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CONDITIONAL EXPERTISE
IN
CHRONIC ILLNESS

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Abstract

The incidence of chronic illness is increasing in the developed world. This means that there is an increased utilisation of acute health care services by people with chronic illnesses, either for treatment of exacerbations or for unrelated health problems. Acute health care services are based on the notion of finite, curable episodes of ill-health, and as such they do not always meet the needs of people with chronic illnesses.

This study uses a grounded theory approach to examine the issues surrounding hospitalisation in acute care facilities for a group of eight people with chronic illness. Participants were interviewed within two months of an admission to hospital. Analysis of data, further interviews and other data collection, and generation of theoretical concepts were performed in accordance with the grounded theory method.

The key finding from the research was a state of conditional expertise for the chronically ill. While living at home, and in a state of relative well-being, participants were acting as experts in the management of their illnesses. During encounters with health providers in the primary care setting, particularly those whom participants knew, a process of negotiation occurred, engendered by mutual trust in each other's expertise. However, once the acute care setting was entered, participants discovered that their expertise was neither valued nor acknowledged. In response, they went through the processes of informing health carers, by repeatedly telling their stories to different health professionals they encountered, and finally withdrawing from participation in care. This withdrawal could be either physical, where the participants sought early discharge, or emotional in terms of becoming passive recipients of care.

The implications of this study, given its limitations, are numerous. In order to provide satisfactory care for people with chronic illnesses, health professionals working in acute care settings must move beyond the dominant model and seek to establish trust relationships which acknowledge and value patient expertise. This requires, first, that education programmes for health carers encourage the recognition of important data about patients that do not relate to biological and disease states. Second, a system of care needs to be developed within the acute care setting that allows ongoing relationships to be established between individual patients and carers. This in turn would generate trust between patient and carer, which would enhance the abilities of each to acknowledge expertise. The Partnership model of nursing care is proposed as a possible solution to this problem.

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CHAPTER ONE

INTRODUCTION

With the ageing population and declining infectious diseases, the number of people with chronic illnesses accessing acute care services is increasing. People with chronic illnesses use the acute care system for a variety of reasons - treatment of exacerbations, assessment of treatment regimes, and for unrelated health problems. While there have been a number of studies which examine what life is like for the chronically ill, most of these have stopped at the hospital doors. Nursing and other authors have speculated that patients in hospital who have chronic illnesses may demonstrate more knowledge about their illnesses and be more assertive about the care they receive. No-one has actually examined the experiences of the chronically ill during admission in an acute care setting.

My interest in this topic began in the early 1980's when, as a newly qualified staff nurse, I began working in a combined urology and renal ward. Half of the patients in this unit were short stay or acute surgical patients, while the other half were long stay or returning patients with chronic renal failure and renal transplants. The contrast between the type of care delivered to these two groups of patients was apparent to me even then. After a number of years working in both acute and long stay care settings, I found myself back in a similar ward. This time patients were admitted either for cardiothoracic surgery or with chronic respiratory and renal conditions.

My own experience, and observation of other nursing staff in the ward, led me to believe that there was a relationship between the chronically ill patients and

staff that did not exist with the surgery patients, even though some of them had longer admissions. Because of repeat admissions, many of the respiratory patients became known to staff. I began to wonder what, if any, benefit this might have both from the patients' perspectives and those of the nurses. It seemed to me that some of these people with chronic respiratory conditions, and numerous admissions, had become 'expert' patients, and might have something very valuable to contribute to nursing.

I soon learned, in conversation with nursing and other colleagues that the term 'expert patient' was, for many, very negative - a malingerer or someone who knew and could manipulate the system. I began to observe that while patients with chronic illness were expected to know about their illnesses and treatment regimes, too much knowledge or expertise were not viewed favourably by some staff. The realisation that hospital admission for this group of patients could be problematic soon surfaced, and this research study was initiated.

Reviews of the literature and conversations with colleagues, both in practice and in education, confirmed my thoughts that there was something problematic occurring for people with chronic illnesses in acute care settings, that had not been examined before. The method I chose for the research, that of grounded theory, seemed most appropriate because it allowed me to go into the field without a priori theorising as to what might be the outcome of the research. Since little was known about the reality of the situation for these people, to go to them with an hypothesis about what might be happening seemed, at best, inappropriate. The experiences of the group of people who participated in this research have demonstrated the appropriateness of the method selected. The outcome of this research, the discovery of conditional expertise, may not have been possible with any other method.

In the chapters that follow, the experiences of a group of eight people with chronic illnesses have been examined and their main problem, that of diminishing expertise in the face of acute care services, is explored. Chapter Two

is a review of the literature. This covers definitions of chronic illness and how these impact on attitudes toward people with chronic illnesses. The review then examines the Parsonian model of acute illnesses, which is held to be the dominant model in operation in acute hospital settings. The contrast between chronic and acute models of illness is made. Other issues related to nursing care in hospital that arose from the grounded theory are also reviewed in this chapter.

Chapter Three examines grounded theory and its utility for nursing research and for this research project in particular. Some of the criticisms made of the method are addressed and means of ensuring validity and reliability are discussed. This chapter then goes on to describe in detail the process undertaken for this study.

The results of the grounded theory research are discussed over two chapters. The first of these describes the core category of the grounded theory, that of conditional expertise. This is related to four theoretical codes which are discussed in the following chapter - controlling, negotiating, informing and withdrawing.

The discussion relates the core category and its theoretical codes to current nursing knowledge and practice and addresses a number of implications of the theory for nursing. Possible shortcomings of the research are acknowledged and discussed. Conclusions about the findings and suggestions for future research in this area are made.

A word about the terminology used in this thesis.

Participants in this study, and others from the literature reviewed, are referred to as people with chronic illnesses when the discussion relates to their experiences in the community or at home. On entry to the acute care setting, they are referred to mainly as patients. The reason for this is the common use of the term patient to describe people in hospitals. The term was used by participants as they related their experiences during interviews and it was used almost exclusively in the literature.

CHAPTER TWO

REVIEW OF THE LITERATURE

The incidence of chronic illness in first world countries is presumed to be increasing with the decline in infectious diseases and increasing life expectancy of the population. This assumption is difficult to confirm however since there are no statistics available about rates of chronic illness. Indeed, there is some difficulty over the definition of chronic illness and its place in the healthcare and social welfare systems (Locker, 1997; Moore, 1995).

Research on the chronically ill as a group, as distinct from research about groups of people with a common medical diagnosis, has been largely within the qualitative domain and concerned with how these people live their lives. Little research is available which examines what happens when people with chronic illness access acute care services. What research there is indicates a unique set of circumstances for this particular group compared with those more commonly identified in the acute care setting, namely people with acute illnesses that are resolved during the admission and from which the person is expected to recover fully (Charmaz, 1991; Strauss, 1975).

Definitions of Chronic Illness

Numerous definitions of chronic illness exist in the literature. Some of these focus on the disease process involved. One widely used example is that by the (United States) Commission on Chronic Diseases (1949):

All impairments or deviations from normal which have one or more of the following characteristics: are permanent, leave residual disability, are caused by non-reversible pathological alteration, require special training of the patient for rehabilitation, may be expected to require a long period of supervision, observation or care. (cited in Strauss et al., 1975, p.1)

Reif (1975), in a critique of traditional models of chronic illness, examines the effect of placing the medical problem central to any definition and suggests that, in this interpretation, the goal becomes management of the illness and the manager is the doctor. However, if the consequences of the illness are made central to models of chronic illness, then the goal becomes managing life with the chronic illness, and the manager is the person experiencing the illness.

Curtin and Lubkin (1990) have also critiqued definitions of chronic illness. It seems clear that most definitions that focus on the disease process ignore the impact of the disease on the person. Some, like the definition cited above are so broad that they could encompass birth defects and disabilities following injuries. At the time of their writing, Curtin and Lubkin could find no nursing definition of chronic illness so created their own, one that is more flexible and comprehensive than current definitions:

...the irreversible presence, accumulation or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability. (Curtin and Lubkin, 1990, p.6)

This definition has become popular in the nursing literature related to chronic illness (e.g. Miller, 1992), but it has a number of limitations. The first of these is the breadth of the term “disease states or impairments”. This term could easily include disabilities following injury and birth defects – the very things for which the authors criticise other definitions. The implications of the use of the term “total human environment” could be that management of chronic illness is, and should be, the sole focus of the person and their carers, leaving no room or

opportunity for other life activities. In addition, this definition, like those before it, does not seem to take account of any variability in the course of the disease. Curtin and Lubkin assume a steady state, with neither remissions nor exacerbations, when they speak of the “maintenance of function and prevention of further deterioration”. In effect, intense effort on the part of the person with chronic illness is required to sustain a steady state, and it may not be possible.

Cohen (1987) examined models of chronic illness in relation to informed consent. Traditional models ignore what a number of studies (e.g. Strauss et al., 1975) have demonstrated, that people with chronic illness are often experts in their own illness and care, and usually are the managers of that care. Cohen redefines chronic illness as a state which:

encompass(es) conditions of ill health that extend over a significant period of time, have no predictable endpoint, are mild to severe due to the nature of the underlying condition or to its effects on daily living, are not usually immediately life threatening, display varying patterns of change in clinical symptoms over their course, and are distinctively accompanied by pain and suffering. (Cohen, 1987, p.30)

Cohen, by describing chronic illness as “conditions of ill health... accompanied by pain and suffering”, appears to exclude birth defects and post-injury disability from her definition. The variable nature of chronic illness is accounted for and, while it is described as “not usually life-threatening”, this does not exclude the possibility of life-threatening exacerbations. Cohen focuses on the subjective nature of chronic illness and, unlike Curtin and Lubkin, does not attempt to address the management of chronic illness.

Within the context of this research, the issue requiring examination is what occurs when these contrasting models meet. In the acute care setting, the dominant model is that which places the medical problem first in order to treat and resolve it. The hospital staff assumes management of the disease

(Tagliacozzo et al., 1972); what happens to the chronically ill person's self-management processes during this time is not really known.

Chinn (1996) has asked:

Why, in the face of clear inability to 'cure' a disease do nurses and other medical care providers continue to move within a frame of reference oriented toward cure? (p.vi)

In order to answer this question, particularly in relation to chronic illness in an acute care setting, it is necessary to examine models of illness in more detail.

Acute versus Chronic Illness and the Sick Role

Parsons' (1952) well-known sociological explanation of the behaviours of ill persons was referred to as the sick role. This is, within limits, still regarded as an adequate explanation for acute illness behaviours (Lubkin, 1990), and it could be argued that this is the dominant model operating in acute care settings (Chinn, 1996; Cohen, 1987; Lubkin 1990; Thorne and Robinson, 1989). Currently, sociologists regard the Parsonian sick role as an ideal view of medicine against which the reality is measured (Pescosolido and Kronenfeld, 1995; Morgan, 1997).

Parsons' (1952) sick role description includes an explanation of a person's capacity to perform physical tasks or to participate in the social system (role performance). He defines health as a "state of optimum capacity of an individual for the effective performance of roles and tasks for which he has been socialised" (Parsons, 1972, p.107). This, it should be noted, refers to a capacity for performance, not a commitment to the role or task.

If health is defined in this way then illness can be viewed as incapacity. Such a view has consequences that have an important impact on everyday views of illness in relation to the chronically ill. The first consequence of the Parsonian view of ill health is that it is beyond the person's power to overcome the illness by an act of will - it cannot be cured by choosing or wanting to be cured. Some form

of therapy is required. Thus, the sick role is designed to prevent allocation of blame for illness – it is nobody's fault that we fall ill (Brody, 1987).

This does not mean, however, that the person should not want to be cured. In fact the exemption from roles/tasks that sickness allows is partially dependent on the acknowledgement that illness is an undesirable state and a person will do their best to get well again. Thus, sick people are required to co-operate fully with their medical and other treatment regimes.

The main import of the Parsonian sick role is that it is a temporary state, and that the person will eventually return to the roles and tasks to which he or she has been accustomed prior to the episode of ill health. If the person fails to recover, there is no room in this model for their continued exemption from these roles.

If a person no longer fits into the sick role then fault can be assigned, either by the individual themselves or by society. Thus, a person may not be doing their best to get well – they may be enjoying the benefits of the sick role too much to make the effort to get better. Perhaps they are not co-operating fully in their treatment or they are using alternative, non-legitimate therapies. The inability to perform normal tasks and roles now becomes viewed as a lack of commitment, and the person can no longer be regarded as truly 'sick.' Within the acute care setting such people may be subject to disapproval and even sanctions by staff (Lawler, 1991; Lupton, 1995).

So, while the Parsonian view of sickness may have some utility in acute health care settings for acute illnesses, it fails the chronically ill who are unable to resume former roles, but whose incapacity in performance is also often incomplete (Fox, 1989; Radley and Green, 1987). In addition, the well-defined social behaviours of the acutely ill do not exist for the person in the chronic sick role and this may cause "conflict between the expectations of the individual and

his family and the surrounding social community” (Craig and Edwards, 1983, p.398).

Others have examined chronic illness in relation to the Parsonian model of the sick role. The model has been criticised as overemphasising professional (i.e. medical) roles in health care (Fox, 1989; Gallagher, 1976) and minimising the importance of social, economic and psychological factors in a person’s recovery (Honig-Parnass, 1981; Stewart and Sullivan, 1982).

Since the Parsonian model was developed, the emphasis in medical sociology has shifted to individuals and their health behaviours. Pescosolido and Kronenfeld, (1995) suggest that, while this has been useful in challenging the dominant status of medicine in Parsons’ model, it has failed to address systemic issues such as funding changes, the shift to community based care, and the rising incidence of chronic illness.

A model based on the behaviour of individuals presumes, it could be argued, a rational decision making process by the ill person in relation to his/her health care. This view underlies behaviourist notions of stress, adaptation and coping in chronic illness (Abram, 1972; Craig and Edwards, 1983; Leidy et al., 1990; Pollock, 1986). Moreover, an examination of these models indicates that notions of the sick/impaired roles are also in operation. Behaviourist models of illness categorise illness behaviours as adaptive if they are directed toward resumption of non-illness roles and maladaptive if they are not (Mechanic, 1962), even though it may be acknowledged that full resumption of previous roles is not possible (Leidy et al., 1990).

When applied to chronic illness, these models simplify what is actually a very complex process. The notion of adaptation in chronic illness appears to be equated with recovery from acute illness and an examination of the literature suggests it is regarded in the same light. Adaptation is often viewed as a permanent ongoing state – the goal of nursing care is to assist the chronically ill

person to adapt to his or her illness and resume at least some of their pre-sickness roles. Failure to do so, like relinquishing sick roles after an acute illness, could result in sanctions.

Within the sick or impaired role, the idea of secondary gain, in the form of an escape from pre-illness social roles, is the advantage conferred by illness (Parsons, 1952), but this is viewed as negative or maladaptive (Abram, 1972; Feldman 1974). This becomes important when examining definitions of chronic illness and rehabilitation that discuss quality of life and maintaining maximum independence. It is necessary to ask who defines what quality is for any individual. If the person who is chronically ill does not equate quality of life with maximum independence, and this is regarded by carers as maladaptive, role definitions created by Parsons are in operation.

Beyond Parsons

In recent years a number of studies have looked at ways in which people live with a chronic illness, and have moved the concept beyond the notions of a single, all embracing sick/impaired role and adaptation.

Radley and Green (1987) describe the ways in which illness and social life impact, inextricably, on one another. The potential range of symptoms, social circumstances and cultural beliefs that can be experienced by the person with chronic illness make it inevitable that there are a range of sick roles. Thus, a person can display evidence of behaviour along two axes: loss or retention of social roles, and oppositional or complementary relations with their illness. The Parsonian view would see only the first of these as important but arguably the second could have much more impact on the well being of the person involved.

Benner et al. (1994) elaborate this aspect of chronic illness. They describe the consequences for the chronically ill of the idea that personal behaviour can influence health. This is discussed in the context of the wellness movement but also has relevance to the idea that, once a person no longer fits the criteria for

the sick role, they are not protected by the notion that their sickness is beyond their control.

According to Benner et al. (1994), the conflict created by an inability to will oneself better establishes an oppositional relationship between the person and their body/illness. The consequences of this are: delayed help seeking, little accommodation to the demands of the illness, and a reluctance to take medications as they become a sign of failure to control the body. The opposite of this is “acceptance with care” (Benner et al., 1994, p.238) where a person lives with their illness without assuming responsibility for cure or being ill. The person does, however, assume responsibility for caring for themselves and the illness.

Benner et al. (1994), and Radley and Green (1987) suggest that people with chronic illness do not display consistent responses to the illness. Over time, their behaviours, in terms of social roles and relationship with the illness, may vary. Neither group of authors discuss whether this variation in response is related to demands placed on them by the illness itself or to personal or social constraints. McWilliam et al. (1996) tested Benner’s model and found that people moved continuously between different patterns of relationships to their illness. Variability as to how a person lives with their illness has some significance for health care providers in that the interventions that are effective in one mode would be different from those that might be helpful in another.

Living with Chronic Illness

A number of studies have examined day-to-day issues for people with chronic illness. Strauss et al. (1975) used grounded theory to develop a list of problems of daily living that the chronically ill must deal with. This list includes the following: prevention and management of medical crises; performance and management of therapeutic regimes; prevention of, or living with, social isolation; adjustment to fluctuations in the course of the disease; normalisation of

lifestyle and social interactions; and finding money to pay for treatment or replace lost income (Strauss et al., 1975, p.7).

Charmaz (1991) also studied the impact of chronic illness on daily lives of sufferers. In this study, chronic illness was perceived as an intrusion demanding continuous attention and accommodation, and over which control was limited and tenuous.

Both Strauss et al. (1975) and Charmaz (1991) discuss the impact of the chronically ill person's contact with health professionals. Strauss et al. (1975) write of the biographies a person brings with them to a hospital admission. The chronically ill bring not only a biography of their illness and its management, but also a history of previous encounters with the health care system and its workers, and a social biography about family, friends and work etc. and the impact of their illness on these.

Strauss et al. describe a sharp dichotomy between home and hospital, where a patient is expected to surrender all control of their care and responsibility for their illness to staff. What is forgotten in this process is that the management of the illness has been, and still is, the patient's business, and this self-management will have to be resumed at discharge. It is difficult to tell from Strauss et al.'s (1975) discussion how much of this writing is based on the grounded theory research and how much is informed reflection on the issues.

Charmaz (1991) describes the way in which contact with health professionals leads to reduced autonomy and increased dependence for people with chronic illness. In her view, the acute care system disadvantages the chronically ill in a number of ways:

1. Frustrations for staff confronted with a multitude of complex, non-curable problems in the one person can lead to victim blaming (see also Lubkin, 1990; Lupton, 1995);

2. Access to services is often limited to episodes of exacerbation and crisis, rather than ongoing care to preserve and enhance current levels of health;
3. Education and rehabilitation are confined to brief episodes following crises and take no account of the ongoing nature of chronicity, the person's readiness to accept chronic status, readiness and ability to learn, and the level of illness in everyday living (not exacerbation states);
4. Rehabilitation is provided on the understanding that it will result in improvement and progress, otherwise access becomes limited;
5. The system focuses on the illness, not the person and their social environment, thus the human consequences of chronic illness can be overlooked.

These findings are echoed by Lindsey (1997) and Toombs (1995) who found that health professionals focus on the objective disease rather than the subjective illness. By doing this, they invalidate the person's experience of their chronic illness and their expertise in self-care.

Lubkin (1990) has speculated about the responses of both chronically ill patients, and nurses, when they encounter each other in the acute care setting. Some of Lubkin's conclusions include the propositions that acute illness behaviour in hospital is often passive, dependent and regressive, while chronic behaviours are 'positive,' retaining much decision making power; and that the professional holds chronically ill patients accountable for their own care and can be easily irritated by them, while acute patients hold professionals accountable for their care (Lubkin, 1990, p.56). It should be noted, however, that these behaviours are based on comparison of the sick and impaired roles and do not appear to have been verified through research.

Other authors have examined care of people with chronic illnesses in hospital. Strauss et al. (1982) used grounded theory to examine the work of patients in hospital, particularly the chronically ill. This work can be explicit, supplementing the health professional's work, or implicit, and not readily being

recognised as work. Examples of implicit work are personal hygiene tasks, giving information, and enduring tests and treatments. For people with chronic illness, who bring expertise with them when they are admitted to hospital, much of the work may involve preventing or rectifying staff mistakes and making decisions about the care they will accept.

Kirk (1992; 1993) used a phenomenological approach to examine the views of six chronically ill people in relation to their nursing care. The main theme to emerge was labelled 'confidence'. The author found that patients perceived that 'good' nursing care was being given when they were confident in the abilities of their nurses. Particular aspects of care that were important included the nurses' physical skills in looking after the patient, qualifications and competence, and manner and characteristics of the nurses. This was a small-scale study undertaken for a Masters thesis and the journal report does not allow an examination of the data analysis methods.

Other than these two studies there appears to be little in the available literature that describes the nursing that occurs for people with chronic illnesses in the acute care setting. A number of models suggest what nursing behaviours and activities should occur both from a behaviourist (Craig and Edwards, 1983; Mishel, 1988; Pollock, 1986) and a more phenomenological perspective (Benner et al., 1994, Strauss et al., 1975). However, there appears to have been no examination of what actually occurs.

The evidence suggests that admission to an acute care setting may be problematic for chronically ill people, and that the care provided normally does not meet their needs. This evidence is derived from conflicting paradigms and cannot identify what occurs in the context of the New Zealand health care system.

Hospitalisation

It is generally accepted that admission to hospital is an unpleasant experience for most people (Clark, 1976; Fairhurst, 1977; Hawkins, 1993; Newman, 1984; Quin, 1996). Familiar environmental cues and social roles are replaced by the unfamiliar and confusing demands of hospital culture, and are exacerbated by the presence of illness. Loss of privacy and independence may also be seen as distressing features of admission to hospital (Christensen, 1990; Lawler, 1991). Christensen (1990) describes a complex sequence of learning and discovery that patients go through during an episode of hospitalisation. This is true even if the patient is familiar with the ward, although that may make the process easier (Bowman et al., 1992).

Under the Parsonian model of sickness, it is the patient's duty to be patient and to display "gratitude from time to time, evenness of temper, acceptance of the regime and a conscious effort to get better" (Clothier, 1989, p.7). Patients are regarded as passive recipients of care. In fact, a number of studies have revealed that, in hospital, patients are active both in their care, and in the evaluation and receipt of the care they are given, even when this is not consistently acknowledged by staff (Christensen, 1990; Kralik et al., 1997; Russell et al., 1997; Strauss et al., 1982).

Christensen (1990) describes the work of the patient during an admission for arranged surgery. Activities such as managing self and coping with the experience, establishing relations with carers, and finding meaning in the experience, all indicate that the patient is more than a passive recipient of care.

Russell et al. (1997) uncovered work by patients related to self-protection and protecting others. In order to protect the self from undesirable consequences of care and from receiving too much care, patients work at educating themselves about their illness and make decisions about who they will accept care from. In this series of studies, patients tended to rely on their own judgement more than that of the doctors and nurses caring for them. Occasionally this involved

confrontation. The patients in these studies were chronically ill but not experiencing exacerbations at the time of care.

Kralik et al. (1997) examined patients' experiences of being nursed in hospital and discovered that patients brought with them to hospital expectations of the type of care they should receive. The nursing care they did receive was evaluated in the light of these expectations. Their response to care was shaped by the type of nursing they received. Those patients who felt their nurses were engaged with them in care, felt confident and able to seek help (see also Callaghan and Williams, 1994). Detached nursing care, where patients believed that nurses treated them as numbers or just a job, led to the patient adopting a passive role during their hospitalisation. Help seeking was reduced to a minimum for fear of seeming a nuisance or of sanctions.

Lawler (1991) also talks of sanctions in relation to care. Some nurses are seen to set a recovery trajectory for their patients which, if not adhered to, can lead to sanctions. This trajectory is set, not by individual circumstances, but by the diagnosis or operation the patient has been admitted for. It is possible that this expectation would be problematic for people with chronic illness admitted for treatment of other conditions: their chronic illness may well affect their recovery trajectory or need for help, and thus they may become subject to sanctions.

Empowerment, Participation and Compliance

With increasing recognition of the negative impact of admission to hospital on patients, nursing and other health professions have become concerned with the notions of patient empowerment and increased participation in decision making. There is a vast array of literature urging increased patient participation in care, and patient empowerment in the decision-making process, particularly in relation to primary nursing. In turn, there is little evidence to suggest that increased participation in care makes a difference or is wanted by patients (Biley, 1989; Trnabranski, 1994).

Margalith and Shapiro (1997) tested the assumption that increased participation in care decreases patient anxiety in the acute care setting. There are conflicting results from similar studies. Some found that this was true. Other studies found increased anxiety and feelings of guilt and inadequacy. Margalith and Shapiro's (1997) research found that the response was variable, and was influenced by education levels, coping styles and perceived participation.

Cahill (1998) in a review of the nursing literature related to patient participation found a variety of meanings attached to the term, and that these could be differentiated by two philosophical approaches: caring and consumerism. In some studies, participation was seen as a way of enriching quality of life and decision-making processes for the patient; in others it was viewed as another tool in the battle of cost containment.

Generally, it has been found that the more unwell a patient is, the less likely they are to wish to participate in care (Cahill, 1998; Caress, 1997), and the less likely it is that care providers will welcome participation (Freidson, 1979).

Empowerment is defined as

a social process of recognising, promoting and enhancing people's abilities to meet their own needs, solve their own problems and mobilise the necessary resources in order to feel in control of their lives. (Gibson, 1991, p. 359)

The presumed outcomes of this process are, among other things, increased quality of life, personal satisfaction and a sense of control (Gibson, 1991; Weaver and Wilson, 1994). By this definition, empowerment is something that health-workers provide for their clients - something of a contradiction. The main method of providing this is through education and communication.

Many critics of the movement believe that "empowerment" and patient participation are other ways of ensuring compliance. The goal of most patient education programmes is to ensure that the patient knows what are the best (i.e. prescribed) treatment options for their condition (Lupton, 1995; Parmee, 1995;

Price, 1996; Rapley, 1997). Studies of doctor-patient communication support the view that giving of information is more directed toward ensuring compliance than encouraging shared decision-making and equal participation (Lupton, 1995). In addition, to ensure that education is delivered in an appropriate manner, nurses are encouraged to “know” the patient (Henderson, 1997; Price, 1996; Radwin, 1996). According to some authors, this makes the patient “more vulnerable to the exercise of disciplinary and possibly coercive power” (Lupton, 1995, p.161; Petersen, 1994).

Underlying the term compliance is the assumption of professional dominance in health-care relations. This fits with the Parsonian perspective of the sick role and “denies legitimacy to any actions that differ from professional prescription” (Playle and Keeley, 1998, p.306). It is assumed that increased compliance leads to better outcomes for patients, and this is particularly so for the chronically ill, although there is little evidence to support this assumption (Gerber and Nehemkis, 1986; Parmee, 1995; Rapley, 1997). Wichowski and Kubsch (1997), in a survey of 106 chronically ill people found that the more healthy the person, the less likely they were to comply with their prescribed medical regime. The authors suggest that non-compliance can be equated with denial.

However, other authors suggest, and have found, that non-compliance, particularly for people with chronic illnesses, is a result of self-empowerment (Berte, 1987; Gibson, 1995; Price, 1996; Rapley, 1997). This process arises from, among other things, conflicting expectations and priorities between the person and their carers, conflicting opinions between carers, and the discovery by people with chronic illness that health providers do not have answers and cannot predict the trajectories of their illnesses with certainty (Thorne and Robinson, 1989). The outcome of this process is that many people with chronic illness continue to participate in their prescribed regimes but in a reasoned and sometimes covertly assertive way.

Gibson (1995) discovered that the process occurred for mothers of chronically ill children as a result of their frustration with the process of delivery of care - having to repeat their children's histories over and over again, having to educate new doctors - and with the lack of answers and cures. The outcome of this process, according to Gibson, is "participatory competence" where the mother is regarded as an authority and a competent carer, with mutual goal setting and communication occurring between health providers and mothers.

Berte (1987, cited in Hawkins, 1993, p.198) describes the process from his own perspective as a cancer patient:

I stopped taking orders and started making decisions. I stopped thinking of my doctors as gods who would deliver me from hell and started thinking of them as merely one aspect of my own, self-designed treatment plan.

Thorne and Robinson (1989) describe a more complex outcome for this process. People with chronic illnesses, or their families, go through a period of disenchantment with, or "shattered trust" in, their health providers. As their trust is reconstructed, a "guarded alliance" is formed that allows continued access to health care. This guarded alliance can take one of four forms depending on the amount of trust the person has in their care provider, and on their perceived self-competence in the personal management of their illness. Thus, high trust and low self-competence leads to hero-worshipping, usually of an individual provider, while high self-competence and trust together generate a team-playing approach similar to that described by Gibson (1995). High self-competence and low trust results in consumerism, where people with chronic illness use health professionals to attain their own self-perceived needs, usually by covert means. An inability to either trust or develop competence leads to a state of resignation where the chronically ill do not really expect their needs to be met within the health care system.

These studies and experiences suggest that notions of patient participation and empowerment, as defined for patients by carers, and the idea of compliance, deny

what other researchers have found: that patients do participate in their care and retain some control, although often by covert means.

Conflicting notions of the role that people with chronic illness should occupy in the health care system, combined with uncertainty about the amount of self-care and degree of compliance, which occur during acute hospital admissions, have lead to the present research study. How do people with chronic illness manage their health in the face of this conflict? The experience of one group of people, as uncovered through grounded theory methodology, presents a fascinating, complex and remarkably contingent picture.

CHAPTER THREE

THE RESEARCH APPROACH

Grounded theory is a method for the qualitative analysis of data - any form of data. Qualitative research allows exploration of a research question in the social setting in which it occurs. It acknowledges the relational aspects between participant and setting, and between researcher and researched. In a profession such as nursing where the practitioner is working with people to help them manage health events, knowledge derived largely from quantitative methods that objectify both people and events seems inappropriate. Utilising methods that uncover knowledge by seeking the viewpoint of those involved fits the humanitarian philosophy of nursing practice. In particular, given the lack of prior work in this area, grounded theory offered an opportunity to explore what happens when people with a chronic illness encounter the acute care system.

The Research Method

Grounded theory is a research method developed by Glaser and Strauss (1967) to provide a framework to guide both data collection and inductive theorisation from that data. Thus, it is “based of the systematic generating of theory from data, that is itself systematically obtained from social research” (Glaser, 1978, p.2). Grounded theory has its roots in the social theory of symbolic interactionism (Bowers, 1988; Chenitz and Swanson, 1986), a theory that arose out of work by George Herbert Mead and which was later explicated by Blumer (Porter, 1998). It is North American in origin.

Symbolic interactionism promotes the view that humans' actions towards things - physical objects, other people, ideas, etc. - are based on the meanings these things have for them (Bowers, 1988; Porter, 1998). Thus it is not sufficient to look at external factors, such as social constraints, which influence people's behaviour; one must also look at the meanings those things have for each person. It is a dialogical process. While meanings are derived from interactions with social systems, these meanings are subject to active and ongoing interpretation by the individual involved (Chenitz and Swanson, 1986; Porter, 1998). This leads to the supposition that the meaning assigned to something can vary from one person to another and can change over time or with context for the same person (Bowers, 1988).

Symbolic interactionism logically supports the use of inductive processes to develop theory. Using deduction to generate theory requires conceptualisation of the issue of concern prior to entry into the field to gather data. By contrast, grounded theory allows the researcher to uncover another's meaning without superimposing the researcher's, or anyone else's, own interpretation on the events or phenomena of concern. Thus, the problem emerges as an area of concern to the people in the area. Having collected the data the researcher uses the strategies associated with grounded theory to generate a theory that "fits" the data in dialogue with the participants, so the theoretical interpretation is derived from both parties participating in the research (Becker, 1993).

The process of induction from data to theory, which generates a conceptualisation of meanings, is rigorous. Glaser, in his descriptions of grounded theory makes it clear that preconception of meanings and their relevance to the emerging theory is to be avoided at all costs (Glaser, 1978; 1992; 1998). He sets down a series of key processes that are characteristics of a grounded theory study.

1. Development of the Research Question and Use of Literature

Glaser and Strauss (1976; Glaser, 1978) emphasise the need to enter the research setting without predetermined theoretical constructs as to the

importance of the events occurring to the participants. Glaser (1992) states that “there is a need not to review any of the literature in the substantive area under study” (p.31). There are two reasons for this. First, the literature review will focus on the specific issues of concern that emerge after entry into the field. Thus, the research question one initially enters the field with is no more than: “What is happening here?” In the current study, the question became “What happens when a person with a chronic illness encounters the acute care system, for whatever reason?” Since the answer to this question cannot be known prior to the discovery of the grounded theory, initial reviews of the literature must be general.

Second, an in-depth literature review may lead to contamination of the emerging grounded theory by preconceived concepts, speculations about non-relevant interpretations, and erosion of the researcher’s theoretical sensitivity (Glaser, 1998). However, as the theory develops, the researcher goes to the literature for further data and to place the new theory within the field of what has already been generated.

The initial research question is a search for the core category or basic social process (BSP) within the area of study. “Social process” is a sociological concept that describes regular behavioural patterns, and their variants, that recur over time (Bigus et al., 1994). The discovery of a core category or BSP in an area under study is the key outcome of a grounded theory. It is a generic description of the phenomena of most concern to the participants in the study, and arises directly from the substantive data. The grounded theory approach proposes that, because it is generic and focuses on the activity occurring in the setting rather than the setting itself, a core category is transferable between settings and over time (Bigus et al., 1994).

Although the researcher approaches the study with only the most general of questions in mind, it would be naïve to think that a nurse is able to enter the arena of health research without a priori theorising or with no knowledge of

the literature in the field. Indeed, some would argue that it is to the detriment of the discipline that the nurse-researcher attempts to shut out her experience as a nurse (Borbasi, 1994; Gardner, 1996; Lawler, 1995). It is also suggested that the unique perspective of nurses enhances their ability to do research within the field (Chenitz and Swanson, 1986; Christensen, 1990; Gardner, 1996). The issue thus becomes one of reconciling the *what* of research (nursing knowledge) with the *how* (methodological rigour).

The role of a sociologist entering a field of study differs from that of a nurse researching within her own discipline. Indeed, Glaser (1995) concedes that the “researcher does not go blank or give up his knowledge, He goes sensitive with all his learning, alert to any possibility and then how to formulate it with concepts” (p.9). I discovered that the literature became a useful way of surfacing unconsciously held assumptions about the area of study. In my early reading, for the development of the research proposal, any concepts that felt “right” or appealed to common sense were highlighted and analysed. In this way it was possible to enter the field not unknowing, but at least being aware of, and questioning, that knowledge. Glaser (1998) also suggests that an initial literature review, if it cannot be avoided, be used as a data collection opportunity and subjected to constant comparative analysis.

2. *Using Grounded Theory*

The grounded theory researcher enters the field of study with a general area of concern or problem in mind and looks for ways to collect data that will allow the problems of concern to the people in the area to emerge. For example, the question in this study “What happens when a person with a chronic illness encounters the acute care system?” led me to approach and interview people with chronic illnesses who had recently been discharged from the local public hospital.

Analysis of the data begins with the first interview as each incident is coded and compared with other incidents given the same code(s) (Glaser and Strauss,

1967). This process is termed constant comparative analysis and is unique to grounded theory research (Keddy et al., 1996). Three questions are asked of the data: What is this a study of?; What category does this incident indicate? What property of what category does this incident indicate? Data collection continues until no new codes are emerging from the data and the properties of existing codes have become more explicit and can be arranged into categories. Theorising about the codes, categories and their properties occurs as memos are written during the data analysis.

Memoing is an important element of grounded theory methodology. This involves the recording of ideas, reflections, questions about the data and emerging conclusions. As the categories become more dense, memos become more abstract and sampling becomes increasingly theoretical.

Theoretical sampling involves allowing the developing theory to dictate where, how and what data will be sampled next (Glaser, 1978, 1998). The eventual emergence of a core category or BSP from the data allows the researcher to begin focusing collection more narrowly, examining the relationship between this core category, its theoretical codes, and their properties (Glaser, 1978; 1992; 1998). Data collection ceases once saturation of categories and codes is achieved, that is, the same properties for categories keep occurring and the theory appears complete.

Sample size in grounded theory is, therefore, dictated not by the need to sample all the elements of the setting and all possible variables, but more by the need to examine the properties of the core category (Bigus, 1994; Glaser, 1998). In addition, types of data available for use by the researcher are determined by the emerging core category. Thus, I not only used interviews with participants as a data source in this current research, but also I was able to use data generated from social conversations, my nursing experience and encounters with patients, literature both within and outside the field, and personal experiences of family and friends suffering from chronic illnesses.

3. *Validity and Generalisability*

Essential to any research method is the assurance that findings reflect what is actually in the data. Grounded theory uses four criteria to assess rigour and validity (Chenitz and Swanson, 1986; Glaser and Strauss, 1967; Glaser, 1978; 1992; 1994; 1995; 1998). The validity of a grounded theory study is determined by its usefulness: it must fit, work, have grab and be modifiable. This means that the categories developed in the theory must reflect the data; it must explain, predict and interpret the events in the substantive area of the study (work); be relevant to the participants and the group for whom the theory is intended (grab); and the theory must be able to be adapted to changing conditions over time (modifiability) (Artinian, 1998; Baker et al., 1992; Glaser and Strauss, 1967; Glaser, 1978).

Trustworthiness (rigour) in qualitative research can be established if a well-documented decision-making trail is available for independent audit (Koch, 1994; Rodgers, 1993). The auditor should be able to trace the effects of events and actions of the researcher on the emergent theory and ensure that it is grounded in the data. The document trail in this study consists of transcriptions of interviews, field notes, memos and reflexive journalling on the research process. The thesis discusses concepts and their associated categories in relation to each other and the data and this discussion is supported by the data.

Critique of Grounded Theory

Criticism of grounded theory comes from both its practitioners and those outside the method. The distinction between the approaches espoused by Glaser (1992) and Strauss and Corbin (1990) has lead to some confusion over the mechanics of performing a grounded theory analysis. Glaser “focuses his attention on the data to allow the data to tell its own story” (Stern, 1995, p.60). Strauss has developed a prescriptive formula for analysis that Glaser believes interrupts true emergence and forces the data into preconceived concepts (Glaser, 1992). Others have criticised the Strauss and Corbin interpretation of method for forcing the

researcher into a rigid, linear process that produces a thin analysis with no “grab”, and often no theory (Artinian, 1998; Charmaz, 1990; Keddy et al., 1996). In this study, the Glaserian method of analysis has been followed.

Many grounded theory studies have been criticised for providing not theory but a descriptive report (Stern, 1995) which does not move beyond the data to conceptualisation. The level of theorising in a grounded theory study can range from discussional to propositional (Glaser and Strauss, 1967). That is, the properties of categories may be treated in depth in a discussional theory and the links between categories dealt with in a propositional theory. In either case, what is provided is more than a rich description of the area under study. The current research has been developed into a discussional theory.

Criticism from outside the method tends to categorise grounded theory with other forms of qualitative research in respect of sampling and sample size for data collection. In fact, any type of data can be used in a grounded theory (Glaser and Strauss, 1967; Glaser 1998), including quantitative strategies such as structured questionnaires designed to gather data on an emergent area of concern.

Therefore, each study must be assessed on its own merits in this respect. Glaser and Strauss also make a distinction between substantive theory, one that remains grounded in the area studied, and more formal grounded theory. This later type incorporates studies from other substantive areas that uncover the same core categories and lead to the creation of a more abstract theory. The researcher must be aware of the level of generalisability of the study with regard to both data collected and scope of the theory. This current study can be classed as substantive.

A further criticism, one discussed extensively by Glaser (1998), is that grounded theory, by examining the concerns of people involved in a setting, cannot move beyond the fictions maintained by those people. However, Glaser argues that a “researcher cannot say what is really going on when the participants cannot or will not say. He cannot force a reality on the research without the data” (1998,

p.89). Clearly, any form of research that relies on information gained in one or a variety of ways from the people in the setting can be subject to overt or covert manipulation of the 'truth' as it is experienced. However, other types of research may attempt to impose a reality on the data that may not be accurate and cannot be proven, while in grounded theory the main interests of the participants will emerge regardless of the vested interests involved.

The Research Process

This study began with the idea that there is something different about the care required by people with chronic illnesses when they are in the acute care setting. I wanted to know what was happening when this group of patients encountered health professionals more accustomed to dealing with acute, finite health episodes. A decision was made to look at the problem from the perspective of patients rather than providers of care.

Participants

Following acceptance of the research proposal and ethical approval, advertisements were placed in the local free newspaper and a poster was displayed in the local hospital (Appendix I). A convenience sample of chronically ill people who had been in an acute care facility within the previous two months was sought. Ten people responded to the advertisements and of these, eight met the criteria for inclusion in the study, namely:

- The admission be within the last two months;
- The chronic illness be of a non-psychiatric or non-malignant nature;
- The person was able to provide an informed consent;
- The person was available for interview by the researcher.

The group were all women, aged between 15 and 76. Relevant descriptive data, assigned according to the pseudonym used for each participant, are given in Table 1.

Pseudonym	Age	Chronic Illness	Reason for Admission
Jill	31	Systemic lupus erythematosus (SLE)	elective hysterectomy
Mrs K.	76	Chronic renal disease and renal transplant	pneumonia and heart failure
Jackie	35	Diabetes	suspected meningitis
Renee	46	Emphysema	acute exacerbation of emphysema
Ants	49	Asthma	acute exacerbation
Sarah	15	Asthma	acute exacerbation
Fiona	42	Multiple Sclerosis (MS)	spinal injection of baclofen
Sally	26	Reflex sympathetic dystrophy	viral meningitis

Table 1: Description of participants in the research.

Ethical Considerations

Ethical approval for conducting this research was obtained from the Massey University Human Ethics Committee, the Southern Regional Health Authority (Otago) Ethics Committee and the Otago Polytechnic Ethics Committee (Appendix II).

1. Access to participants

Issues of privacy precluded direct access to participants via patient records or hospital admission records. By advertising for participants privacy was not compromised since response to these advertisements was entirely voluntary. Permission to place advertisements in the local hospital was sought once ethics approval had been granted.

2. Informed consent

Potential participants who responded to the advertisement, and who met the inclusion criteria, had a broad outline of the research explained to them on the telephone. An information sheet (Appendix III) and consent form (Appendix IV) were posted to them. Two days later they were contacted by telephone, any further information about the research that they requested was given, and they were asked for verbal consent. An initial meeting was then arranged in their home or other place selected by the participant. At the meeting, any further questions about the research were answered and participants were invited to sign the consent form. The initial interview was then conducted.

Potential participants were informed that their involvement in the study was entirely voluntary and that they could withdraw at any time. Any information collected up to the time of withdrawal would be disposed of if they so requested. None of the participants withdrew from the study. Signed consent forms were held by the researcher until the end of the research.

3. Confidentiality

All tapes and transcripts have remained confidential. The only person, other than myself and my supervisor, with access to the tapes was a typist who was required to sign an undertaking of confidentiality prior to transcribing the tapes. Data tapes, hard copies of transcripts and coding materials were kept in a locked filing cabinet. Computer files were secured by password and floppy disks kept in locked storage. No identifying information about any participant has been included in any reports of the research.

4. Potential harms and benefits

No information about any individual participating in the research is available to health care professionals involved in their care, either in the hospital or the community. Other than providing an opportunity to talk about the issues involved, there is no immediate benefit to participants. The knowledge gained, however, will be useful in informing nursing practice in the future.

Process

Data were collected via unstructured but focussed interviews held with the participants in a setting of their choice. These were audiotaped and transcribed for analysis. Participants were initially asked biographical details including family and social circumstances, occupation, etc. They were then asked about their experience of their chronic illness - its duration, pathway to diagnosis, effects of daily life and types of treatment and therapy they had received. Participants were then asked to describe their recent hospital experience, beginning with the events leading up to their admission.

Data analysis began soon after the transcription of the first interviews and a range of codes began to emerge. Interviews with later participants were influenced by the ongoing analysis and included detailed questions regarding the emergent codes. Participants were contacted for a second interview once the initial analysis was completed but, because of the time gap between first and

second interviews, four of the eight participants were unable to be traced for follow-up.

Analysis

Analysis began with open coding of, and reflection on, the transcripts. The data were broken down into incidents that were examined and compared with other incidents, both within the same transcript and between participants, for similarities and differences. From this process a number of theoretical codes and categories were developed and further reflection and analysis on these gave rise to the core category of the research, that of *conditional expertise*. The literature was then approached for further sampling within the core category and codes, and these were further developed. In the process of generating the core category a number of other promising codes or themes were set aside. The core category that was finally arrived at seemed to be the one of main concern to participants, and seemed best to encompass most of the codes discovered in the data.

A second interview was held with four of the participants, during which the core category and its codes were discussed and the participants confirmed that these were indeed relevant to them and their own experiences. Further data were collected at this time and coded for inclusion in the theory. At the same time, I was working with people suffering from chronic wounds in an outpatient setting. Reflections on the care of these patients and conversations held with them were included in the memoing and journalling processes I was undertaking at the time, although no formal data collection was undertaken. Because of my own departure from New Zealand at this time, I was unable to complete any further interviews with the research participants. Sampling of the literature continued as the grounded theory began to emerge and took shape. As the theory was taking shape discussions with colleagues, and with friends and family suffering from chronic illnesses, led to some further data analysis and modification. This also provided evidence of grab.

Constraints provided by time and the fact that this is a Masters-level research project, meant there was a real danger of failing to achieve theoretical saturation during data collection. Indeed, it is possible that readers will perceive that saturation has not been achieved. However, sufficient data were collected to allow the emergence of a core category that has been described, confirmed by participants, and can now be investigated in a larger study.

CHAPTER FOUR

THE RESEARCH OUTCOME PART I:

CONDITIONAL EXPERTISE

Line by line analysis of the data and constant comparisons, together with additional, theoretically driven, data collection yielded a number of disparate substantive codes. As analysis progressed these codes were continuously modified, grouped and reduced, and their properties were identified. This process was the beginning of the generation of a grounded theory. Gradually the underlying patterns in the data became clear and a possible core category was identified. A process of selective coding around the emergent core category led to the generation of an integrated grounded theory that identifies the key issues for the people in this study.

Glaser (1998, p.137) says of this process:

Grounded theory often starts off with a study located within a structural unit, such as in a particular business, hospital or school. The conceptualisation going on in grounded theory automatically leaves the time and place of this unit. The theory is no longer generalised to a unit but to a process which goes on in many other similar units.

However, the core category discovered in the data can only refer to the data from which it was generated. It is a substantive theory, and it remains tentative and potentially modifiable when additional data are collected from the same setting or any other setting to which it may have relevance. Another research study,

using a different methodology, would be necessary to both confirm the pattern and its applicability in other settings and circumstances.

The presentation of the research outcome which follows is grounded in the particular data gathered in this study, and is shaped by the understandings of the analyst about the method, the selected literature, the acute care setting, and nursing itself.

The Grounded Theory: Conditional Expertise

The area of concern to the people in this study related to what happened to their expertise in their own experience of living with a chronic illness when they moved from relationships of mutual trust with health care personnel in the community to short term encounters with health care personnel in an acute care setting. As participants related their stories around the events leading up to their hospitalisations in an acute care unit, a core category and four theoretical codes emerged which together comprise the grounded theory that was generated from the data.

Theoretical codes: *Controlling*
 Negotiating
 Informing
 Withdrawing

Each of these generated codes is situation-specific, conditioned by the circumstances of the person with chronic illness. The four theoretical codes will be addressed in more detail in chapter 5, but the following brief introduction will demonstrate their essential nature and their contribution to understanding the core category.

Conditional expertise describes the experience of this group of participants as they move from relative health in their homes into the acute care setting. At each point in this journey the recognised expertise of the person with chronic illness

changes and, on entry into the acute care setting, it diminishes. The participants' responses to these changes comprise the four theoretical codes of the research and can therefore be viewed as stages in the journey from home, to acute care and back again.

While the participants were at home, they, or their main carers, were expected to be knowledgeable and skilled in the management of their chronic illnesses. They managed daily activities, medication and other treatment regimes, and minor exacerbations. They were also expected to monitor and recognise when they required specialised assistance. This highest level of expertise at which the chronically ill operate has been labelled *controlling*.

The second code generated while participants were at home arose as they described encounters with general practitioners, medical specialists and, to a much lesser extent, specialist nurse practitioners. This is *negotiating* and usually involved contact with known health professionals who, in turn, knew the patient. Negotiating occurred from a position of acknowledged expertise, involved exchanges of information and sometimes led to the postponement of the person's admission to hospital.

A third code, that of *informing*, became evident following entry to an acute care setting. Here the chronically ill person was not known to individual health professionals, except via old notes. Participants believed they spent a great deal of time explaining their illness and requirements. During this time the participants often felt their expertise was questioned or denied.

This loss of expert status lead to the fourth code - that of *withdrawing*. As patients in an acute care setting, the participants spoke of losing their ability to be assertive and becoming passive recipients of care. This resulted in one participant being sent home from accident and emergency when she knew she was not fit, and in another participant allowing a drug error to occur. Conversely, others insisted on early discharge knowing they were not fully fit to be going

home but perceiving this as preferable to remaining where their specific illness-related needs were not being acknowledged or met. During this stage, particularly for those who surrendered control of their care, expertise was denied them by both health professionals and their own loss of confidence in themselves.

Core Category: *Conditional Expertise*

The integrating concept of *conditional expertise* starts to become clear when the parameters of the four distinctive theoretical codes are identified. It proposes that the person who has a chronic illness has expert knowledge of their own illness and its management only outside the acute care setting. Once that setting is entered, either due to an acute exacerbation or for unrelated reasons, expertise diminishes, is questioned or ignored. On discharge the person is abruptly required to resume control of their illness, and from then on must actively seek knowledge of any alterations in regimes from whatever sources are available to them in the community.

This core category of conditional expertise was arrived at after considerable time spent with the data and with the emerging theoretical codes. Because the four codes were situation-specific, arising when the participants were either in the community or in the acute care setting, the use of the word conditional seemed appropriate. Other conditions, such as knowing, and being known by, their health professionals and state of well-being, also exist for this group of people with chronic illnesses to be allowed expert status.

While none of the participants actually used the word expert to describe their knowledge about their illnesses, it was readily apparent from the data that this was the case. It is important to emphasise that the term does not apply to biological or physiological knowledge about the disease processes involved. Rather, for this group of people with chronic illnesses, their expertise is in self-management - living with their illnesses on a day-to-day basis and incorporating it into their other spheres of living. It is this knowledge about themselves and their illness that the participants deemed to be of importance during their

admissions to the acute care setting, and it was this same knowledge that was, they believed, ignored or dismissed by the health professionals that they encountered.

There have been numerous studies about the experience of chronic illness (Charmaz, 1991; Kirk, 1992; Lindsey, 1997; Strauss et al., 1975; Strauss et al., 1982). All acknowledge the expertise of sufferers in relation to managing their illnesses. None have followed the patient into an acute care setting in a way that would uncover the different patterns associated with this concept of conditional expertise, so they have not been recognised in this form before. However, those studies that do examine the experience of hospitalisation for people with chronic illnesses have all revealed problems for this group in the acute care setting.

Strauss et al. (1975) found that the chronically ill were expected to surrender control of their care in hospital but do not specifically address this as an issue for them. Admission to hospital was regarded as a legitimate time to cede responsibility for care to health personnel. This occurred with a sense of either relief or one of failure in self-care on the part of the patient. Strauss et al.'s (1975) failure to regard this process as problematic may be related to the era in which the study was performed. During the early 1970's Parson's (1952) sick role was the dominant model operating in the acute care setting, and it could be argued went unquestioned by the researchers and the practitioners of that time.

By the time of Strauss et al.'s later study in 1982, the work the chronically ill person was doing while in hospital was being acknowledged. They were no longer seen as passive recipients of care. Work undertaken by patients was largely viewed as being co-operative, for example giving information and undertaking personal hygiene tasks. However, the study also discovered that people with chronic illnesses were actively making decisions about whether or not to accept care, and also spending time rectifying or preventing mistakes.

This current study echoes the work of hospitalised patients identified by Strauss et al., but their 1982 study failed to examine the impact of loss of expertise, and the surrendering of their control of care, on the person with chronic illness. The data from this study revealed that the participants became less active in their care during admissions as their status as experts in their own illnesses was undermined.

Charmaz (1991) uncovered more of the issues relating to acute care for the chronically ill. However, her focus was on the structural elements of the acute care system - limited access, frustration for staff faced with multiple, non-curable health problems, and a focus on the disease rather than the person - rather than on the personal or subjective elements. The study acknowledges the presence of problems for people with chronic illnesses in an acute care setting but, because it did not explore the personal issues involved, the concept of conditional expertise, or its equivalent, did not emerge.

Kirk (1992, 1993) used the term “confidence” to describe the process of good nursing care as perceived by six people with rheumatic disease in an acute care setting. Under the umbrella of this concept, she groups components of care such as safety, physical care and competence. Providing, or allowing, independence and control, and showing an interest in the patient as an individual were also perceived as important elements of good nursing care for these participants. The consequences of loss of independence or not being treated as an individual were not examined in detail in the study, although there were occasional quotes from participants like the following one that indicate that this was problematic: “I don’t think a nurse should pooh-pooh anything a patient tells them. It must be hard sometimes, when a patient is always calling, to judge.” (Kirk, 1993, p.101).

There are a number of studies and commentaries that examine relations between nurses and patients (Callaghan and Williams, 1994; Kirk, 1993; Kralik et al., 1997; Lindsey, 1997; McWilliam, 1996; Morse, 1991; Peace, 1996; Russel, 1997;

Strauss et al., 1982). In all these studies, where patients' unique needs and status were recognised, a satisfactory caring experience occurred.

Lindsey (1997), in particular, addresses the issue of expertise. She claims that most dissatisfaction with health care occurs when the expertise of the health professional takes precedence over the expertise of the person with chronic illness. This is due mainly to the professionals' focus on disease processes, in which they are presumed to be the more expert, rather than the patients' subjective experiences of their illnesses. Participants in the Lindsey study talked of the energy required to maintain control in the face of health professionals' expertise. This is also found in the current study where participants were unable to maintain their own expertise when very unwell.

Thorne and Robinson (1989) describe the expertise of parents of chronically ill children, where the issue of loss of control is not so dependent on state of health because it is the child suffering exacerbations, not the parent. The key element in the establishment of satisfactory health care relationships in their study was found to be reciprocal trust - a mutual acknowledgement of expertise. In the current study this phenomenon was most often witnessed between participants and health providers in the primary care setting. It became problematic when the person moved from home to the acute care setting. This study has made it apparent that satisfaction with a hospital experience, and care received, depends on maintenance of the patient's expert status while in hospital.

In the next chapter, the actual data is used to support the presentation of each of the four codes that comprise the core category of conditional expertise.

CHAPTER FIVE

THE RESEARCH OUTCOME PART II:

CONTROLLING AND NEGOTIATING; INFORMING AND WITHDRAWING

Introduction

The core category of conditional expertise is composed of four theoretical codes. Each is determined by the conditions in which the participants found themselves and by the health personnel with whom they were in contact, but they can be grouped into two separate patterns - at home and in the acute care setting. Each code is a separate stage in the journey from home to acute care setting and back to home again. However, controlling and negotiating are also part of the everyday management processes for this group of people with chronic illnesses.

In this chapter the four theoretical codes are addressed in turn. The operation of the core category of conditional expertise becomes apparent as each code is discussed. Expertise is readily apparent in participants' actions in their home environments but it clearly diminishes as they move into the acute care setting.

Controlling

Repeatedly during the interviews with participants, I was struck by their knowledge about themselves in illness. For some this included knowledge about pathophysiology and understanding of their medication. For others their knowledge focused on daily management of their illness and self-monitoring of their state of well-being. Participants were using this knowledge to control the impact of their chronic illnesses on their lives. Accommodation to the illness and

its symptoms on a daily basis involved knowing themselves and balancing the demands of living with those of the illness.

Sally: I use my crutches. Occasionally I use it [wheelchair] if I'm really tired or sore and need a break...because I don't want to become dependant on it.

.....

Sally: It's enough work for just a wee bit of extra money but not enough to tire me, it fits quite nicely.

.....

Jill: ...sometimes I've got to have a sleep in the morning or afternoon and if I have all day without a rest it will tire me out the next day.

.....

Renee: I'll go back [to university] because I feel as though, because I can't do a lot of sewing and a lot of other things, my brain's half dead.

.....

Jackie: And I can tell perhaps if I've been out for a meal somewhere and it's hard to gauge sometimes how much insulin you're going to need...it makes everything high and ...once it [blood glucose level] gets over 20, which it doesn't do very often, but I just know.

.....

Renee: I was taking my inhalers, actually I'd been overdosing on them I think... you sort of get side effects like headaches and blurred vision.

.....

Jackie: Ketoacidosis needs to be long-term and I hadn't been that unwell for that long. I've had ketoacidosis so I know what it's like.

For these participants knowledge about self came with experience of the illness but expertise about the medical condition and its treatment came from a variety of sources.

Mrs K: I'm noseey you see and I thought now Ellen's taking these [tablets] for high blood pressure, I've got a low BP, why am I taking them? So I took the book along to Dr J. to get him to explain why... and I thought maybe my kidney's starting to fail and they're not going to tell me.

.....

Ants: ...when I first started I knew nothing...like I didn't know you could have a cough with asthma and I was going to the doctors you know I've got this cough. He kept saying to me its an asthma cough and I thought if I got cough medicine and got rid of the cough then I wouldn't get asthma.

.....

Ants: I've read up a lot [about medication]. I've got pamphlets from the hospital and the ones you get with the medication...but they didn't have any information [about the side effects of a particular drug] so they rang up the chemist and they gave me as much as they could. And there were three of us on it and we were all comparing notes.

Controlling also involved balancing risks. Participants described deciding when to seek help for exacerbations. This was based not only on their self-perceived well-being but on other factors in their lives.

Sally: I thought I'm not paying horrendous money to go and see the After Hours Surgery, I can hold out till tomorrow...but it got so bad that I went, and they sent me straight to hospital.

.....

Renee: It's like, when I get a chest infection I'm supposed to go to the doctor straight away as soon as there's a sign...and I feel like I'm going to become a hypochondriac and I don't want that and I can't afford to go to the doctor if I don't know that there's something wrong anyway.

.....

Ants: Well we have a safety limit [for going to hospital] even though we push it sometimes.

Assuming control of the future in the face of changed expectations was also a feature of most interviews. Jill had her hysterectomy because she could not risk any more children. Sally had her kitchen and bathroom remodelled in anticipation of becoming wheelchair dependent. Both Jill and Renee were planning to shift houses in the near future because neither could manage the hills and stairs associated with their current homes. Sarah was planning to leave school and do correspondence lessons because she was missing classes but the school were slow getting her work to her at home.

This code of controlling is described in other studies of the chronically ill. Reif (1975) describes similar processes of management, redesigning lifestyle and balancing in a study of people with ulcerative colitis. Strauss et al. (1975) list a series of tasks that the chronically ill undertake in the community, all of which, it can be argued, relate to controlling illness and require expertise on the part of the sufferer. Lindsey (1997) describes a covert process whereby participants assumed control and gained expertise through alternative forms of healing and avenues of knowledge. This is also a finding in the study by Thorne and Robinson (1989) of the process parents of chronically ill children go through in acquiring expertise in their children's illnesses. Parents seek alternative sources of information and in some cases, sought referral to more sympathetic health professionals.

Negotiating

In encounters with health professionals in the primary care setting, participants developed, extended and retained much of their expertise. This held true during hospitalisations when patients encountered their own specialists or, to a lesser degree, nursing and other staff who knew them well from previous admissions. Retention of expertise allowed a process of *negotiation* to occur.

Sally: ...I only told my GP [about her decision to wean herself off medication] and I think it's sort of like he trusts my decision ...well he knows that I know my body really well and he listens to me ... he trusts my judgement and my decision.

.....

Renee: If they don't tell me [test results from the outpatient chest clinic] I ask. I never have trouble getting information like that. I always ask.

Other participants described being believed and feeling able to question decisions about care.

Brody (1987) describes encounters in primary care as being based on a “relational ethic”. Over a series of encounters health professionals come to know patients’ medical and social histories. They work to convey information and dismantle barriers to communication. At the same time patients come to know their doctor and learn to judge competence and the quality of information given.

Participants displayed varying amounts of knowledge about their disease and varying amounts of trust in their primary health providers. At one extreme was Jackie who, in encounters with the diabetes education nurse in her old home town, became frustrated because she was unable to obtain medical knowledge to the depth she desired.

Jackie: she [diabetes educator] sort of gave me this lecture like she'd give to new diabetics...that irritated me a wee bit. I felt she should know that I could cope, and could understand a lot deeper.

At the other extreme was Jill who, in the interview, was unable to convey much information about her disease apart from the diagnosis, but who had implicit faith in her GP.

Jill: They're really good - they are good. Every time I ring her she goes "I've always got you in my mind." It's good 'cause there's a lot of GP's would sort of put you in the too hard basket and she'll tell you whether there's something or if they can't do anything or whatever.

Thorne and Robinson (1989) in their study of relationships between parents of children with chronic illnesses and health professionals, describe two continua: trust in health professionals and self-competence. When both were high there was mutual recognition of expertise and overt negotiation occurred. High self-competence but low trust in the health professional (a state that Thorne and Robinson label consumerism) leads to a more covert form of negotiation where symptoms are denied or exaggerated to obtain desired outcomes. Both these states were apparent for participants in the current study depending on which of their primary providers they were describing (for example locum GPs were regarded with little trust). Jill, with low self-competence and a high degree of trust in her general practitioner is in a state that Thorne and Robinson describe as hero worship.

The important factor in satisfaction with health care encounters from this current study, and which is apparent in the Thorne and Robinson work, is that the patient's expertise be acknowledged. Gibson (1995) also discusses this in her study of parents with chronically ill children. Parents found that being seen as competent carers meant being heard and being able to set goals through negotiation.

As with McWilliam et al (1996), it was apparent from this current study that participants valued being known by their health providers. It meant that the negotiation process was easier and mutual acknowledgement of expertise was a possibility. Not being known became immensely problematic for all participants as they moved further into the acute care setting.

Informing

Researcher: Were you able to ask for what you needed?

Sally: As much as you try, it's kind of like trying to explain the situation. It's like, please listen to what I'm saying, I've been through this so many times and this is my body, I know what it feels like. This is what's happening and this is what I need... This is not my first time in hospital, you know, I'm not sort of over-reacting because I'm scared, you know this is all familiar to me.

Sally's statement echoed that of the other participants as they encountered health professionals in the acute care setting. All felt they had to let carers know about their chronic illness and their uniqueness as patients.

Jackie: ... whereas some tended to treat me as if I was just any sort of normal person.

In part, this was seeking acknowledgement of their own expertise so they would be given information in turn about test results and procedures.

The extent to which participants had to explain, together with their own knowledge of the illness and usual hospital procedures, allowed them to gauge the expertise and competence of doctors and nurses they encountered. Most participants found the process of informing tiring and frustrating, resenting the necessity for it. This finding is echoed in Peace's (1996) survey of people with chronic illness in relation to health carers.

It seemed the less well the participants were on admission, the less able they were to undertake this process.

Ants: They don't really know me and I can't tell them, you'd think it would be written in my notes ... they obviously don't read it.

The key determining factor in this stage was whether the patient was known by staff.

Sally: I'm quite happy in the wards I'm known in ... but if I get somebody I haven't had nurse me before, it's like every five minutes, you know, "OK do you need a hand to go to the toilet or spread your bread."

.....

Ants: Like last time I went there was no bed [on the respiratory ward] and the registrar knows me and she got me a bed there. You feel safer on that ward because you know they know you... And the other thing is if I have my attack and I ask for another nebuliser they won't give it to me on that [general medical] ward whereas up there they know, OK. In the other wards they've got to go to the doctor first, you know and that takes time.

.....

Jackie: They tended to treat me as if I didn't know a lot. Some of them. And I actually found that it was demeaning. I think they didn't really look at the notes to see how long I'd had it [diabetes]. I've had it for twenty-three years and I know what's going on.

Participants often expressed surprise at the lack of knowledge about their diseases shown by health professionals.

Ants: I was quite shocked. I thought they'd know what to do.

.....

Jill: The main problem is they don't, a lot of them don't understand what it [SLE] is.

.....

Jackie: Some of them [nurses] didn't know anything about the insulin infusion ... so she was just going to pull it straight out.

.....

Sarah: They [junior doctors] say all these different things and come at different times and one will say “oh you might be out tomorrow if you’re feeling a bit better” and I’m still having three-hourly nebulisers, so I know I’m not going out.

During this stage of the admission, participants generally spent time trying to inform carers and correct misapprehensions. Strauss et al (1982) describe the work of hospitalised patients as including the giving of information and prevention or rectification of staff mistakes. A contrast is drawn between health professionals’ views of patients as ‘medically innocent’ (p.978) and placing themselves in the hands of carers, and the reality for patients, which is that of knowledgeable and skilled managers of their own care.

Christensen (1990) also discusses the work of patients on admission to hospital for elective surgery. These patients also questioned the expertise of carers and learned which doctors and nurses were to be trusted or were “authorities”. This current study demonstrates that the situation for those with chronic illnesses is more accentuated. Increased self-expertise and experience in the “system” allow more information to be given and also allow a more acute assessment of health professionals’ expertise.

Callaghan and Williams (1994), in their study of people with diabetes, found that acute care nurses were seen by some participants to be lacking in knowledge and expertise in relation to diabetes. When in hospital for other reasons, the participants in that study found they had to take sole charge of their diabetes management. Again, they spent time informing staff in order to receive appropriate care.

Lindsay (1997) claims that the root of dissatisfaction for the chronically ill with healthcare is that the expertise of the professional takes precedence over that of the patient. This current study demonstrates this problem. Sometimes

“informing” required a large degree of assertiveness by participants, which they ascribed to previous experience.

Sally: I think, like I say, you go through enough you learn to be assertive ... you look back and think well I was really trampled on last time in hospital, it's like I'm not going to go through that again.

.....

Jackie: Whether or not it was the fact that I did ask questions, 'cause I do. I've been there often enough to know that if you don't ask you don't get told a lot of the time.

.....

Ants: You have to be strong, like say no to being discharged if you don't think it's right.

There were two major problems for participants in the need to get through this process of informing. First they sometimes felt they were being labelled as difficult.

Sally: That's the thing too, you know, you try and stand up for yourself and ... you sort of get almost like labelled “oh here's that whingeing patient again” ... or it's like you're being labelled as difficult. The only reason I'm supposedly difficult is because my needs are different to most patients.

.....

Renee: Some of the nurses got really snarky when I tried to tell them.

.....

Jill: I didn't want to ring the bell (to get assistance with meals etc) 'cause I find they go mad at you all the time.

The second problem with this informing process is that the ability to persist with it depended on how unwell the participants were and the type of response they

received. All participants experienced difficulty in getting their special needs met and this led to the stage of withdrawal.

Withdrawing

Withdrawal as a code within this study could be either physical, as in gaining an early discharge, or emotional where participants became more passive in their care.

Sally: ... you're lying helpless in a hospital bed and you've got this medical professional towering over you, looking down at you, you're looking up at them and you're trying to be assertive ... and you're feeling quite helpless.

.....

Researcher: ...when the A and E registrar sent you home, did your mother say anything?

Sarah: Well mum was really upset because she normally doesn't get upset when I'm sick 'cause she's so used to it, but she was holding my hand and she was nearly in tears. I was that sick but the doctor couldn't see it.

.....

Jill: There was another nurse more or less just chucked the soap and sponge at me and says "well you can do it." I had to explain that I can't, I've got my husband to do it [at home]. She says 'well you can try'. So I didn't want to fight anyway so I tried to do it myself and it was pretty hard.

This withdrawal can be extreme. One participant in particular had problems due to her very poor health.

Ants: ...like they gave me two lots of steroids. I should have been assertive enough to say no ...and I knew that I shouldn't have had them but I just, when you're not well, you're just not probably assertive enough...

.....

Ants: The doctor said "let's have a peak flow" and I don't do peak flows now because that triggers my attacks. So I did the peak flow. You give in because you can't be bothered saying "oh I can't have that."

.....

Jackie: I don't actually tend to say anything ...I should have said to them "look this is not on" but as I said I wasn't feeling like anything.

Some participants used outward compliance and deception to achieve their needs. Jill was on a morphine infusion via a patient controlled dosage pump. This was intended to relieve her post-operative abdominal pain but Jill found it was very effective in relieving her arm pain (related to her SLE). She said: *I just made out it was my stomach more*, but because she was using so much of it, the infusion was discontinued.

Mrs K., while outwardly very compliant, took every opportunity to read her medical file.

Mrs K.: That's one thing I always read. Of course I'd get caught sometimes. I remember one time ...the orderly said "don't read those notes" and I said "I don't find out about myself unless I read"!

Other participants got themselves discharged from hospital. This ultimate form of withdrawal could be viewed as a way of regaining control of their chronic illness and resuming their own expert management.

Jill: I stayed there for five days. They wanted me to stay for six but I'd had enough so I wanted to go home.

.....

Sally: I was there for two days and I said "look this is crazy, I'm going home"... "if you don't let me go I'll discharge myself"... I said "what's my care plan from here on in, like what are you planning on doing for me? Is there anything that has to be done here that can't be done at home?" So I had to convince them that I could manage it at home. So basically he had no choice [but to discharge her].

.....

Renee: So I only stayed in until Monday. I came out because it was too hot, I couldn't stand the heat.

Mrs K. resumed control by refusing to be discharged.

Mrs K.: but I was six weeks by myself and then all of a sudden the doctor said you can go out. And I said I'm not going out... that was the one time I complained ...tucked away in bed and I hadn't even had any time with walking and to cope with three bags [drains]

Christensen (1990) refers to the process by which patients retain autonomy (either overt or covert) by choosing whether or not to seek assistance, concealing information or deciding whether to follow prescribed regimes. These were all apparent in the current study but participants appeared to find the process problematic and they had expectations (or perhaps hopes), not readily apparent in Christensen's study, that staff would accept their self-expertise. Failure by staff to do so lead to withdrawal.

Summary

Conditional expertise in chronic illness exists as a reality for the participants in this study. The development and possession of expert knowledge by people with chronic illnesses is confirmed in the literature. Other studies of people's experiences in the acute care setting show that diminished recognition of expertise occurs and that this leads to unsatisfactory care experiences for the patients involved. This study is describing, for the first time, the core category of conditional expertise as people with a chronic illness journey from home to the

acute care setting. The study is unique in that it describes the four theoretical codes, and their conditions, in which expertise changes and diminishes.

Discovery of this grounded theory has numerous implications for the care of people with chronic illnesses when they are utilising the health services. The experience of care in the acute setting did not meet the expectations and felt needs of this group of participants and this group. By examining and describing the core category of conditional expertise and the codes of controlling, negotiating, informing and withdrawing, current practice can be evaluated. Some ways in which the health professions, and particularly nursing, could address these issues are discussed in the next chapter.

CHAPTER SIX

DISCUSSION AND CONCLUSION

The incidence of chronic illness is increasing in the developed world. This is leading to increasing utilisation of acute care services by the chronically ill, either for treatment of exacerbations of their illnesses or for unrelated health problems. Therefore, it is timely that nurses and other health professionals examine the experience of hospitalisation for this group of people and their perception of the care they are receiving in the acute setting.

This grounded theory study has determined that not all the needs of a group of chronically ill participants are being met when they are hospitalised for an acute episode or exacerbation. This is partly determined by the approach to care that pervades the acute sector of the health system. In this model, the person coming into hospital surrenders themselves to care of expert professionals for a short period of time in order to effect a cure. People with chronic illnesses do not fit this model for a number of reasons: their diseases are not curable; management of their illnesses is an ongoing, dynamic process that occurs mainly in the community either by the people themselves or in negotiation with primary health carers; they have experience and expertise with the management of their illnesses and with the health system which allow them to make judgements about the type of care they wish to receive.

Review of the Findings

The eight participants in this study were people with a chronic illness who needed care within the acute setting of a general hospital. Each person was

interviewed and their experiences analysed using strategies associated with grounded theory. This process uncovered a core category of *conditional expertise* and four theoretical codes that are states of being experienced by the participants.

Two of these theoretical codes could be identified during the person's experience of living in the community:

Controlling - where the person with chronic illness has the knowledge and ability to manage their chronic illness and believes they are able to do so; and

Negotiating - an ongoing process where the person with chronic illness interacts with known health professionals within the community, and there is an awareness of mutual acknowledgement of each other's expertise.

On entering the acute care setting, participants in this study found that their expertise was questioned and dismissed, and they reacted to this. During this time two distinct theoretical codes could be identified:

Informing - a process which occurs on admission to hospital where the person encounters a variety of health professionals who are unfamiliar with either them, their illness or both, and they are required to give information to health care personnel who do not know about their health circumstances and experience; and

Withdrawing - a process where the perceived loss of expertise and control leads either to physical withdrawal so that self-management can be resumed, or surrender to the 'experts' and the loss of self-confidence in their own management skills.

The data revealed that the participants perceived the care they received in the acute care setting as focusing on technical aspects (Henderson, 1980; Lindsey, 1997; Strauss et al., 1982), and failing to take into account their specific, and

unique, set of circumstances. The key issue of concern was the failure by the health professionals in the hospital to either acknowledge, or value, each participant's expertise in relation to their own illness.

Conditional expertise seems to be determined, in part, by the relationship between a caregiver and a person needing that care. In a well-established relationship, the knowledge each has of the other, and the trust they develop in each other, results in mutual acknowledgement of complimentary areas of expertise. This particularly holds true in the primary care setting, but participants in this study also spoke of it happening when they had repeated admissions to the same acute care setting. However, even this was diminishing. Not long before the commencement of this study charge nurse positions were disestablished in the local hospital. Participants, especially those with respiratory conditions were unhappy at the loss of a familiar 'expert' on whom they could rely when they were acutely ill and needed to be admitted to hospital.

Implications of the Research Outcome for Practice

In this study the participants' experiences of a loss of their expert status on admission, and the need to repeat histories repeatedly, led to a perception of their care experience as unsatisfactory and their eventual withdrawal from the hospital setting. Nurses and other health professionals working in the acute care setting must challenge the dominant model currently in operation.

Acknowledgement of the chronically ill person's expertise in the management of their illness would be the first step. In order to do this increasing value must be placed on the stories about their illness that the chronically ill bring with them to the hospital. One key issue that needs to be addressed by health professionals relates to the processes for gathering and disseminating information about patients. Another is the importance of acknowledging, and valuing, the existence of important 'data' that do not relate to biological and disease states.

Individualised care has long been an overt goal of nursing. The 'nursing process' and primary nursing are examples of approaches to the planning and delivery of

nursing care that are designed to promote this goal. It might be thought that primary nursing, in particular, would provide a solution for some of the problems encountered by the participants in this study as it was evident that they experienced frequent changes of staff. It appeared that no single participant received care from the same nurse(s) consistently during their admission.

The promise of primary nursing - that a nurse and patient or client would be able to establish a caring and therapeutic relationship throughout a whole episode of health care (Henderson, 1980) - has been undermined to some extent by the increasing acuity and reduced length of stay of patients in acute care settings. The primary focus on the immediate health problems of the acutely ill does not allow for the establishment of long-term relationships between staff and patients. In this context, it is still important for nurses to ensure that there are opportunities for people with chronic illness, particularly but not exclusively those with repeated admissions, to establish effective relationships with nurses as well as other health professionals. However, it is apparent from the participants in this study that most health professionals they encountered in the acute care setting appeared to make little attempt to establish the extent of the patient's expertise, or to clarify their unique strengths and needs. Those nurses who did attempt to meet patients' expectations were regarded positively by participants.

Waters and Easton (1999) in an ethnographic study of care in a medical ward found three barriers to individualised care: the priority placed on this form of care by the nurse involved; the workload demands of the ward; and the skill-mix available on particular shifts. Staffing issues and heavy workloads are often raised by staff as reasons for their failure to establish individualised care programmes (Henderson, 1997). There may also be high staff turnover as well as a high use of temporary or agency staff. Patients admitted for acute care may encounter different nursing students, graduate students, newly registered nurses, medical students, house surgeons, or registrars each time they are admitted to the same unit. Even when they are admitted for a longer term into a

specialised unit there will be a constantly rotating range of staff. Clearly, there can be both structural and personal constraints on the establishment of satisfactory care relationships from the perspective of people who have a chronic illness.

The acute care setting seems to be structured on the assumption that satisfactory care does not require the patient knowing, and establishing relationships with, individual health carers, and vice-versa. Is individual knowledge and mutual trust really necessary? It could be argued that patients should regard all nurses and doctors caring for them as equally competent, caring and knowledgeable, and, following the acute care model (Parsons, 1952), to surrender all control of their care to these professionals, but this is an unreasonable expectation. This study, and others including Christensen, 1990; Kirk, 1992; Kralik, 1997; Russell et al., 1997; Strauss et al., 1975; Strauss et al., 1982 have demonstrated that this rarely happens.

It has been argued that the emphasis given to the biomedical model and disease processes in health professional education, combined with the continuing dominance of aspects of Parson's model of illness, relegates the human experience of illness, and thus acknowledgement of the individual patient's expertise, to a very minor role in health care (Davis and Horobin, 1977; Radley, 1993; Strauss and Corbin, 1988; Thorne, 1999; Toombs, 1992; 1995).

It is important to encourage the developments in both nursing and medical education curricula towards emphasising the importance of listening to, and taking note of patient "stories" (Brody, 1987; Carson, 1995; Hawkins, 1993; McLellan, 1997; Moore, 1978). Radley (1993) suggests "to speak about illness in a biographical context is to invite a rethinking of the relationships of patients to health care staff" (p.6). Nursing education in New Zealand is ensuring that a significant proportion of students' learning experiences occur outside the acute hospital setting. Students are encouraged to discover that the person's own experience is of major importance in the provision of effective health care.

Numerous studies have shown an increase in patient satisfaction with care where health professionals show interest in the experiences - or biographies - of patients in relation to their illnesses (Brown, 1986; Kralik et al., 1997; McWilliam et al., 1996; Strauss et al., 1975). Currently it appears that this type of information is not being systematically gathered or utilised. This was true in the present study where participants expressed frustration at having to repeat the most basic of information and they questioned whether staff actually read their notes.

It may be that nurses are not gathering some forms of information because they are difficult to document and/or may not seem to be valued by other staff (Strauss et al., 1975), and are unlikely to be used in any meaningful way. Miller (1998), in a review of literature regarding shift hand-over styles, discovered that these sessions are almost universally viewed as an essential process but that they are also seen as time-consuming, inaccurate and filled with trivia. Parker et al. (1992) found that the verbal hand-over contained stories and information about the patients not found in documentation. Often, in my experience, relevant biographical information is conveyed verbally during shift hand-overs but this is a haphazard process. Whether this information is valued or not by individual nurses probably determines its categorisation as trivia or useful information about the patient.

Clearly, the type of information that can be collected and documented about people with chronic illness while they are in hospital for a short-term, acute episode is problematic. Although one of the main problems experienced by participants in this study was having to repeat their stories to many individuals, collecting this information and documenting it in a relevant and easily accessible form is not easy. Much of the information that needs to be conveyed to carers is biographical, subjective and dynamic. Can it, and should it, be committed to paper or to a computerised information system? In addition, information given by

a patient to a health professional with whom they have established a relationship of trust, might not be appropriately passed on (Morse, 1991).

Those health care personnel with whom the participants in this study were able to establish useful relationships - particular consultants, registrars, charge nurses, nurse educators - all had knowledge of the participants in the primary setting, and had worked with them over time. Perhaps this enabled the mutual acknowledgement of each person's expertise to occur more readily. Nurses and other health professionals who work exclusively in the acute care setting are disadvantaged in that they are unable to provide continuity of care as it is usually described, and do not see people with chronic illness in states of health where they do control actually their illnesses.

The promotion of a partnership approach to care that recognises and values the expertise of each partner (Casey, 1993, 1995; Christensen, 1990) may go some way toward addressing these concerns, but the process of coming to know and trust individual nurses has not been discussed to date. Indeed Christensen's (1990) model, which was generated in acute settings, proposes a partnership with 'nursing' rather than individual nurses. Perhaps nurses in acute settings can develop alternate strategies to ensure that the care they give is individualised, and is perceived as such by the patient, while not being dependent on continuity of personnel.

Partnership models do, however, promote the notions of negotiation, autonomy and patient expertise (Christensen, 1990). In addition, within a partnership model is the idea of choice of degrees of participation (Casey, 1993). Importantly, the partnership model is the only one in which patient expertise is viewed as an important component in care, thus making it more appropriate for the chronically ill. The use of this model in practice, along with other types of individualised care models, depend on the value placed on this type of care by both individual practitioners and the hospital in which the care is occurring.

In an environment where there is acknowledgement of the patient's expertise by health care providers, issues such as compliance and, to a lesser extent empowerment, do not arise. When a mutual negotiation process is in place, each partner in the process is able to perceive the other's viewpoint and work toward mutually set goals. Empowerment of the chronically ill becomes not so much a process of 'doing for' but of creating opportunities for the person with chronic illness to become more knowledgeable and skilled in their illness management as far as this is possible (Tang and Anderson, 1999). Such a process depends on the person's physical and emotional state at any given time and would not assume a steady state of progress toward generic, externally determined goals associated with disability rehabilitation (Benner et al, 1994; McWilliam et al., 1996; Price, 1996; Radley and Green, 1987).

In an ideal situation, an appropriately qualified nurse could follow the person with chronic illness into and out of the acute care setting in a seamless care approach. This is a role envisioned by Shiell et al (1993) as a patient care manager and, perhaps, may occur in the future. Strauss and Corbin (1988) describe this role as an articulator of care, although they see it as more of an information resource. A liaison nurse role, such as that described by Campion (1996), also goes some way to achieving this goal. However, these nurses, while ensuring some continuity of care seem to operate mainly from hospital to community, and not the other way. It is time for creativity in the development of new nursing roles attuned to the circumstances and needs of those who will benefit from that service.

Grounded Theory and Nursing Practice

The use of research and, particularly, theory in practice has been problematic for the nursing profession. Over a number of years in the 1980's and early 1990's, nursing literature was full of the theory-practice and research-practice gaps (e.g. Chinn and Kramer, 1991; Fawcett, 1992; Field, 1987; Grossman and Hooton, 1993; Ingram, 1991; Kim, 1993; Meleis, 1991). These discussions emphasised the need for practitioners to develop conceptual bases for their actions while, at the

same time, acknowledging that practitioners found theory, and theoretically-based research, had little relevance in their daily work.

These discussions usually focussed on the so-called 'grand theories' of nursing - those which attempted to explain everything and guide all practice in nursing (Field, 1987). However, as a rule, these were developed deductively, often without research verification, and they tend to remain nurse-focused despite claiming to place the client of nursing in a central position. Thus their relationship with the reality of practice as has been, at best, uneasy. Indeed, some authors believe that nursing practice is secondary to theory, and may indeed limit theory development. Fawcett (1992) wrote that "if practice were the starting point [in theory development] then the boundaries of nursing knowledge would be severely restricted ... much time would be wasted and much vital information would not be recorded because the wrong questions might be asked." (p.226).

This attitude toward the relationship between nursing practice and theory contrasts strongly with the philosophical basis of grounded theory. Being grounded in practice, it seeks to address issues of concern to nurses in the everyday happenings of their work. By valuing the viewpoint of all participants, it places the nursing recipient's perspective as central to any problem which involves nursing and health care. Grounded theory can be utilised to produce mid-range, substantive theories, as well as more formal abstract theories. It is argued that the mid-range theory is more immediately useful in practice and is a realistic approach to the development of the discipline of a practice profession such as nursing.

Because it is developed using a rigorous, systematic methodology, grounded theory can be used by practitioners without the need for prior empirical testing. However, as Glaser (1998) discusses, while a grounded theory may be developed using non-forcing processes to arrive at a core concept, it has been generated from a specific set of data, at a particular time. People seeking to use a grounded theory in practice may force the situation to fit the theory, rather than see this

form of theory as always tentative, always modifiable. Thoughtful application of the theory is required; nurses must constantly compare their practice situations with the theory for fit, work and relevance (e.g. Nolan and Grant, 1992).

Thus, grounded theory is ideally suited to the practice environment, both as a research methodology and as a source of practice-relevant nursing theory. The originators of the approach suggest that a well developed grounded theory provides, for the practitioner, a theory that has grab, works, fits and is modifiable (Glaser and Strauss, 1967; Glaser, 1978; 1992; 1994; 1995; 1998). Ideally, this would be the outcome of the current research.

Limitations of the Research

Unfortunately time, the necessarily limited size of the project, and ethics constraints have all impacted on the conduct of the research. In particular, theoretical sampling was limited due to the requirement for ethical approval that the participant group be defined at the start of the research. In a larger research project with a longer timeframe, ethics committees could have been approached again for permission to move beyond this initial group for formal data collection purposes as the problem/area of concern emerged from the data. It is important to acknowledge that grounded theory is a process of discovery and the issue of concern, the nature of the data required to explore the issue, and the outcome cannot be anticipated at the beginning of the project.

Thus while the core category of *conditional expertise* was discovered during analysis of data gained from people with chronic illnesses who had recent admissions to an acute care setting, all the defining features and contributing categories may not have been uncovered at this point in time. Because of this, it is difficult to recommend that the concept of conditional expertise be adopted as is in nursing practice. However, the research outcome could immediately be used to raise awareness of the existence of a problem for some people with chronic illness. Nurses who are sensitised to the issues can make their own judgement

about the relevance of this discussional grounded theory to their own nursing practice.

Future Research

A larger and more complex study would be needed to uncover all aspects of the process that occurs when people with chronic illness encounter the acute care system. However, the data obtained from participants in this study was rich with potential for other research on different aspects of admission to hospital. For example, participants talked about gauging the seriousness of their condition by observing the actions of staff. Sometimes it seemed that this process was misleading, but discovering its extent would be a valuable and interesting research project on its own.

If the key process generated from this grounded theory study, *conditional expertise*, can inform practice, it may also contribute to enhancing the utility of existing models of care, such as the partnership model, when they are used with people who have a chronic illness. Further research could provide confirmation of the characteristics and relevance of this concept, as well as its ability to enhance the value of partnership as a philosophy on which to base nursing practice.

Conclusion

Given the ageing population and increasing incidence of chronic illness, it is vital that nursing, other health professionals, managers and policy leaders in health care examine and address issues related to the provision of care for this group of people. Changes are required both in the system of acute care delivery and in the value individual practitioners place on the expertise people with chronic illness bring with them to hospital. Nursing, with its claims of commitment to holistic and humanistic care, must surely be the ideal profession to initiate this process.

APPENDIX I

POSTER FOR DISPLAY IN THE HOSPITAL

**Do you have a long-term
illness or a chronic
medical condition?**

and

**Have you been admitted
to hospital for any
reason during the last
two months?**

**If so, would you be interested in participating in
a research project about your chronic illness ?**

My name is Georgina Casey and I am a lecturer at Otago Polytechnic's Dept. of Nursing and Midwifery. For my Masters thesis through Massey University I am doing a study about what it is like for someone with a chronic illness to experience an acute episode in hospital. If you would be interested in sharing your experiences I would like to hear from you. Please call me at:

Georgina Casey
Department of Nursing and Midwifery
Otago Polytechnic
ph. 479-6135

This research has been approved by the Massey University Ethics Committee (HEC96/125) and the Southern Regional Health Authority Ethics Committee (Otago) (96/09/087)

APPENDIX II
LETTERS OF APPROVAL FROM ETHICS COMMITTEES



**MASSEY
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**FACULTY OF
BUSINESS STUDIES**

FMBS

**DEPARTMENT OF
HUMAN
RESOURCE
MANAGEMENT**

16 September 1996

**Georgina Casey
Nursing & Midwifery Department
Otago Polytechnic
Private Bag 1910
DUNEDIN**

Dear Georgina

Thank you for your amended poster, information sheet, and consent form. The amendments you have made now meet the requirements of the Human Ethics Committee and the ethics of your proposal are approved.

Yours sincerely

**Professor Philip Dewe
Chairperson
Human Ethics Committee**

c.c. Dr Judith Christensen
Department of Nursing and Midwifery

OTAGO ETHICS COMMITTEE

17 October 1996

Georgina Casey
Nursing and Midwifery
Otago Polytechnic
Private Bag 1921
DUNEDIN

Dear Georgina

The experience of chronically ill patients in an acute care hospital

Investigators: Georgina Casey, Dr J Christensen

Protocol Number: 96/09/087

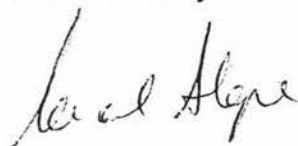
Thank you for your letter of 13 October 1996 and the enclosed amended information sheet and consent form. I confirm that this study has now been approved in full.

Approvals granted to protocols are for 12 months. If, after 12 months the study is not completed, it will be necessary to forward to the Committee a brief report on progress made to date and a request for an extension. Please quote the above protocol number in all correspondence relating to this study.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Please advise the Committee on the completion of the study or if, for any reason, you decide not to complete it. On completion of the study a brief report should be forwarded to the Committee.

Yours sincerely



Carol Algie

Ethics Committee Administrator

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16 September 1996

Georgina Casey
Nursing & Midwifery Dept
Otago Polytechnic
Private Bag 1910
DUNEDIN

Dear Georgina

RE: RESEARCH PROPOSAL NO. 118
An exploration of the experiences of the chronically ill patient in an acute care hospital

Thank you for your research proposal which was submitted at the last meeting of the Ethics Committee for ratification of the decision from Massey University Ethics Committee.

Subject to receipt of their final letter of approval we are happy for you to proceed with this research.

Yours sincerely



Jenny Conder
Chairperson
Ethics Committee

APPENDIX III
INFORMATION SHEET



**MASSEY
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**FACULTY OF
SOCIAL SCIENCES**

**DEPARTMENT OF
NURSING AND
MIDWIFERY**

The experience of people with chronic illness in an acute care hospital.

Information Sheet.

Thank you for your interest in this research. Here is some information to help you make a decision about whether you wish to participate in this research project. As we discussed in our telephone conversation, I will contact you again in a couple of days to answer any questions you may have after reading this information sheet. If you wish to participate in the research we will then set up a time to meet. You are free to withdraw at any time.

Who is the researcher?

My name is Georgina Casey. I am a registered nurse and a lecturer at the Department of Nursing and Midwifery at Otago Polytechnic. This research project is being undertaken as part of my Masters degree in Nursing at Massey University. It will be supervised by Dr Judith Christensen, a senior lecturer in the Department of Nursing and Midwifery, at Massey University.

How can you contact me?

I can be contacted at Otago Polytechnic during normal working hours by phoning 479-6135 or after-hours by leaving a message on the answer phone.
Dr Judith Christensen can be contacted during working hours at Massey University by phoning 06-350-4329.

What is this research study about?

There have been a number of research projects performed overseas about chronic illnesses and their impact on the lives of the people who have them. Very little research has been done in New Zealand and none of this research has looked at what it is like to have a long term illness or chronic medical condition and be a patient in hospital.

By interviewing people such as yourself about your hospital experiences, and analysing these interviews, I hope to find out about your unique needs and circumstances. This information will guide nurses in the future caring for people with chronic illness so that they are able to understand the special requirements that people such as you may have.

What will you have to do if you agree to participate?

I wish to interview you in your home or another setting that is convenient for you. During this time I will ask you to describe what your experience of being in hospital was, including the events leading up to your admission. I may also want to interview you again at a later date to check my understanding of the information you have given me and follow up any points that need clarifying or expanding. With your permission, interviews will be audiotaped.

How much of your time will be involved?

I do not anticipate having more than three interviews with you. The first interview may last up to an hour, but I would expect later interviews to be shorter. Interviews will be at a time that is convenient for you and at a place which suits you.

What can you expect from the researcher?

If you agree to participate in this research you have the right to:

- refuse to answer any particular questions
- withdraw from the study at any time and have any information you have already given destroyed or returned to you
- ask any further questions about the study at any time
- complete confidentiality of information that you may choose to give. The only people with access to the tapes and their transcriptions are myself, my supervisor and a typist who has undertaken to keep this information confidential. Tapes and transcripts will be kept in a locked filing cabinet.
- select a pseudonym which will be used in place of your real name in any written account of the research. Small excerpts of transcripts may be included in reports of the research, using your pseudonym.
- choose whether the information recorded on tapes and transcripts will be destroyed or returned to you at the completion of the project, or retained by the researcher for use in a larger study at a later date.
- be given the opportunity to edit the transcripts of your interviews
- be given a summary of the research findings when the study is completed.

If any serious concerns about your hospitalisation arise for you during interviews, you should contact the Patient Advocacy service at the hospital.

This research has been approved by the Massey University Human Ethics Committee (HEC96/125) and the Southern Regional Health Authority Ethics Committee (Otago) (approval number).

Thank you for your interest in this study.

Yours sincerely

Georgina Casey

APPENDIX IV
CONSENT FORM



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FACULTY OF
SOCIAL SCIENCES

DEPARTMENT OF
NURSING AND
MIDWIFERY

The experience of people with a chronic illness in an acute care hospital.

Consent Form for the Participant

I have read the Information Sheet for this study and have had the details of the study explained to me. My questions about the study have been answered to my satisfaction and I understand that I can ask further questions about the research at any time.

I understand that, if I consent, the interviews will be audiotaped and that I have the right to decline to answer any particular questions if I choose, or to have the audiotape switched off at any time. I also understand that I have the right to withdraw from this study at any time and the information I have already given will be destroyed if that is what I desire.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I agree / do not agree (*please delete one*) to have my interviews audiotaped.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signed (participant) _____

Signed (researcher) _____

Date: _____

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