. These processes occur within the contextual conditions of the Workforce shortage of GPs and patients' Perceptions about the role of doctors. Intervening conditions affecting Navigating Care are patients' Perceptions of nurses and their Attitude towards their own condition/s.

Patients determine their care needs through a process of monitoring and self-assessment. If they consider that the PN is the appropriate person to provide for their care needs, they then proceed to Forming a Relationship with and Having Confidence in the PN. These two processes are concurrent and interdependent. The patient's experience during these processes also provides a feedback loop to further determination about their care needs. The two stages involved in Forming a Relationship are

Building Rapport and Working Together. Time, Communication and Continuity are important properties of Forming a Relationship. The confidence that patients have in PN-led chronic disease management is situated in four areas, Trusting the Model of Care, Trusting the Role of Nurse, Trusting their Doctor and Evaluating the PN. The extent to which each of these areas influence the level of confidence depends on the individual patient. Communication is also an important property of Having Confidence, especially in Evaluating the PN

The details of the theory of Navigating Care will now be discussed in the light of the available literature related to the different concepts.

The context of the study and the changing role of practice nursing

The context in which this study was undertaken was one in which primary health care is being given a greater focus by the Federal government of Australia and the role of PNs is changing and extending (Australian Government Department of Health and Ageing, 2009). Participants perceived that there was a workforce shortage of GPs. This perception, combined with their views concerning the respective roles of doctors and nurses, influenced their decisions as to who they considered to be the most appropriate health professional to manage their chronic condition/s. However, as they experienced PN-led care their awareness of what sort of care the PN offered was changed.

The shortage of GPs

As participants in the PN Project were aware of the shortage of GPs they often felt under pressure of time when consulting with their GP and did not want to 'waste' his or her time with concerns or conditions that they

considered to be trivial or minor. Under these circumstances the participants were content to consult with a PN in order to save the doctor time. Their awareness of the shortage of GPs came from both the media and personal experience.

Other studies have also found that patients perceive GPs to be under pressure of time (Caldow, et al., 2006; Cromarty, 1996) and Cromarty (1996) also found that patients thought the doctor's time was valuable and they should not keep other patients waiting by taking up too much of the doctor's time. Calnan (1988) suggested that this type of attitude in patients was likely to result from the ideology of government-funded health care and was unlikely to occur in a private system. Both Caldow et al.'s (2006) and Cromarty's (1996) studies were conducted in general practice in the UK, which is fully government funded. However, Australian general practice is financed through a mixed system of government and private funding and even though none of the practices in the PN project were totally government funded, the participants repeatedly expressed their opinion that the doctors' time was precious because of the number of patients waiting to be seen and not to be wasted with trivialities or minor conditions. This indicates that in the current context of a shortage of GPs in Australia, patients may feel that they should not take up too much of a GP's time regardless of whether they are in a private or state funded system.

Perceived roles for doctors and nurses

Participants considered that doctors and nurses had very different roles in health care and their perceptions regarding these roles influenced their decisions as to whether it was appropriate for the PN to provide for their

care needs. In the case of doctors these perceptions were quite specific and homogeneous. They viewed the doctor as the expert who should be responsible for diagnosis, treatment and particularly prescribing medication. There was also a feeling that the doctor should be free to deal with urgent and acute problems and not have to be concerned so much with on-going monitoring of chronic conditions.

A view of doctors as being experts and available to diagnose and prescribe treatment is one that is commonly found in the literature (Caldow, et al., 2006; Cheek, et al., 2002; Hegney, et al., 2004a; Redsell, et al., 2006; Wright, et al., 2001). Patients repeatedly report preferring to see a doctor rather than a nurse for problems that they consider to be serious (Caldow, et al., 2006; Redsell, et al., 2006; Wright, et al., 2001). However, while reserving the right to see a doctor if their condition became unstable, participants in the PN Project felt that because doctors were the experts it was inappropriate to 'bother' them with, what participants perceived to be, routine or minor matters when doctors were so busy. Rather than viewing the PN as an acceptable substitute for a doctor for minor conditions, they felt that the PN was the more appropriate person to undertake regular monitoring of chronic conditions.

Participants' perceptions of the role of nurses were much more varied than those of doctors. They viewed PN-led management as routine monitoring that did not require the PN to be involved in diagnosis or changes of treatment, particularly changes to medications. Perceptions of nurses ranging along a continuum from doctor's assistant to autonomous health professional are commonly seen in the literature (Hegney, et al., 2004a; Phillips & Brooks, 1998; Redsell, et al., 2006; Wiles, 1997) as was the case among participants in the PN project. Studies have also found that patients

feel nurses are able to deal with minor ailments and routine care (Caldow, et al., 2006; Hegney, et al., 2004a; Redsell, et al., 2006; Turner, et al., 2007; Wright, et al., 2001) although there has been more uncertainty about expanding the role of PNs, particularly into the area of prescribing (Cheek, et al., 2002; Redsell, et al., 2006; Wright, et al., 2001). However, Cheek at al. (2002) found that patients who had experienced PNs working to a greater capacity than the traditional treatment room role were happy with the care provided and thought that PNs could be involved in chronic disease management.

PNs in Australia have increasingly taken on a larger role in chronic disease management, especially since the introduction of the Chronic Disease Management Medicare item numbers in 2005 (Department of Health and Ageing, 2005, 2007), although PN-led chronic disease management, as in the PN Project with its more autonomous role for PNs, is new to Australia. Participants' overall perceptions of nurses did not markedly change, in terms of their ability to work autonomously, as a result of experiencing PN-led care. However, they did become more aware of the type of care that PNs could offer seeing it as complementary rather than substitutionary care and appreciating what it offered to them in managing their chronic condition/s. This is something that has not been explored in other studies although patients have reported that they feel a PN's role should be complementary to that of the doctor and enhance care rather than be a substitute for care from the GP (Cheek, et al., 2002; Hegney, et al., 2004a; Redsell, et al., 2006). Most studies that have looked at patients' views of PNs have tended to concentrate on the substitutionary role (Caldow, et al., 2006; Chapple, 2001) or the approachability of PNs (Chapple, 2001; Wiles,

1997; Wright, et al., 2001) rather than the complementary care that they can provide.

Nurses are skilled in helping patients manage their condition in the context of their everyday lives whether in an acute setting or in the community. In the context of the PN project this was manifested by PNs being able to provide the support and encouragement for participants to adjust lifestyle behaviours and self-manage their condition/s. The PNs provided specific and detailed advice and accountability that helped participants to make changes and achieve goals. Participants' perceptions of nurses as less important than doctors actually assisted in this as participants were open to discussing what they considered to be trivial or minor issues and thus worked together with the PN to manage their condition/s in a way that they had not done with their doctors.

Changing expectations

As participants became more aware of the type of complementary care that PNs provided, it changed their expectations of PN-led care, which informed future decisions regarding their care needs. Participants' initial opinions that PNs would be appropriate health professionals to provide routine monitoring of their condition/s and would save time for the doctors were informed by their perceptions of the role of nurses. None of the participants had previously experienced the more autonomous role of PN-led management being trialled, as this was new to Australian general practice. Once participants had experienced PN-led care their understanding of what care the PN offered changed. Calnan (1988), in his conceptual framework of patient satisfaction suggested that expectations are formed by experience with health care.

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Expectations are often thought to play a significant role in patient satisfaction and many studies are, implicitly if not explicitly, based on the theory that met or unmet expectations are responsible for patient satisfaction or dissatisfaction (Pascoe, 1983). However, expectations have been found to account for only small variations in patient satisfaction and the actual effect they have on the process has been unclear (Like & Zyzanski, 1987; Linder-Pelz, 1982b; Locker & Dunt, 1978). Studies have concentrated on how expectations correlate with patient satisfaction in a single health care encounter (Fitzpatrick & Hopkins, 1983; Like & Zyzanski, 1987; Linder-Pelz, 1982b). The present study was able to capture changing expectations as patients were interviewed over a period of 18 months and some of them were interviewed more than once. It also explored the process of satisfaction with repeated encounters over a period of time rather than for only one encounter. What this study shows is that expectations played a part in the on-going overall process of Navigating Care by providing feedback to the process of Determining Care Needs, rather than there being a simple direct effect of met or unmet expectations, as is often assumed.

Scope of practice and collaboration

The confidence that participants had in the PNs working to their full capacity in the present study, which in turn affected their level of satisfaction, was partly founded on their belief that the PNs would only work within their scope of practice. This confidence grew as participants experienced PN-led care and was evident from their increasing willingness to rely on PNs to decide if patients needed to see the GP. Cheek et al. (2002), in their study of patients' perceptions of PNs, found that there was an assumption that PNs would work within their scope of practice. Other

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studies have reported that patients were confident that PNs would seek advice if something was outside their scope of practice (Caldow, et al., 2006; Chapple, 2001; Wiles, 1997).

Working within a scope of practice is not limited to nurses. There are also times when GPs identify that something is beyond their expertise and consult with others or refer the patient to a specialist. Other researchers have found that patients appreciate GPs who will admit that they do not know something and seek further advice (Pettigrew, et al., 2004, 2005; Smith, et al., 2008). In fact older Australians have nominated prompt referrals to specialists as the most important aspect of their interactions with GPs (Pettigrew, et al., 2004, 2005). Therefore, this model of PN-led care can be seen to mirror the relationship between GPs and specialist medical practitioners, which has long been accepted by patients and doctors alike.

In addition to PNs working within their scope of practice, participants gained confidence and, therefore, satisfaction from the knowledge that the PNs were collaborating with the doctors. They wanted the doctor to be kept informed about their condition/s, but also had an expectation that the doctor and PN would work together as a team for the benefit of the patient. Real collaboration between GPs and PNs has been a contentious issue and is often constrained in practice by factors such as the funding arrangements for Australian general practice, the PN's traditional role as an assistant to the GP and GPs protecting their 'turf' (Baldwin, 1996; Patterson & McMurray, 2003).

Patterson and McMurray (2003) proposed a model of collaboration that recognised the areas of practice that are specific to either the GP or the PN,

but also encompassed functions that could be undertaken collaboratively, including chronic disease management. The role of PNs already includes contributing to chronic disease management, albeit under the supervision of the GP, through the introduction of the Medicare payments for chronic disease management. GPs and PNs working together in the preparation of GP Management Plans may facilitate a better understanding among GPs of the complementary care that PNs can provide and that they can enhance the care of patients, thus leading to a more collaborative practice. If patients are to be satisfied with PN-led management of chronic conditions then there is a need for real collaboration between GPs and PNs.

To summarise, a much greater focus is being given to the importance of primary care by the Australian government at the present time and the role of the PN is rapidly evolving. Patients perceive that there is a shortage of GPs and that the PN can have a role in alleviating the pressure this puts on doctors. They view doctors and PNs as having very distinct and different roles, but their understanding and expectations of what sort of care a PN provides can be changed by experiencing PN-led care. This then affects their decision as to who is the best provider to meet their care needs. In order to ensure that patients are satisfied with PNs working to their full capacity in providing nurse-led chronic disease management, PNs should provide complementary and collaborative care. Patients are confident that PNs would not work outside their scope of practice and, in this respect, the model of PN-led management of chronic conditions is very like the GP-specialist model of care with which they are already very familiar.

Patient Autonomy

Autonomy and choice of provider

Patient autonomy is a guiding principle for every aspect of health care. It is fundamental to having respect for the individual and ensuring that they retain the right to make their own decisions regarding their health care. One area where this is evident is the patient's right to choose which health professional to consult. In the PN Project participants held firmly to their right to decide for themselves whether to see the GP or the PN for management of their chronic condition/s. They made this decision based on what they considered their care needs to be and who could best provide for those needs. Many other studies have highlighted that patients do not want to have their choice of provider removed when PNs are working in to their full capacity (Barnett, Ogden, & Daniels, 2008; Caldow, et al., 2006; Cheek, et al., 2002; Hegney, Price, Patterson, Martin-MacDonald, & Rees, 2004b; Redsell, et al., 2006). Some studies have also shown that patients make up their own minds about the nature of their illness and what their care needs are and will choose their health care provider accordingly (Caldow, et al., 2006; Infante, et al., 2004; Wiles, 1997).

No studies were found that examined how patients assessed their health to arrive at their decision as to the best person to deal with their problems. The way in which participants in the present patient satisfaction study assessed their health status was not always the way in which health professionals would do so and all of them relied, to some extent, on subjective feelings of wellness or illness. However, their perception of the stability of their condition was directly associated with their choice of provider and, therefore, their satisfaction with seeing a PN. It is important,

therefore, that patients' perceptions of their health status are taken into account when introducing a PN-led model of chronic disease management.

Autonomy and self-management

Patient autonomy not only concerns the choice of provider but also extends to the type of relationship patients have with their health care providers and the extent to which they become involved in managing their own condition/s. The way in which participants wanted to work with the PN ranged along a continuum from being actively involved and working in partnership with the PN to being very passive and expecting the PNs to 'look after them' with very little or no active involvement from themselves. This range of attitudes has been seen in other research (Barnett, et al., 2008; Bastiaens, et al., 2007; Furler, et al., 2008; Infante, et al., 2004). It is possible that these differences in attitude could be related to their health locus of control (HLOC), which is one factor that can influence health behaviour (Wallston & Wallston, 1978). The continuum of HLOC ranges from strongly internal at one end to strongly external at the other. Those participants who monitored their conditions closely and objectively could probably be considered to have an internal HLOC. In contrast, those who were fatalistic and did not worry about their condition, even when their lives were significantly limited by it, could be said to have an external HLOC.

Holman et al.'s (2008) research could also be useful in explaining the different approaches participants in the PN Project had towards their conditions. They developed eight health personality profiles, such as the Active Positivist, Comfortable Romantic and Anxious Fatalist to help explain individuals' health management behaviours. Certainly the Active

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Positivist profile would fit those participants who were proactive and wanted to work in partnership with the PN, setting goals together with her and objectively and actively monitoring their condition/s. Those who wanted their condition/s monitored closely but relied on the GP or PNs for this and took limited responsibility for their management by following the PN's advice could be described as Comfortable Romantics. However none of the profiles really account for those who were fatalistic, did not see a need for self-management and accepted limitations caused by their condition/s, attributing them to growing old. Holman et al. (2008) did note that older people in their sample had the lowest physical health score, but with a low impact indicating that their poor health did not matter to them. Maybe this is because they accepted poorer health as a natural consequence of old age, as was expressed by participants in this patient satisfaction study.

In addition to the attitude participants held towards their condition/s, understanding of their conditions also contributed towards their involvement in its management. Most participants in the present study felt that they understood their condition as much as they wanted to. They used a variety of sources to access information about their conditions, such as the internet, books and publications from the Diabetic Association. Explanations the PNs used to back up their advice were appreciated, but gaining greater understanding about their condition/s was not part of the process of satisfaction with PN-led care. This is in contrast to the findings of other studies that indicate that a desire for understanding was very important to participants, and gaining greater understanding was a significant factor in satisfaction with health care encounters (Anden, et al., 2005; Avis, et al., 1997; Collins & Nicolson, 2002; Edwards, et al., 2004;

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Fitzpatrick & Hopkins, 1983; Flynn, 2005; Koinberg, et al., 2002; Shaw, et al., 2000). This could be because in those studies consultations were not for stable on-going conditions and so there was more uncertainty for the participants and a need to understand what was happening to them. Possibly, if patients were newly diagnosed, understanding would be a more important factor in satisfaction with PN-led management.

Facilitating self-management is considered desirable in order to improve control of chronic conditions and empower patients. However, the extent to which this is possible is going to depend on the attitude of patients towards their involvement in managing their condition/s. It is possible that as patients develop an on-going relationship with PNs they will begin to share management of their condition/s, if they do not do so already, and PNs can work towards this. However, patient collaboration in self-management cannot be assumed and patients' choice of the extent of their involvement has to be respected. Understanding patients' attitudes towards their health and level of self-management can help health professionals adapt their approach to best suit the individual and facilitate patient satisfaction.

The significance of time

Time, both in quantity and quality, was instrumental in the process of patient satisfaction with PN-led management of ongoing conditions. It had a significant effect on the establishment of rapport and, therefore, the relationship between patients and PNs, which was part of the overall process of Navigating Care. Time is a construct that has often been included when studies investigate or measure patient satisfaction. Items on surveys rate satisfaction with the amount of time spent with the provider

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and the amount of time it took to see the provider (Greco, et al., 2001; Grol, et al., 1999; Jung, et al., 1997; Pettigrew, et al., 2005).

Qualitative studies have explored the construct of time further and found that having plenty of time is important to patients so that they feel that they have been listened to and that their concerns have been properly addressed (Collins & Nicolson, 2002; Flynn, 2005; Infante, et al., 2004; Pooley, et al., 2001; Williams & Jones, 2006; Wong, et al., 2008). The findings of the PN Project shed more light on this aspect of consultations, showing how it contributes to the ongoing process of satisfaction by impacting on the relationship with the PN. Longer consultations with the PNs allowed the participants to feel more relaxed, which alone facilitated rapport. However, the longer consultations also allowed participants to share their concerns and raise issues, further contributing to the building of rapport. Other studies have not explored how having enough time with a provider contributes to an on-going provider/patient relationship through enabling the building of rapport. This could be because most patient satisfaction studies, even qualitative ones, have not examined satisfaction with a model of care over time as the present satisfaction study did.

Participants in the present patient satisfaction study repeatedly commented on the benefits of not feeling rushed with the PN. Not wanting to feel rushed in a consultation has been found to be important in other studies (Collins & Nicolson, 2002; Haskard & DiMatteo, 2009; Wong, et al., 2008) and patients report that nurses generally provide a less rushed consultation (Flynn, 2005; Williams & Jones, 2006). There was a general perception amongst the PN Project participants that PNs were not as busy as GPs and had more available time. This perception is fairly common among patients (Cheek, et al., 2002; Flynn, 2005; Redsell, et al., 2006) as is the feeling that

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patients should not prolong consultations with a doctor (Cromarty, 1996; Pooley, et al., 2001; Williams & Jones, 2006). It is interesting that when participants in the PN Project felt rushed in a PN consultation they blamed the nurse, but when they felt under pressure of time with the GP they made allowances.

Collins and Nicolson (2002) and Fitzpatrick and Hopkins (1983) found that patients made allowances for shortcomings of health care because of extenuating circumstances such as the pressure of too many patients. The reason participants did not blame the GP but did blame the nurse may be related to Williams, Coyle and Healey's (1998b) theory of duty and culpability. They posited that patients first evaluate whether a health professional has a duty to provide a desired service and then, if that service is not forthcoming, whether it was the fault of the health service or professional or whether there were extenuating circumstances. Patients only report dissatisfaction if they feel there is both a duty to provide a service and culpability on the part of the health professional/s in not providing it. While PN Project participants wished for unrushed consultations with both the GP and the PN and possibly felt that, ideally, these should be provided, they clearly did not hold GPs culpable because of the perception that there was a shortage of GPs.   Conversely, PNs were seen as being able to provide longer consultations, that their time was not a valuable as the GPs' and, therefore, PNs were culpable if consultations were rushed. It is possible that if PNs were perceived to be as busy as GPs that some pressure of time would be felt by patients. However, it is likely that the PNs' time would still be considered less valuable than the GP's because of the perception that doctors should be treating the more severely

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ill or urgent cases. Therefore, patients would still feel less pressure of time with a PN than a GP.

If PNs begin to take on a larger role in the management of chronic diseases then they too may find that they are under pressure of time. This could have a negative effect on building relationships with patients and thus affect the ongoing process of satisfaction. Patients may also continue to believe that PNs have more time than GPs or that their time is less valuable, and hold them accountable for rushed consultations, decreasing satisfaction. The reasons for PN consultations are usually known before-hand, enabling the PN to plan for longer consultations where necessary. Good planning and time management would, therefore, be a way to contribute to patient satisfaction. However, longer consultations have cost implications. In a review of studies investigating the substitution of doctors by nurses, Laurent et al. (2004) found that nurses provided longer consultations than doctors and concluded that this could affect their cost-effectiveness.

The importance of communication

The findings of the present patient satisfaction study revealed that different aspects of communication; communication style, communicating-with, communicating-self and communicating knowledge, were important to the process of patient satisfaction. Communication has been linked with patient satisfaction in many studies (Bastiaens, et al., 2007; Bower, et al., 2008; Charlton, Dearing, Berry, & Johnson, 2008; Greco, et al., 2001; Haskard & DiMatteo, 2009; Infante, et al., 2004; Jung, et al., 1997; Litaker, et al., 2003; Pettigrew, et al., 2004; Shaw, et al., 2000; Tarrant, et al., 2003; Tung & Chang, 2009; Wong, et al., 2008), but it is generally treated as a

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single construct and rarely broken down into the different aspects of communication as present satisfaction study had done. It seems that there is an assumption that what constitutes good communication is self-evident; however, no studies were found that clarified how different aspects of communication facilitate patient satisfaction. The present study adds an understanding of how communication affects patient satisfaction by showing how different aspects of communication relate to the process of satisfaction. It was shown in this study that the different aspects of communication facilitate the breaking down of barriers between participants and PNs, help participants to work together with the PN, and are instrumental in building confidence in the PN.

Redressing a power imbalance

Although patients do not regard nurses in the same light as doctors in terms of importance, nurses are still in a position of authority with patients. Edwards, Staniszweska and Crichton (2004) found that the inequality between nurses and patients pervaded participants' experiences with health care. Their participants were being cared for in hospital, which would increase the sense of an inequality but the imbalance of relationship still applies in general practice. Conversely, a feeling of equality with health care professionals in diabetic care has been reported as facilitating patient satisfaction (Hornsten, et al., 2005). Much of the inequality between health professionals and patients comes from the knowledge imbalance that exists between them. Nurses have knowledge, understanding and skills that patients do not have. In addition, they generally know a lot more personal information about the patient than the patient knows about the nurse. This may make patients feel at a disadvantage.

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The findings of the present satisfaction study reveal that different aspects of communication help to redress this power imbalance, making the patient feel more on the same level as the PN and facilitating a good working relationship. A friendly and open communication style has been found to be appreciated by patients (Haskard & DiMatteo, 2009; Shaw, et al., 2000; Tarrant, et al., 2003) and to make them feel on the same level as their health provider (Smith, et al., 2008). In the present satisfaction study the PNs' friendly style of communication helped put participants at ease and to relax, reducing the distance between nurse and patient. Listening carefully is another aspect of communication that has previously been found to be important to patients (Infante, et al., 2004; Tarrant, et al., 2003). The present satisfaction study showed that when PNs listened carefully, the inequality between nurse and patient was reduced because patients felt that they were important to the PN and that their concerns were taken seriously. This was particularly important when patients considered their concerns or issues to be too trivial or minor to bother the doctor with.

Communicating-self was also important in closing the gap between nurse and patient. Tarrant et al. (2003) and Shaw et al. (2000) found that when social talk was included in consultations it made for a less formal setting and put patients at ease. If PNs are willing to share something of themselves, patients are able to relate to the nurse as a person, placing them on a more even footing with the nurse. Finally, the way in which information and explanations are communicated is important in reducing inequality. Use of medical jargon and technical terms highlights the difference in knowledge between the nurse and patient. Communicating information without using medical jargon and explaining technical terms

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not only ensures understanding but assists in reducing the distance between patient and nurse.

Communication and self-management

Communication was an important property of Working Together with the PN in the process of patient satisfaction. The extent to which participants were willing to work together with the PN to manage their condition/s depended, to some degree, on their attitude towards their own health. However, communication was important in facilitating a working relationship that participants found satisfying. Other studies have also shown that listening, a component of communication, is important to patients in order to individualise care, particularly in the area of management of chronic conditions (Hornsten, et al., 2005; Infante, et al., 2004; Pooley, et al., 2001; Tarrant, et al., 2003; Wright, et al., 2001). Roter's interaction analysis system (2000) includes physician communication behaviours such as questioning, positive and negative talk, social talk and giving information, which she suggested facilitates active patient involvement in a consultation. In a similar way, the present patient satisfaction study shows how the style of communication affects the involvement of the patient in the consultation, but also how it extends beyond the consultation in encouraging patients to self-manage at home.

One significant aspect of the working relationship with the PN in supporting self-management was the sense of accountability participants reported. Because the patient and PN set goals together and the patient returned regularly to see the PN for management of their condition/s, patients were more inclined try and follow the PNs' advice and achieve the goals they had set. No literature was found that explored accountability and

it is not a construct that is included in the available literature on patient satisfaction. Feeling accountable contributed to working together with the PN and helped participants to self-manage their condition/s by giving them an incentive to make lifestyle or behavioural changes. The PNs' communication style was very important in facilitating accountability and needed to be adjusted to allow for the preference of individual participants. Some participants appreciated a firm approach and felt that this spurred them on, whereas others responded better to a gentler approach. Smith et al. (2008) found that some men preferred a more directive approach from the general practitioner, although this was not in relation to accountability.

Communication and Having Confidence

In the present patient satisfaction study, communication was also instrumental in facilitating confidence in the PN and, therefore, affecting the level of satisfaction. Participants partly evaluated the competency of the PNs by their ability to communicate their knowledge to them. Part of this was explaining advice and treatment approaches in ways that were easily understood by participants. Other studies have also shown the importance of communication in relation to confidence. Jung et al. (1998) found that information giving was instrumental in patients' evaluations of a doctor's competence and Shaw et al. (2000) found that nurses communicating knowledge increased patients' confidence in the service they were providing. Wright, Wiles and Moher (2001) found that participants felt nurses were particularly good at giving explanations that patients could understand. While this was one of the aspects of a nurse-led clinic that their participants appreciated, they did not relate it to confidence. Thom and Campbell (1997) found that communication, both careful listening and explanations, was important in building trust. Trust is a

similar concept to confidence and, as the following discussion shows, an antecedent to confidence.

Trust and patient satisfaction

Trust was found to be very significant in the process of patient satisfaction with PN-led care. This finding is similar to other studies that have found that there is a very strong correlation between trust in the treating physician and patient satisfaction (Alazri & Neal, 2003; Baker, et al., 2003; Platonova, et al., 2008; Wensing, et al., 1994). However, in the present patient satisfaction study it was trust in three different areas, the model of care, the participant's doctor and the role of nurses, that was instrumental in the process of satisfaction.

Part of Trusting the Model of Care in the present patient satisfaction study was that participants knew the doctor was always available if there was a problem. No other studies were found that investigated trust and the model of care being trialled, that is, PNs working autonomously but in collaboration with the GP. Thom and Campbell (1997) did find that a willingness on the part of physicians to refer to others engendered trust, which is perhaps similar to nurses referring back to GPs.

Trusting their own doctor was also important to the process of Having Confidence in the present patient satisfaction study, as participants were confident that their doctor would only employ a nurse capable of the role. This is consistent with the findings of other studies that also found patients would have confidence in a PN because they trusted the doctor to pick the right nurse for the job (Cheek, et al., 2002; Hegney, et al., 2004a; Wiles, 1997).

The third area of trust that was important to the process of satisfaction was Trusting the Role of Nurses. Redsell et al. (2006) and Wiles (1997) also reported that patients tended to have an implicit trust in nurses as health professionals. In the PN Project the level of trust in the PNs was strongly affected by the participants' perceptions of nurses and what they were capable of doing. This has been discussed earlier.

In relation to trust, the present study shows that satisfaction with PN-led management of on-going condition/s is not a straight forward relationship between trust in the provider and satisfaction. Participants generally trusted the PNs because they were nurses, but trust in the model and previously established trust in their own doctor also contributed to their level of confidence in PN-led care and thus the process of satisfaction.

This discussion has shown how the findings of the present patient satisfaction study fit with what is already known about patient satisfaction and those domains of care that have an impact on satisfaction. It has also highlighted how this study has contributed additional knowledge about patient satisfaction, particularly with nurse-led care. The greater understanding about the process of patient satisfaction with nurse-led chronic disease management that this gives can be used to inform practice and help in providing care that is acceptable to patients. Understanding more about patient satisfaction can also be used to inform policies about new models of care, particularly nurse-led care.

Implications

This section will discuss the implications of Navigating Care for patients with chronic conditions, GPs, PNs and the health care system. How the

knowledge gained from understanding the process of Navigating Care can be used to inform practice and contribute to the provision of acceptable management for chronic conditions will also be discussed.

The findings of the PN Project can be used to help in identifying those patients who might benefit from PN-led management of chronic disease. This study has shown that patients are willing to see a PN for management of their ongoing condition if they feel that their condition is stable. Therefore, those with stable chronic conditions would be the most appropriate patients, in terms of satisfaction, for PN-led care. The findings also showed that patients make their own assessment as to the stability or control of their condition. GPs need to ascertain how patients view their condition, in terms of stability, before suggesting or recommending PN-led management. They may need to reassure patients that their condition is stable enough for PN-led management. One aspect of PN-led care that participants greatly appreciated was the extra care in terms of lifestyle advice and support that was provided by the PNs. Those patients who need to make lifestyle and behavioural changes in order to improve the control of their ongoing conditions would be very suitable for PN-led care. This would be particularly so if patients were finding it difficult to make the necessary lifestyle changes.

As has been stated before, participants in the present patient satisfaction study found that PNs offered different care from the GP, and most had not been aware of these complementary role activities before. If participants had any previous experience of consulting with a PN it was largely in a traditional treatment room role or, occasionally, for aged health assessments. Even with aged health assessments patients still had to see the GP as well as the PN. Raising awareness of the full capacity of a PN's

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role could make PN-led management of chronic conditions more acceptable to patients. This would be particularly so in the early stages of the process of satisfaction when patients are still deciding if a PN is the most appropriate provider for their care needs.

Part of the confidence that participants had in PN-led care came from the trust that they had in their personal GP. Because they trusted their GP they had confidence that he/she would only employ nurses who were capable of the roles assigned to them, including management of ongoing conditions. This means that the GP's recommendation to patients that their ongoing condition be managed by a PN in collaboration with the GP is very important. If GPs are not fully convinced of the value of PN-led management this may be conveyed to the patient, reducing their level of confidence and thus satisfaction. It may also discourage patients from engaging with PN-led care all-together.

The findings of this study can be used to inform the practice of PNs. The importance of communication and continuity in Forming a Relationship can help PNs to foster good relationships with patients. This is true for many aspects of a PN's role, not just in management of ongoing conditions, as general practice usually offers opportunities for ongoing relationships with patients over years. Building good relationships with patients should, therefore, increase satisfaction with whatever type of care is being provided by PNs. However, some PNs may not wish to undertake the more autonomous role of PN-led chronic disease management, or may not feel confident to do so, which would then affect patient satisfaction. For other PNs, being able to work to their full capacity in the management of patients with chronic diseases may enhance their job satisfaction and possibly improve retention of nurses in general practice.

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In order for PNs to undertake this role of chronic disease management, on-going education will be needed, not only in the clinical guidelines for chronic disease management but particularly in the area of communicating with patients. In this patient satisfaction study communication was found to be essential, not only in building rapport but in developing a working relationship with patients. This working relationship facilitates goal-setting and self-management. Gaining skills in motivational interviewing would help PNs to identify whether patients are ready to make behavioural or lifestyle changes and the extent to which they are willing or able to self-manage their condition/s. It would also help them in assisting patients in self-management.

A significant implication of the findings of this study is the way in which they can be used to facilitate self-management. The Working Together process of the patient-PN relationship is especially important in encouraging patients to become involved in the management of their conditions and, therefore, improve clinical outcomes. As well as encouraging patients to self-manage, PNs can also facilitate self-management by using communication skills to improve health literacy. There are several different definitions of health literacy but the following definition, provided by the World Health Organisation, is the most comprehensive (Nutbeam, 1998, p. 357). "Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health."

Poor health literacy has been found to be associated with increased mortality, including death from cardiovascular disease (Baker & Thompson, 2007). It has also been shown to be related to poorer glycaemic

control for those with diabetes type 2 and to higher rates of diabetes-related complications (Schillinger, et al., 2002). A report by the Australian Bureau of Statistics (2008a) revealed that 85% of the Australian population aged between 65 and 74 had sub-optimal levels of health literacy. As this is the age group that generally suffers most from chronic disease such as diabetes type 2 and IHD, there are significant implications for the management of chronic diseases.

PNs can contribute to patients' health literacy through the use of good communication to provide relevant health information in terms that patients can understand. In addition, they can foster health literacy skills, such as knowing how to read and understand nutritional information on food packaging in supermarkets. Participants in the present patient satisfaction study repeatedly reported having more relaxed consultations with PNs. If patients feel more relaxed they are more likely to feel free to ask questions, which is another way of improving their health literacy.

Proactive, systematic and planned management of chronic conditions has been shown to be more effective than episodic care (Wagner, Austin, & Von Korff, 1996). If patients feel more relaxed and less anxious when consulting with a PN than with a GP, they may be more willing to attend for regular, systematic reviews. This should then lead to better clinical outcomes than if they only attend the GP when they are feeling unwell, need to see him/her for another condition, or when they need prescriptions. It is possible that if this sort of care results in improved health outcomes that there might be an impact on satisfaction.

Participants in this present patient satisfaction study repeatedly reported that they felt they could raise concerns or issues with the PN that they

perceived as too minor or trivial to 'bother' the doctor with. In fact, these issues were often of a nature that could have a significant effect on their health and, therefore, needed to be addressed. Satisfactory PN-led management offers the opportunity for patients to raise these issues so that they can be addressed. Also, hypertension was often referred to as a minor problem that 'everyone has' and, therefore, not something they always wanted to bother the doctor with. This means that hypertension may not be managed as well as it should be. If patients are happy with PN management then they are more likely to attend for regular management of their hypertension.

The theory, Navigating Care, makes explicit how and why communication is important in the process of patient satisfaction with PN-led care. Nurses' relational skills are often taken-for-granted and seen as 'women's work' rather than an essential component for optimal patient outcomes. As a result they are undervalued and much of what a nurse does becomes invisible (DeFrino, 2009). Australian PNs do not always have a private room in which they can consult and many PNs have desks in treatment rooms or even corridors (Phillips, Dwan, & Pearce, 2007). The present study has highlighted the importance and necessity of good relational skills to ensure patient satisfaction. If these skills are recognised and valued more by employers, it is hoped that they will be better supported in the workplace. For instance, allowing for longer PN consultations and providing a dedicated, private area for PNs to hold consultations so that relationships with patients can be developed and maintained.

There are funding implications that arise from the findings of this study. Under current Medicare funding arrangements, there is only a small rebate for PNs to provide chronic disease management on behalf of and under the

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supervision of a doctor. This may not compensate for the extended amount of time that patients want when PNs manage their on-going conditions. Other investigators on the PN project are examining the cost-effectiveness of the model of PN-led chronic disease management for general practices. However, the extended time with PNs that contributes to patient satisfaction and the provision of suitable, private space for PN consultations would incur extra costs for general practices. These costs could be recouped, at least in part, by charging patients an out-of-pocket fee or they could be absorbed by the practice. Charging a fee might not be acceptable to patients and practices are unlikely to willingly increase their costs. Therefore, practices may be reluctant to implement a PN-led model of care even though patients find it satisfactory.

Alternative ways of funding Australian general practice for chronic disease management need to be considered to address this issue. A change in funding for chronic disease management in general practice was recommended by The National Health and Hospitals Reform Commission (2009). Their recommendation was that patients suffering from chronic diseases could voluntarily enrol with general practices. These practices would then receive extra funding, in proportion to the number of enrolled patients, to provide chronic disease management. Some of this money could pay for PNs to be employed to manage patients with chronic diseases and to offset the costs of extra infrastructure if necessary. Other funding options that could be considered include introducing a PN consultation Medicare rebate or extending the PN grants already paid to some general practices based on geographical area.

Limitations of the study

There are some limitations to this study related to the sample. Participants were drawn from only three general practices and two of those were in SE Queensland. It is possible that if participants were drawn from other, different types of practices there may have been further findings. However, the three practices did represent metropolitan, regional and rural areas, although no inner city or remote practices were involved. Also all the participants were English speaking and none of them were from culturally or linguistically diverse backgrounds. People with different cultural backgrounds could have different perspectives about their health and about PN-led care. Also, those who speak English as a second language may have particular issues that impact on patient satisfaction with PN-led care.

Participants were chosen from those patients who had consented to be part of the PN project. It can be assumed that, as they had consented and were therefore willing to be randomised into the PN arm of the study, they were positively pre-disposed to PN-led care. However, this is really part of the satisfaction process. They had, in effect, already gone through the first part of Navigating Care and decided that PN-led care would be appropriate for them. Not all participants started with really positive attitudes towards PN-led care. There were some who were very hesitant at first and only consented because they knew that they could return to seeing the doctor at any time. If choice for patients was removed and they had to see the PN for management of their ongoing conditions, other processes might occur if PNs were able to overcome an initial resistance.

A fourth issue with the sample is that only three chronic diseases were covered, diabetes type 2, IHD and hypertension. The process of

satisfaction may be different for those who suffer with other chronic diseases such as asthma, cystic fibrosis or arthritis. Also, the three conditions included in the PN project are particularly prevalent among older people and very few of the participants were under 50 years of age. The process of satisfaction may be different for younger adults or adolescents as it is likely that they will have other issues that affect the process. In addition, the study investigated the process of satisfaction with nurse-led chronic disease management. The process of satisfaction with PN-led management of acute conditions may be very different.

The model of care trialled in the PN project was one involving ordinary registered nurses working in general practice, not nurse practitioners. At present the PN workforce in Australia is made up of mainly registered nurses and there are very few nurse practitioners working in general practice. The process of satisfaction with nurse practitioners, who are educated and licensed to assume a much more independent and extended role, may be quite different. Other research would need to be conducted to ascertain how patients decide on their level of satisfaction with nurse practitioners working within general practice.

Finally, chronic disease management provided by the PNs to participants in the PN project was free of cost to participants. If nurse-led chronic disease management attracted a fee from patients, the process of patient satisfaction could be altered. While it has been pointed out that patients do not act in a purely consumerist fashion when paying for health care (Wiles & Higgins, 1996), payment for chronic disease management provided by a PN may introduce a different dynamic that changes the process of patient satisfaction.

Recommendations

There are several recommendations for practice that arise from the findings of this study. As participants were largely unaware of the sort of care that PNs were able to provide, it would be constructive to raise awareness of the capacity of the PN's role; that PNs are not limited to be doctors' assistants but are educated to undertake more autonomous roles. PNs' expertise in lifestyle advice, support and encouragement should also be made more widely known. This could be done locally through the use of posters and practice information letters in GPs' surgeries perhaps in conjunction with a national media campaign led by one of the stakeholders such as the Australian Practice Nurse Association. GPs could also inform patients about how PNs can help them with lifestyle and behavioural issues that are affecting their health.

The role of the personal GP is very important in facilitating confidence and therefore, satisfaction with PN-led care. GPs can help facilitate satisfaction with this model of care by providing whole hearted support recommendation for it. In order for GPs to be able to recommend PN-led care to patients, they need to be aware of what PNs offer and what patients think about this sort of care. Therefore, awareness among GPs also needs to be raised about how PNs can contribute towards the management of ongoing conditions and in particular the care that PNs offer that GPs may not have time for, such as detailed lifestyle advice, support and facilitating patients' accountability. The findings of this study can also be used to inform GPs of the views of patients in respect to PN-led care. They may be more willing to recommend PN-led care if they are aware of how patients value the different but complementary care that PNs provide and that patients want the nurses to work in collaboration with GPs.

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When suggesting PN-led care to patients, the collaborative nature of the model of care should be carefully explained to help the patient feel confident in the model. The present patient satisfaction study has shown that the level of confidence patients have in the model of care is enhanced by the knowledge that the nurse and GP are working together as a team. They also want to be assured that the GP is still in touch with what is happening with them. PNs can also let patients know that they are in touch with the GP about their care to reassure them of on-going collaboration. Another way in which confidence in PN-led care can be enhanced is by the PN providing explanations about the management of patients' on-going conditions. Explanations about their condition/s, the reasons for and meaning of tests, and the reasons for the advice given by the PN help to convey the PNs' competency to the patient. These explanations should be given in language that the patient can understand and any medical terminology also explained.

Careful planning of the way in which PN-led care is implemented is also important if it is to be acceptable to patients. Continuity is important in both forming a relationship with the PN and in the on-going working relationship between the PN and the patient. Where a general practice has more than one PN, arrangements should be made for patients to see the same PN, as far as is possible. It could be that the PNs in a practice specialise in particular areas with one taking responsibility for the chronic disease management, while other PNs undertake other roles such as immunisation or wound care. Alternatively, the chronic disease management of specific patients could be assigned to specific PNs. Planning the way chronic disease management is undertaken in a practice also extends to ensuring that sufficient time is made available for

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consultations. The findings of the present patient satisfaction study show that having enough time is very important to building the relationship with patients and so, particularly in the early stages of getting to know a patient or if they are going through a difficult stage, extended consultation time is necessary. As chronic disease management is usually planned care it should not be difficult to make these arrangements.

A further recommendation in regard to the planning of PN-led care is the provision of a private room in which the PN can consult with patients. PNs do not always have access to their own private space at present as discussed earlier (Halcomb, et al., 2008a; Phillips, et al., 2007). However, it is essential that this facility is made available in order for PNs to provide the type of relational care that patients want and to facilitate the desired outcomes of improved self-management and health literacy.

The first process of Navigating Care, Determining Care Needs, demonstrates how patients make an assessment of their own condition. They often base their assessments on subjective feelings alone. An aim of providing chronic disease management can be for PNs to help patients learn to monitor their own conditions effectively. This may include providing information about what different tests measure and how to interpret the results. It can also involve teaching patients to use an automatic sphygmomanometer at home or a home glucometer. Being able to effectively monitor their own conditions would assist patients in self-managing their on-going conditions. In addition to helping patients to assess their condition/s more effectively, PNs should also be aiming to contribute to the health literacy of their patients. PNs need to find out what patients know and understand about their condition/s, correct misinformation, and try to assist them to a greater understanding in ways

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that are meaningful. PNs can also teach patient skills, for instance, how to find out the nutritional value of foods, to further improve health literacy.

In encouraging patients to self-manage through a working relationship with patients, there should not be a one-size-fits-all approach. PNs need to be sensitive to the individual situation of each patient and encourage and facilitate self-management to the extent that patients want, or are willing, to self-manage at that time. This is one area where the relational skills of PNs are very important in order to find out what approach best suits each individual. The way in which PNs communicate with patients needs to be adjusted to suit the individual. While making allowances for individual differences, PNs should also encourage a sense of accountability in order to provide an incentive for patients to make the lifestyle and behavioural changes necessary to optimally manage their condition.

If PNs are to undertake a role in chronic disease management, then it is necessary that they keep up-to-date with the latest guidelines for management and are able to provide evidence-based care. In order to do this there will be a need for on-going PN education so that patients, PNs and doctors feel confident that that the best, evidence-based care is being provided. The provision of education for PN-led chronic disease management is already available through such workshops as the Primary Nurse Clinical Education workshops in association with the Australian Practice Nurse Association. However, there is a cost in terms of time and money to attend these workshops. Financial assistance and paid time off work to attend would be beneficial to PNs. Some employers and Divisions of General Practice already provide financial assistance. If employers are persuaded of the benefits of PN-led chronic disease management, they may be willing to contribute towards on-going education for nurses. Divisions

of General Practice could also provide free educational workshops for their members.

Recommendations for further research also arise out of this study. Research in other substantive areas, such as with patients from different cultural and linguistic backgrounds would be useful. In addition, extending the study to other ongoing conditions could yield additional findings. Research focusing on PN-led chronic disease management with younger adults and adolescents would also be beneficial in extending the work of this study. Further work could be conducted to investigate the link between patient satisfaction with nurse-led care in general practice and health outcomes. Also, the results of the present study could be used to quantitatively investigate patient satisfaction with PN-led chronic disease management using a large sample.

Conclusion

This study was an investigation of the process of patient satisfaction with PN-led management of chronic conditions. Although there are a multitude of studies of patient satisfaction, very few have provided a theoretical understanding of the concept as a process. Navigating Care provides an explanation of the process patients go through as they decide if PN-led care is right for them. Other studies have shown that constructs such as time, communication, continuity and trust are important to patient satisfaction. By revealing the mechanisms involved in the process of satisfaction, Navigating Care explains why and how these constructs are important. It becomes clear from this study that patients want to choose who manages their ongoing condition based on their own assessment of their health

needs. They also want to choose the level of involvement they have in self-managing their on-going conditions. They appreciate and want PNs to provide complementary care in collaboration with their GP.

A greater understanding of the process of patient satisfaction provided by the theory of Navigating Care can be used to help identify patients who would be suitable for PN-led care, inform the practice of nurses to facilitate satisfaction with care and inform the implementation of nurse-led models of care. The findings in regard to building the patient-PN relationship can be used to help nurses understand the patients better and facilitate patient self-management in ways that are more satisfying to the individual patient.

Appendices

Appendix A: Protocols

Appendix B: Letter of invitation

Dear

Dr ……………………. would like to invite you to take part in the Practice Nurse Project. There are three aims of the Practice Nurse Project and these are to:

1. demonstrate that practice nurses, working with the doctor, can manage long-term illness in general practice

2. find out if this model of care is acceptable to patients, practice nurses and GPs

3. measure the cost of this model of care and to see if it is cost effective for general practice.

The study is trialling a different way of providing care to patients in general practice where people with diabetes, heart disease and high blood pressure are managed by the nurse rather than the doctor. However, at the commencement of the project, the doctor, the nurse and yourself will meet and plan the way the doctor and yourself wish your health to be managed. The nurse and doctor will meet regularly to discuss your history and if necessary the nurse will recommend that you see the doctor if she feels that

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this is necessary. When you are being cared for by the nurse, you can visit your doctor whenever you like for other health problems. You can also, if you are unhappy with the care you receive from the nurse, change back to just seeing the doctor. Your visits to the doctor or the nurse will be at your usual surgery. You will not be required to go to the university.

Included with this letter is an information sheet and consent form which will give you more information about the project. Once the study is completed, we may contact you again to ask you to participate in an individual interview or a focus group to see what you thought about the project. If you have any questions or would like to know more about the project, please contact either your doctor or the Project Officer, Robyn Synnott (telephone 07 3720 5618).

Yours faithfully,

Appendix C: Consent form and Information sheet

Appendix D: Consent to interview form

Practice Nurse Project

It is very important as part of the Practice Nurse Project that we find out what patients think of practice nurse-led care. Rosemary Mahomed and Jacqui Young are members of the project team and will want to talk to some of the people who are assigned to the practice nurse group about their experience. They will interview people in groups (focus groups) and one to one. Some focus groups will be held soon, before the project starts. Most of the interviews will be at the end of the project in 12 to 18 months time.

Please indicate below if you are willing to be involved in:

q   A focus group

q   An individual interview

q   Both

q   None

If you are willing to be interviewed please fill in your details below so that Rosemary can contact you if she needs to.

Name…………………………………………………………………………

Address…………………………………………………………………………

………………………………………………………………………………

Tel. No………………………….

Age q under 50 q 50 – 65 q 67 – 75 q over 75

I am being treated for:　q Diabetes　q Heart disease　q High blood pressure

(Please tick one or more boxes)

Appendix E: Interview guides

Mid-intervention question guide

When you first got the letter inviting you to take part in the project what did you think?

Did you talk to anyone about it?

How did you explain it to them?

When you found out you were in the PN group what did you think?

Why do you think you are going to see the PN?

What do you want to get out of seeing the PN?

What concerns did you have before going to see the PN?

What did you want to get out of seeing the PN when you went to see her for the first time?

Did you get what you wanted?

Can you tell me about anything that you wanted from seeing the PN that didn't happen?

What happens when you go and see the PN?

What did you like most about going to see the PN?

What didn't you like about going to see the PN?

What do you think could or should be done differently?

Were you able to discuss things with the PN?

Did seeing the PN help you to understand your condition?

How did she help you?

Did you have enough time with the PN?

Did you already know the PN?

(If not) Do you feel you know her now?

What helped you to get to know her?

Other people have talked about being more relaxed with the PN. What are your thoughts about that?

Do you talk to other people, family or friends, about the project?

What do you tell them?

Probes

Can you give me an example of that?

How?

In what way?

Could you explain that for me?

Could you tell me a bit more about….?

What makes you say that?

What exactly do you mean by….?

Mid-intervention question guide 2

Condition

How much do you feel you know about your condition?

How do you feel about having diabetes, heart disease, high blood pressure?

How does it affect your life?

How do you feel about the PN looking after your diabetes, heart disease, high blood pressure?

What do you worry about and what do you leave to the doctor or PN?

Why don't you worry about it?

General

What concerns did you have before going to see the PN?

Can you think of anything that would make you unhappy for the PN to be looking after your diabetes, heart disease or high blood pressure?

What do you want to get out of seeing the PN?

Do you get what you wanted?

Can you tell me about anything that you wanted from seeing the PN that didn't happen?

What happens when you go and see the PN?

What did you like most about going to see the PN?

What don't you like about going to see the PN?

What do you think could or should be done differently?

Relationship questions

What things help you to get on well with the PN?

Were you able to discuss things with the PN?

Can you think of any things that would make it difficult to talk to her?

Can you think of anything that would make you not want to go and see a PN?

Did seeing the PN help you to understand you condition?

How did she help you?

Did you have enough time with the PN?

Did you already know the PN?

(If not) Do you feel you know her now?

What helped you to get to know her?

Other people have talked about being more relaxed with the PN. What are your thoughts about that?

Is it important to you that you always see the same PN?

Why?/Why not?

Question guide mid-intervention 3

Attitude towards condition

What sort of health problems do you have?

How do they affect your daily life?

Do you know much about your diabetes/heart disease/hypertension?

Do you think it would be helpful to know more?

Has seeing the PN helped you to understand your condition more?

What sort of things do you do to help with your diabetes/heart disease/hypertension?

Who do you consider to be the most suitable person to manage your diabetes/heart disease/hypertension?

Why is that?

In what circumstances would someone else (doctor of nurse) be more suitable?

Assessing condition

Some people have said that they are happy for the PN to manage their condition provided it is stable or under control. What do you think about that?

Can you think of any circumstances when you wouldn't be happy for the PN to manage your condition?

What is it that makes you feel that your condition is stable?

What would make you feel that it was not as stable or under control?

Attitudes to nurses in general

What do you think of when you think of nurses?

Do you think about hospital nurses differently from nurses in general practice?

In what ways?

Has your attitude towards nurses changed over the years?

In what ways?

Has your attitude towards nurses changed as a result of seeing the PN?

In what ways?

Relationship with PN

What things make it easy to relate to the PN?

What things would make it harder to relate to the PN?

Question guide late/post intervention 1

Attitude towards condition

What sort of health problems do you have?

How do they affect your daily life?

How much do you feel you know about your diabetes/heart disease/hypertension?

Do you think it would be helpful to know more?

Has the PN helped you to understand more about your diabetes/heart disease/hypertension?

What sort of things do you do to help with your diabetes/heart disease/hypertension?

Who do you consider to be the most suitable person to manage your diabetes/heart disease/hypertension?

Why is that?

In what circumstances would someone else (doctor of nurse) be more suitable?

Assessing condition

Some people have said that they are happy for the PN to manage their condition provided it is stable or under control. What do you think about that?

Can you think of any circumstances when you wouldn't be happy for the PN to manage your condition?

What is it that makes you feel that your condition is stable?

What would make you feel that it was not as stable or under control?

Attitudes to nurses in general

What do you think of when you think of nurses?

Do you think about hospital nurses differently from nurses in general practice?

In what ways?

Has your attitude towards nurses changed over the years?

In what ways?

Has your attitude towards nurses changed as a result of seeing the PN?

In what ways?

Questions about advice given by the PN

What do you think about the advice the PN gives you?

Do you follow her advice?

When you go back do you tell her if you've followed her advice or not?

What would make you not tell her something?

Relationship with PN

Did you know the PN before you started seeing her for your diabetes/heart disease/hypertension?

Do you feel you know her now?

What helped you to get to know her?

What things make it easy to relate to the PN?

What things would make it harder to relate to the PN?

Were you able to discuss things with the PN?

Can you think of anything that would make it difficult to talk to the PN?

Did you have enough time with the PN?

Do you see the same PN each time?

Is that important to you?

Why is that?

(If not) How does that make you feel?

Other people have talked about being more relaxed with the PN, what do you think about that?

Question guide late/post intervention 2

How does you diabetes/heart disease/hypertension affect your daily life?

How much do you feel you know about your diabetes/heart disease/hypertension?

How do you find out about your diabetes/heart disease/hypertension?

Do you think it would be helpful to know more?

Has the PN helped you to understand more about your diabetes/heart disease/hypertension?

What sort of things do you do to help with your diabetes/heart disease/hypertension?

Do you think the PN is able to manage your condition?

Why is that/what makes you think that?

Assessing condition

Some people have said that they are happy for the PN to manage their condition provided it is stable or under control. What do you think about that?

Can you think of any circumstances when you wouldn't be happy for the PN to manage your condition?

What is it that makes you feel that your condition is stable?

What would make you feel that it was not as stable or under control?

Do you think your health has improved since seeing the PN?

Why do you think that is?

Attitudes to nurses in general

The PNs have suggested that a lot of patients have an implicit trust in nurse in general. What do you think about that?

How do you decide that the PN knows what she is doing?

What sort of things would make you feel less confident that she knows what she is doing?

Is it important that the PN appears confident to you?

Why is that?

How does is make you feel when she seems confident in what she is doing?

How would you feel if she didn't seem confident?

Does the PN explain things to you?

Questions about advice given by the PN

What do you think about the advice the PN gives you?

Do you follow her advice?

When you go back do you tell her if you've followed her advice or not?

What would make you not tell her something?

Some of the PNs have said that they try to personalise the advice that they give. What do you think about that?

Relationship with PN

Did you know the PN before you started seeing her for your diabetes/heart disease/hypertension?

Do you feel you know her now?

What helped you to get to know her?

What things make it easy to relate to the PN?

What things would make it harder to relate to the PN?

Were you able to discuss things with the PN?

Can you think of anything that would make it difficult to talk to the PN?

When the PN is chatting with you does she talk about things in her life?

Does this help in getting to know her or feel relaxed with her?

How?

Did you have enough time with the PN?

Do you think it is important to see the same PN each time?

Why is that?

Other people have talked about being more relaxed with the PN, what do you think about that?

Do you think being relaxed with the PN helps your diabetes/heart disease/hypertension?

In what way?

Returning to Usual Care

Under what circumstances would you want to go back to seeing just the Doctor?

Would that be permanent or would you return to seeing the nurse after a while?

What would make you willing to go back to seeing the nurse?

Question guide late/post intervention 3

Assessment of condition

How does your diabetes/heart disease/hypertension affect your daily life?

What sort of things do you do to help with your diabetes/heart disease/ hypertension?

What is it that makes you feel that your condition is stable?

What would make you feel that it was not as stable or under control?

Do you think your health has improved since seeing the PN?

Why do you think that is?

Some people have said that they are happy for the PN to manage their condition provided it is stable or under control. What do you think about that?

Can you think of any circumstances when you wouldn't be happy for the PN to manage your condition?

Have you had any not so good results (BP, blood results) while seeing the PN?

What happened?

How did you feel about that?

If /when you had to go back to see the doctor for your diabetes/heart disease/hypertension would you be or were you happy to return to seeing the PN later?

Follow up question

Understanding

How do you find out information about your diabetes/heart disease/hypertension?

Do you talk to her about it?

Can you give me an example of that?

When the PN gives you advice does she explain the reasons for it?

How does that help?

Does the PN talk to you about your blood results and what they mean?

Do you like them to do that?

Why's that?

Are there things you understand better since seeing the PN?

Can you give an example of that?

Has understanding more been useful?

How?

Are you more likely to ask the PN questions now than when you first started seeing her?

What sort of questions do you ask?

Goal setting:

Do you have goals that you want to achieve in relation to your diabetes/heart disease/hypertension?

Who decides those should be your goals?

Has the PN talked to you about goals?

How does that make you feel?

Do you find the PN gives you encouragement in managing your condition?

How does she do that?

Why is that important for you?

PNs advice

What sort of advice does the PN give you?

What do you think about the PNs advice?

Why is that?

What do you like about it?

Are there anything's you don't like about it?

Would you tell the PN that?

The PNs have said that they try to personalise their advice, what do you think about that?

Why do you think that?

Some people have suggested that going back to see the PN and knowing she will be weighing and measuring them and that sort of thing makes them think a bit more about it. What do you think about that?

What do you think about the advice the PN gives you?

Do you follow her advice?

When you go back do you tell her if you've followed her advice or not?

General:

What makes the visit to with the PN different to seeing the doctor?

What do you think of when you think of nurses?

How do you decide that the PN knows what she is doing?

What sort of things would make you feel less confident that she knows what she is doing?

Do you feel you have enough time with the PN?

Why is that important?

Do you feel you have the PNs attention during the consultations?

What makes you feel that?

What things have helped you to get to know the PN?

Does talking about things that you have in common or things that are happening in your lives help?

Why do you think that might be?

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