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Controlling involvement to promote confidence in palliative care decisions - a grounded theory from the patient's perspective

Susan F. Lee
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**CONTROLLING INVOLVEMENT TO PROMOTE CONFIDENCE
IN PALLIATIVE CARE DECISIONS – A GROUNDED THEORY
FROM THE PATIENT’S PERSPECTIVE**

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**This thesis is presented in fulfilment of the requirements for the degree
of Doctor of Philosophy**

**Faculty of Computing, Health and Science
Edith Cowan University**

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USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

ABSTRACT

Decision making in the context of palliative care is particularly complex given the unpredictable illness trajectories experienced by patients and the number of individuals who may be part of the decision making process. This grounded theory study explored and described from the perspective of patients with advanced illness, their experiences of making care decisions.

A review of literature at the commencement of the study indicated that there was a lack of evidence to support the best way of ascertaining patient's preferences for involvement in decisions in a palliative care context and almost no research to guide clinicians about the involvement of patients and families in decision making.

Data was collected from patients, families and health care professionals in Australia and Japan about their experiences in hospitals, hospices and in the community. Fifty-eight (58) individual interviews and over one-hundred (100) hours of field observations of decision making practices were undertaken. The Decision Role Card Sort (Degner & Sloan, 1992) was used to determine the decision making intentions of patients, family members and health professionals. The data was transcribed verbatim and managed using the Nud*ist Vivo computer software. The constant comparative method was used for analysing the data.

The substantive theory of *controlling involvement to promote confidence in palliative care decisions* described patients' common experiences of issues related to their perceptions of lack of involvement in decisions about their care; in terms of their assessment of the character, approach and focus of their health professionals and in how they accessed information. Patients who perceived a lack of involvement experienced a lack of confidence, distrust and uncertainty. Their experience and responses were influenced by four conditions: 1) the relationship they developed with health professionals, 2) how information was shared, 3) their personal characteristics, and 4) the nature of their relationships with, and culture of, their family. The basic social process of Controlling Involvement described how patients responded to these concerns by attempting to control the involvement of others in making decisions about their care.

These findings indicate that partnerships between health professionals and patients provide the most favourable conditions for decision making in palliative care, where patients can comfortably communicate their decision making needs. However, these findings contradict models of patient participation, which favour patients being independent decision makers. Further implications are related to the content and process of communication with patients and the importance of identifying the needs of family members as separate to the needs of patients in care decision making.

Recommendations from this study include education of health professionals and the community regarding the development of collaborative relationships between patients and health professionals. Further, clinical practice recommendations include the assessment of decision making preferences as a component of care planning improvements in access to information about care planning. Directions for further research include the identification of interventions to improve collaborative relationships between patients, their family members.

DECLARATION

I certify that this thesis does not, to the best of my knowledge and belief:

- (i) incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education.
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I would like to acknowledge and thank a number of individuals and organisations that have contributed to and supported me during this study:

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Penetrating so many secrets,
We cease to believe in the unknowable.
But there it sits nevertheless,
Calmly licking its chops.

-H.L. Menken

(in Adler J. & Coughlin, P. (2003) *Zen Cat*. New York: Rodale)

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CHAPTER 1

Background and Purpose

Introduction

I rang my doctor and asked him what was I going to do, and he said, "Put him in hospital." It was the combination of my doctor and the district nurse's [decision], and I just had no say in it, they just took him. (Lee & Patterson, 1997)

A small qualitative study conducted in the mid 1990s examined the decision to enter hospital at the end of life (Lee & Patterson, 1997). The authors of this study noted that a number of participants made reference to the doctors and nurses who contributed to the decision to go to hospital rather than patients or family members. The participants, all family care givers, described the decision in positive terms, often with a sense of relief that others were better decision makers at that time than they were. However, the study also indicated that the family caregivers believed that neither they, nor the patient had been given a decision to make (Lee & Patterson, 1997).

Despite the predominant view in health care being that health care professionals have an obligation to respect patients' rights to make decisions about their care, how patients and health care professionals go about making decisions remains unclear.

The focus of this grounded theory study was on the processes of care decision making in advanced illness. This first chapter outlines the background and reasons for undertaking the study. In addition, the literature reviewed and the significance and purpose of the study are presented.

Background of the Study

Decision making is a complex process in any social interaction. In the context of a terminal illness, decision making processes may be particularly difficult, stressful and

characterised by uncertainty. Fundamental principles underpin the delivery of palliative care and subsequently the overall framework in which decision making occurs.

One of the more fundamental principles of palliative care is that patients have choices about the care that they receive. This principle of choice has been reinforced in the last 30 years by the consumer movement that has encouraged patients as consumers of health care, to be aware of their rights (Rakich, Longest, & O'Donovan, 1977). In particular, it is now widely acknowledged by health care providers that patients have the right to determine what happens to their bodies; that is, that patients have the right to make informed choices about their care.

Another important principle of palliative care is that the family is considered to be the 'unit of care' (Kemp, 1999). In recognition of the centrality of family in a person's life and the significance of serious illness and loss in the lives of family members, the patient and family are considered recipients of care.

A further feature of palliative care is the role of a multidisciplinary team in complex care decisions. Doctors, nurses, counsellors and volunteers work with patients and families to create a decision-making environment of consensus, collegiality and support.

The nature of decisions in palliative care ranges from physical care decisions, location of care decisions, preparation of other relatives and friends for the death, preparation of wills and funerals and plans for what will happen with children and property after death. Many of these decisions are confounded by complex family relationships. The characteristics of families have become more variable: step families, extended families, and estranged, isolated and nuclear families. A patient's simple decision to go home might be complicated by the demand for care that this decision creates. A neighbour may be the primary caregiver and unable to provide personal and physically invasive care, or there may only be a daughter who lives interstate, or a spouse who is also ill. Communication barriers may exist due to past behaviours and events or due to different cultural or religious practices, or the fact that fundamental belief systems are challenged by terminal illness.

Decision making in palliative care, therefore, is characterised by a complexity rarely identified in acute situations. In these cases, where the episode of illness is one

from which the patient is more likely to recover, family members may change roles temporarily or acquire a different role permanently, in cases where disability occurs. However, in palliative care, roles are often constantly changing with the altering condition and deterioration of the patient. The 'round the clock' care required and the roller coaster sequence of remissions and exacerbations of a terminal illness often exhaust families. Their own grieving processes often complicate this exhaustion. Rarely would a decision simply relate merely to the patient's preference; there are also competing desires, strengths, weaknesses and resources of each family member. As well, recommendations and available resources and skills of the members of the health care team interact with family and patient issues making decisions complicated beyond an individual's particular desire.

Despite the complexity of the decision making process, guidelines for palliative care decision making in the United States, the United Kingdom and in Australia have tended to be oversimplified, primarily emphasising individual choice (American Cancer Society & National Comprehensive Cancer Network, 2003; Australia and New Zealand Society of Palliative Medicine, 1999; West Lothian Council, 2004). Thus, notwithstanding the advantage of multidisciplinary team decision making with a central core of patient and family, the ethical principle most commonly appealed to is that of a respect for individual autonomy.

Palliative care teams, whose practice is reflected in the early influences of Anglo-Saxon and Christian traditions in the United Kingdom, are being challenged to respond to wider range of patients representing more diverse cultural groups. Not all cultural groups place the same emphasis on individual autonomy. In environments where individual choice is culturally subsumed by family imperatives, there is obvious tension created by the practice of palliative care. Yet in western countries, families also have a decision-making role in palliative care, though their role is only described in terms of supporting the patient's autonomy. A failure to describe the processes of decision making in palliative care as it is practiced in western cultures may lead to inaccurate assumptions about how palliative care should be incorporated in other cultures.

Review of the Literature

The methodology used in this study was grounded theory. As discussed in the following chapter, the conduct of a literature review prior to commencement of a grounded theory study is sometimes viewed as controversial. However, in this study, an initial literature review was undertaken in the year 2000, for the purpose of setting the scene of the study; to determine the state of knowledge about patient decision making in palliative care, and to assess the need for an investigation in this area (Chenitz & Swanson, 1986). An initial review of the literature, mostly textual, was related to the ethical principle of autonomy. In addition, a review of the literature was conducted from the databases CINAHL, Medline and PsychInfo using combinations of the terms: Palliative Care, Decision Making, Patients, Family and Health Professionals. The literature on decision making in health care fell roughly into three broad categories: guidelines for health care professionals, the roles of patients and the roles of families. Though there were few empirical studies, the breadth of literature informed the selection of the most appropriate method and questions about decision making in palliative care.

The Ethical Principle of Respect for Autonomy and Ethical Theories

Beauchamp and Childress describe personal autonomy as “self-rule that is free from both controlling interference by others and from limitations, such as inadequate understanding, that prevent meaningful choice” (2001, p58). Respect for the principle of autonomy has at its foundation the fundamental dignity of human beings and their capacity to determine what is in their own interests (Johnstone, 1999). Many of the decisions related to patient care, it might be argued, should be made with respect to the principle of autonomy. Beauchamp and Childress (2001) locate the principle of respect for autonomy as one of the four basic principles of moral behaviour in professional ethics that include; nonmaleficence or the avoidance of harm, beneficence or the balancing of benefit and risk and the principle of justice or fairness. Respect for these basic moral principles are considered *prima facie* obligations; that is an obligation dependent on the presence of “equal or stronger obligations” (Beauchamp & Childress, 2001, p14). How these principles are viewed in practice, they argue, is dependent on moral theories regarding rules, obligations, rights, outcomes and moral character.

Some moral theories, known as deontological theories undertake that right action is based on the nature of the action itself and if it conforms to various rules or duties (Husted & Husted, 1995). These rules or duties exist independently of the person who is acting and of the person/s affected by the action. For example, in a situation where a patient asks for the results of a surgical procedure, in a deontological context, he or she ought to be given these results despite that he or she might be greatly distressed by this knowledge. Johnstone (1999) notes that deontological theories are often criticised for their focus on abstract rules rather than the individuality of the people involved, their unique relationships and wellbeing.

Another moral theory, known as teleological is contrasted from the deontological perspective by having little concern about the nature of the action and far more concern for the consequences of the action (Johnstone, 1999). A utilitarian perspective, one of the more commonly held teleological theories (Husted & Husted, 1995) would advise in the example used earlier that the nurse ought do what would produce the most good for the most people. The individual patient's interests are in this case, only one set of interests in the calculation, even though they would be viewed as significant, but the nurse, the patient's relatives, health professionals and even other patients could also be considered in the assessment of what might produce the most utility. In practice, Utilitarianism is also often criticised as "too abstract to be able to deal effectively with the concrete circumstances of life" (Johnstone, 2004, p61).

Other moral theory, particularly Virtue Ethics, concentrates attention on the nature of the person rather than their actions or the outcomes of those actions. Because it is the character of a person that motivates them to live in a particular way, it is their moral motivations that make choices less abstract (Beauchamp & Childress, 2001). The moral virtues are the morally valuable characteristics of a person who strives to live a morally good life. Beauchamp and Childress (2001) note that the most important virtues of health professionals include compassion, discernment, trustworthiness, integrity and conscientiousness. Husted and Husted suggest that the standard of autonomy expressed as a virtue means the "ability to sustain one's unique and rational nature – those qualities of character that enable a person to be the person one desires to be" (1995, p23). A virtuous health professional, they argue, will recognise that all people, and patients, should want to be better people. Helping patients thus involves nurturing their virtue as well as the health professional's own virtue (Husted & Husted, 1995).

The theory of Caring, often referred to as a theory of nursing ethics (Brown, Kitson, & McKnight, 1992; Husted & Husted, 1995) explains the moral relationship between health professional and patient. Originally described by Leininger (1981) and by Noddings (1984) who described Caring as a theory of teacher-student relationship, the theory subscribes to a feminist view that traditional views of moral development have a masculine and paternalistic view that morality can be objective, leaving women, who tend to focus on subjective experience, of lesser moral character. The theory of Caring involves a disposition or feeling towards another person and an understanding of his or her situation. The demands of an ethic of Caring go beyond an expectation that health professionals will care for patients, and that they will care about patients. It involves a relationship that is other-centred rather than self-centred. Caring also demands mutual and positive regard and a commitment to use one's knowledge and skill in acting on behalf of the other (Brown et al., 1992). For a caring nurse, respect for a patient's autonomy is integral to his/her other-centred relationship.

Critics of Caring as a nursing ethic (Kuhse, 1997; Veatch, 1998) emphasise that caring is too vague to provide guidance to action. Kuhse (1997) suggests that the demands of a gender-based ethics of caring reinforce stereotypes of women and create unfair burden of responsibility for the creation and maintenance of impossible relationships. Caring has been defended, to some extent, by placing it in a virtues framework (Johnstone, 2004; Lee, 1994). Johnstone (2004) suggested that Caring was an ideal for all health professionals because it describes a balance between indifference and over-involvement, reciprocity and attempts to clarify what it means to be a good nurse. Veatch (1998) suggested that as a theory about relationship, the theory of Caring would be significantly different to other ethical theories, but has not been sufficiently explained.

Respect for the ethical principle of autonomy is an integral part of a range of theories regarding ethical behaviour. Therefore, in this study regarding patient decision making, an underlying assumption is that all health care professionals ought to respect the right of their patients to make decisions about their health care.

Decision Making and Health Care Professionals

The notion that patients ought to be able to freely make informed decisions about the care that they receive is underpinned by respect for the moral principle of

autonomy. Beauchamp and Childress acknowledge that "[V]irtually all medical and research codes of ethics now hold that physicians and researchers must obtain the informed consent of patients and subject before undertaking procedures" (1989, p74).

Despite the fact that philosophers since Aristotle in the 3rd century BC have supported the concept of individual autonomy, authors still find the application of respect for the principle in health care decision making problematic.

Scanlon (1998) highlighted the difficulties associated with relying on patients to make decisions. In a discussion on ethical issues in palliative care, she acknowledged that although the primary concern in making decisions in palliative care is the "preferences and interests of the patient" (1998, p138), the context of that decision is the relationship between patient and clinician. She goes on to comment on the challenges to that relationship posed by patients who may be unable to be involved in decisions, who may not have expressed their wishes when they were able and health care providers who disagree about their care wishes.

Disagreement between clinicians was a feature of the case study presented by Taube and Bruera (1999). In this paper the authors highlighted the issue of treatment boundaries in palliative care, where palliative care clinicians are criticised for aggressive treatment decisions. They acknowledged that there was a lack of research into the reasons why physicians are less likely to listen to their patients. These authors exhort readers to focus on the patient's values and wishes as central to ethical decision making. Though not explicitly stated, the problem they faced in the case of a man whose treatment was limited by his palliative diagnosis rather than his expressed wishes or overall condition, was a situation of medical paternalism.

Although the term paternalism refers literally to "in the manner of a father dealing with his children" (Delbridge, 1986, p449), in ethics paternalism refers to intervening in a person's decisions for their own sake; in order to protect or benefit them (Johnstone, 2004).

Taylor, Pickens and Geden (1989) explored the theme of medical paternalism and maternalism in decision making. They cited an earlier 1983 study by Buchanan as describing paternalism as the most prevalent mode of physician patient relationship. In their own study that analysed the interactions of 85 physicians and 42 nurse

practitioners with their clients, they found that statements of command, a feature of paternalism, were the most common forms of attempt to influence decision making. Although they provided insight into the similarities and differences between men and women and the ways in which attempts to influence are made, the conclusions were too broad to provide guidance to health care providers on appropriate processes for communication. The researchers themselves advised that further conceptual and pragmatic studies were needed.

At least one of the difficulties described by doctors in relation to patient-driven decisions, (Gawende, 1999; Taylor, Pickens, & Geden, 1989), occurs when patients make decisions that are contrary to the advice of doctors. Gawende's (1999) article succeeds in provoking an examination of the suggestion that individual autonomy is paramount in decision making. He raised a range of cases where patients refused the doctors advice, were over ridden and then appeared grateful for the paternalism of their caregivers. He stopped short of suggesting that doctors were infallible in good decision making by suggesting that good doctors operate in a particular way so that most patients see the sense in their advice and change their minds in accordance with their doctor's wishes. Although this paper provided some interesting reflections, it failed to provide evidence for the conclusions made in relation to the behaviour recommended to doctors in involving patients and families in health care decisions.

Despite the discomfort Gawende's (1999) paternalistic suggestion engendered, though it was balanced by beneficent intent, cases and situations where patients prefer the doctor make their health care decisions do exist in other health care environments. In a significant Canadian study, Degner and Beaton (1987) observed life and death decisions in a range of health care environments. They found that although there were some patients and families who wished others to make their health decisions, there were others who wanted control. They expressed concern that medical practitioners may exclude patients and families from decision making because of prior poor experiences when trying to involve patients in decisions. They concluded "[P]erhaps the real challenge is to discover effective ways of fostering such involvement rather than negating its importance" (Degner & Beaton, 1987, p37).

The Degner and Beaton (1987) study involved three years of data collection in acute settings such as intensive care units, medical and surgical wards, labour wards, a

neonatal intensive care unit and one adult palliative care unit. They utilised direct observation; short interviews of patients, family and health care providers, and an analysis of medical records to guide opinion on treatment decisions. They then conducted a constant comparative content analysis of the data and found a range of factors affecting decision making. The breadth of hospital environments included in this study was considerable, but the focus was on life and death decisions only. It predates significant developments in health care treatments in the provision of palliative care and more widespread commitment to patient and family involvement in decision making.

Whilst informative, the Degner and Beaton study is heavily contextualised in the hospital environment and therefore concentrates on health care professionals and patients rather than an examination of the patient and family and health care decisions in the community, where significant decision making now occurs. This study focuses on the serious moral dilemmas associated with life and death decisions, but does not address the burden of the complex and day-to-day decisions of patients, their families and professional caregivers. Furthermore, this study is now more than 20 years old and no similar study has been undertaken in an Australian environment.

Despite the importance of respecting patient autonomy, these studies indicate that health professionals who are also concerned about their responsibility to help people, sometimes disagree with patients about what is in patients' interests. Some patients appear to be grateful for their health care professionals' paternalism and others appear to want health professionals to make their health care decisions, potentially leaving health professionals confused about how to respect patients' autonomy. None of these studies focused on a palliative care context across a range of clinical environments and a focus on these modern clinical contexts and patients' experiences is warranted.

Patient Decision Making

The particular role taken by patients in decision making has also been discussed in the literature. Degner and Sloan (1992) asked a significant number of newly diagnosed cancer patients and members of the Canadian general public, what role they wished to take in the selection of cancer treatments. Participants were asked to sort by preference two sets of decision role preference cards and the results were analysed using "unfolding theory" (Degner & Sloan, 1992, p944). Though half of the subjects in both groups wanted their family and doctor to share the decision making if they were not

able to participate, the patients with cancer were 50% less likely to want to make decisions about treatment than the members of the public. This finding indicates that the role a person chooses to take in decision making is influenced by the presence or absence of a diagnosis of life threatening illnesses such as cancer.

In contrast, a specific study of women with breast cancer found that 66% preferred to be involved in decisions about their treatment in active or collaborative roles (Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, & Mueller, 1997). This study used the same decision role preference card sort described in the previous study. Only 42% of women in the study believed that they had achieved their preferred decision role. The contrast in desired decision roles between the 1992 study and 1997 study may have been due to the particular diagnosis of breast cancer, a cancer about which women are becoming increasingly aware (Degner et al., 1997; Degner & Sloan, 1992). The researchers in the later study recommended the assessment of desired decision roles, using the card sort technique in clinical assessment to avoid confusion about the actual decision role particular patients desired (Degner et al., 1997).

Following this study, Davison and Degner (1998) reviewed the literature on factors that influence decision making in life and death situations. They found a range of influences regarding attitudes of health professionals, conflict between them, the setting of the decisions, economic situations, knowledge of disease factors and prognosis to have been explored in the literature. However, a lack of empirical data on the decision process meant, "little is known about how these treatment decisions are made in clinical practice." (Davison & Degner, 1998, p129). Though they also acknowledged a lack of empirical research on interventions to assist patients and families in decision making in terminal illness, they also propose that individual decision characteristics should be assessed using the card sort technique identified previously. The long-term effect of decision making has not been explored; therefore, no prediction can be made about whether role preferences change over time or with changing circumstances. Therefore, it was judged to be appropriate to use the decision role card sort in this current study as a way of determining initial intention of patients and family members in decision roles. Use of this technique would also help to assess how decision roles might change over time and circumstances, and would assist in determining the preferred roles of health care professionals.

The need to assess patient's preferences in decision roles was also apparent in the literature regarding specific ethnic groups. Blackhall, Murphy, Frank, Michel and Azen (1995) examined the attitudes of 200 elderly people of various ethnic backgrounds, to the disclosure of information regarding terminal illness. They found that "ethnicity was the primary factor related to attitudes towards truth telling and patient decision making" (Blackhall et al., 1995, p820). However, their conclusion that patients should be asked if they would prefer that their family or they as individuals receive information and make decisions, oversimplifies the cultural requirement. This conclusion was drawn from a quantitative examination of very limited types of decisions such as who should take responsibility for that regarding life sustaining treatment. Other, less urgent decisions such as whether the side effects of a drug might be too much of a burden were not explored. It is unclear then that all decision making would be preferred in the same way as it would be for questions of life and death.

The literature reviewed indicates that a range of conditions may affect the decision roles that patients choose, though little is understood about those conditions or the stability of those choices over time and in the context of different decisions. The role card sort (Davison & Degner, 1998) was identified as a tool to assess the desired decision roles of patients and their families in this current study.

Families And Decision Making

The literature that explores family involvement in decision making is largely drawn from the field of Gerontology where families are often making decisions on behalf of a relative who is not sufficiently competent to make decisions for themselves. One study by Iris (1988) examined the guardianship process through the exploration of the roles of physicians, guardians and judges in an ethnographic study. Her findings indicated some conflict in the role of the temporary guardian appointed to investigate guardianship issues and conflict between medical and legal criteria for decision making competency. In her discussion of the findings in this study, the author notes that personal identification and attitude sometimes interfered with decisions made. She concluded that societal attitudes desiring to protect the frail elderly might be at the expense of individual autonomy (Iris, 1988).

Sherlock and Dingus (1988) also identify concern about vulnerable people and their protection from harm. They discuss the roles of families in decision making for a

range of situations where patients are not competent to make decisions themselves. In many of the cases cited, family roles are criticised either because of the perceived lack of recognition of the duty to protect from harm or because of their failure to adequately represent the wishes of the ill person. Sherlock and Dingus conclude that "the typical practice of family consent cannot be fully adequate and mechanisms must be found to either to review the decisions made by individual families or to locate the authority for surrogate decision making elsewhere altogether" (Sherlock & Dingus, 1988, p110).

In an attempt to resolve their concerns about family involvement in surrogate decision making, Sherlock and Dingus' (1998) solution is a model of independent advocacy. However, High (1988) expressed concern about the rush of legislation and advocacy groups pressing for mechanisms of advance care directives and asked elderly people what their preferences were for these types of devices. In High's 1988 study, forty men and women were interviewed about their preparedness to use family as surrogates for decision making and advanced directives. Though a small study, High found that "so long as elderly persons have immediate family, they perceive that their individual autonomy...is extendable and can be carried forward by familial surrogates" (High, 1988, p50). She concludes that instruments that clarify advance care directives should also be designed to assist family surrogate decision makers. In effect she acknowledges that the structure and function of families affects their preferred mode of decision making.

The studies of family involvement in decision making express some concern about the issues of surrogate decision making, but fail to address the issues created for families and patients making decisions when the patient is competent. In the fields of oncology and palliative care, where little work has been done on family decision making, families and patients are involved in a myriad of decisions when the patient is competent as well as during phases of incompetence. Despite this, the literature related to decision making suggests that individual choice should guide decisions, and fails to address the issues for families created by a patient's illness.

In a broad ranging literature review, it has been identified that the ethical principle of autonomy, supported by a range of ethical theories forms the basis of health care professionals' duty to respect and support patients to make decisions about their care. Studies in the decision making of health care professionals note the experiences of

conflict between their duty to respect patients' decisions and their duty to help patients and the confusion of health professionals in knowing when patients want them to make decisions on their behalf. Studies related to patients use a role card sort to identify the decision role preferred by patients, but few recent studies have been conducted with palliative care patients and noted the resilience of preferred roles over time. Many studies of decision making in palliative care focus on the decisions related to difficult ethical end-of-life decisions such as withdrawal of treatment rather than decision making in general. There are limited studies of family involvement in palliative care decision making and literature related to family decision making ignores the role of family when patients are competent. The literature supports the need for an Australian study of the processes of decision making in palliative care from the perspective of patients that examines the roles of patients, their family and health professionals in making broad ranges of care decisions over the time of patients' illnesses.

The Significance and Purpose of the Study

Although health professionals are guided in decision making by the principle of autonomy (Beauchamp & Childress, 2001; Johnstone, 2004; Veatch, 1998), when faced with complex palliative care situations, health professionals are paternalistic, believing they know what is best for patients (Gawende, 1999). It is unclear what processes should guide decision making in palliative care. The dominant discourses in this field result in potentially insensitive processes, dominated by individual interests. In such a process, decisions may be plagued by a lack of information leading to poor care and poor care outcomes for patients and families. A clearer understanding of appropriate decision making processes in Australian palliative care may be used in the education of palliative care providers, to improve clinical practice and for further research, particularly related to other cultures.

The purpose of the current research is to develop a substantive theory that describes the processes of decision making in palliative care from the patient's perspective.

Study Objectives

To understand the role of patients, family members and health professionals in care decision making during advanced illness.

To differentiate the desired role from the actual role of patients, family members and health professionals in care decision making during advanced illness.

To describe the significant issues experienced by patients in making care decisions during advanced illness.

To describe the factors that influence the processes of care decision making during advanced illness.

Definition of Terms

The following provides definitions of important terms used in the thesis:

Advanced Illness

Advanced illness is a term used to describe the phase of illness where curative measures are unlikely to succeed and supportive and symptom control measures only are more likely to be offered. Thus where an illness such as cancer is progressing beyond attempts to halt it and has progressed to this point, it is unlikely that the person suffering the illness will survive. The terms ‘terminal illness’, and ‘life limiting illness’ are considered synonyms of the term ‘advanced illness’.

Autonomous Decision

An autonomous decision is made when a person exercises their autonomy by making a decision that “is free from controlling influence of others and from limitations, such as inadequate understanding, that prevent meaningful choice” (Beauchamp & Childress, 2001, p58).

Decision Making

The term, decision making, refers to the act of determining a resolution of a question (Delbridge, 1986, p155). The scope of decision making discussed in this study includes decisions related to care planning and medical and nursing interventions, site of care, referral decisions and family caring decisions.

General Practitioner

The general practitioner is a medical practitioner providing “primary, comprehensive and continuing whole patient care to individuals, families and their community” (Royal Australian College of General Practitioners, 2001, p2). The General Practitioner in Australia is most often based in consulting rooms in the community, although many also visit less mobile patients in their homes.

Family and Significant Others

In palliative care, the patient and family are described as the ‘unit of care’ (Kemp, 1999), which means that the health care team focuses on them as a group, each individual and the group needing care. In a modern society, definitions of who makes up a family are diverse (O'Toole, 1992). Therefore, it may be that the people directly affected by and affecting the ill person may not have a ‘blood’ relationship with them. These individuals may, however be significant to the ill person. In engaging the family of an ill person in this study, any person significant to the ill person would also be included.

Multidisciplinary Teams

Multidisciplinary teams are groups of individuals with different discipline backgrounds working together with “a common purpose and a unified identity” (Ingram & Coyle, 1999, p260). In the context of this study, the common purpose of the palliative care team is the coordinated care of the patient with advanced illness and their family.

Palliative Care

Palliative Care is defined by the World Health Organisation (2002) as:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;

- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients [sic] illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (World Health Organisation, 2002).

Palliative Care Unit

A palliative care unit is an in-patient setting that provides palliative care to people with terminal illness and support for their family. Palliative care units in Australia most commonly admit patients either for symptom management or terminal care. In addition palliative care units will try to offer admission for patients when respite for families is required.

Summary

This study sought to clarify the processes of care decision making during advanced illness. A review of literature indicated that although much has been written on the issues regarding palliative care decision making and on the responsibilities of health care professionals, most of the literature assumes that a respect for the principle of individual autonomy is of paramount importance. There is a small body of empirical work in North America, that indicates that some patients would prefer that others make at least some decisions on their behalf, though little research has been conducted to examine the process of decision making in practice. There is a lack of evidence to support the best way of promoting patient and family decision making. No studies on the process of decision making in Australian palliative care have been published. The Decision Role Card Sort (Degner & Sloan, 1992) was identified as useful in the assessment of patients and families involved in the study. A grounded theory study was undertaken to develop a substantive theory of the processes of care decision making during advanced illness, from the perspective of patients.

CHAPTER 2

Methods

Introduction

In this study, a grounded theory design was used to describe a substantive theory of patient decision making in palliative care. This chapter describes how grounded theory enabled the concurrent collection and analysis of data, allowing the theory to emerge and be verified. The settings and participants who contributed to the data are described and the processes of data collection and analysis detailed.

The complex ethical issues that arose during data collection are discussed and the trustworthiness of the findings is proposed.

Research Design - Grounded Theory

The process of decision making in palliative care was studied using the grounded theory method. The grounded theory method was first described by Glaser and Strauss in 1967 and further developed by Glaser (1978; 1998), Strauss (1987) and by Strauss and Corbin (1990). Glaser and Strauss were sociologists who discovered the grounded theory method while working together on a study of the sociology of illness that resulted in the book, titled “Awareness of Dying” (Glaser & Strauss, 1965). Glaser had been trained in quantitative sociology and Strauss in symbolic interaction as a student of Herbert Blumer (Glaser & Strauss, 1967). The approach they developed was a systematic method of discovering theory from data involving inductive processes.

Prior to the development of the grounded theory method, Glaser and Strauss (1967) found that qualitative research consisted of detailed description, mostly giving background to quantitative studies but generating little theory. At the same time, quantitative researchers were developing rigorous methods for testing and reproducing facts. Glaser and Strauss proposed that each form of data, qualitative and quantitative was “useful for both verification and generation of theory” (Glaser & Strauss, 1967,

p18). Their focus on grounded theory as a method of qualitative research stemmed from the usefulness of qualitative data in adequately and accurately describing social worlds.

The process of developing a grounded theory is essentially inductive rather than deductive. Deducting from qualitative research occurs when a hypothesis is tested by collecting data that reinforces or otherwise, the hypothesis. In grounded theory, preconceived hypothesis are prohibited since they would unduly influence the way the researcher collects and interprets data (Glaser & Strauss, 1967).

Strauss and Corbin (1990) explain that the process of generating and grounding theory includes the provisional verification of the theory through “systematic data collection and analysis of data” (p23). This process is known as theoretical sampling because the “data collection is controlled by emerging theory” (Glaser & Strauss, 1967, p45). In theoretical sampling, the researcher is sensitive to the gaps in the emerging theory and by the questions generated by answers to previous questions. The researcher selects subsequent groups of subjects on the basis of these questions and gaps and for specific theoretical purpose (Glaser & Strauss, 1967).

Central to generating theory is comparative analysis. Ideas generated by the data and the emerging theory are constantly compared with the data to “check that the ideas are well grounded in the data” (Gibbs, 2002, p240). The technique of comparative analysis is used to check the accuracy of initial evidence, to fully describe concepts and categories, to improve the descriptive power of categories so as to make generalisations, to specify a concept to analyse and to verify and generate theory (Glaser & Strauss, 1967).

Symbolic Interactionism

According to Chenitz and Swanson, grounded theory was developed from the "implications of the symbolic interactionist view of human behaviour" (1986, p7). Symbolic interactionism is a social theory that explains that people interact with each other on the basis of the meaning (symbols) they attach to situations. Thus, the theory is based on the premise that no object, situation or person has meaning of itself. The meaning is attached to the experience of that situation.

From a symbolic interaction perspective, social development is a process of reflection and interaction. Individuals learn a sense of self and rationality through a process interacting with others, of seeing themselves reflected in their relationships with others. Mead (Strauss, 1962) described this process of developing a concept of self, unique to human beings, as leading to self-directed behaviour. Blumer (1962) proposed that symbolic interaction also explains the ways that groups of people are able to function together because of their shared meanings in the phenomena around them. "The individual as part of the collective aligns his or her self-definition with those of others and acts according to shared meaning" (Chenitz & Swanson, 1986, p6).

Chenitz and Swanson (1986) suggested that a study underpinned by symbolic interaction must examine both the human behaviour and the symbolic meaning attached to interaction. Therefore, observations of a range of verbal and non-verbal interactions in the natural settings they would occur are essential. They also suggested that the researcher needs to be able to experience the meaning of the interaction and therefore cannot remain a disinterested bystander, but must take on the participants perspective by being "both a participant in the world as well as an observer of the participant in that world" (Chenitz & Swanson, 1986, p7).

The symbolic interaction perspective focused this study on the interactions and meanings shared among health care professionals, patients and families when care decisions were made and enabled an understanding of the processes undertaken during these events.

The Difference Between the Approaches of Glaser and Strauss

Following the publication of the book "The discovery of grounded theory" by Glaser and Strauss (1967), Glaser went on to publish further explanations of the process in the book "Theoretical Sensitivity" (Glaser, 1978). Strauss collaborated with Corbin on an explanatory text of grounded theory techniques and procedures (Strauss & Corbin, 1990) which called attention to the divergence between Glaser and Strauss in their interpretation of the method.

Strauss and Corbin (1990) emphasised an evolved systematic approach of grounded theory, often viewed as more constructivist or interpretive (Charmaz, 1995; Gibbs, 2002; Strauss & Corbin, 1990). In contrast, Glaser has held to a more positivist

approach that emphasises the objectivity of the researcher. Holloway and Wheeler claim that the major difference between the two approaches is in the ways that “concepts are generated and relationships explained” (Holloway & Wheeler, 1996, p111). In Glaser’s response to the Strauss and Corbin (1990) text, he accused the authors of ‘forcing’ their conceptual descriptions by suggesting that researchers start with a research problem rather than a broader and less prescriptive research area, and by undertaking a literature review (Glaser, 1992). Theoretical sensitivity is a concept explored by Glaser that refers to the sensitivity of the researcher to data relevant to theory. This sensitivity, Glaser suggests might come from the professional experience of the researcher of the field under study (Glaser, 1978), and Strauss and Corbin (1990) emphasise, from knowledge of the field’s technical literature.

Why Grounded Theory was Chosen as the Method for This Study

The literature regarding palliative care decision making indicated that little is understood about the process of decision making beyond the need for health professionals to respect the autonomy of patients. This study is well suited to the grounded theory method because the question identifies the area to be studied (patients with advanced illness and their families) and is oriented to both action (decision making) and process (patterns) (Strauss & Corbin, 1990).

The author of this current study has drawn heavily on the work of both Glaser and Strauss in the development and analysis of the project but because concepts were generated using a more interpretive than objectivist approach, adhered more closely to the grounded theory approach advocated by Strauss and Corbin (1990).

The Settings

This section presents the background information about the organisational settings from which the data were drawn. Data were collected from participants at three distinct settings including in-patient palliative care units, an acute hospital and from the community.

First Setting

On commencement of the study, data were collected in an outer suburban region in Melbourne. In this setting, the palliative care services were generally well integrated in the community and local hospital although the palliative care unit was newly established. There were three health care organisations identified as providing palliative care to patients in the study; the acute hospital, inpatient palliative care unit and community palliative care service, in addition to a number of general and specialist medical practitioners.

The region has a rapidly aging population with predominantly an Anglo-Saxon cultural background. Palliative care services provided in the local acute hospital and in the specialist palliative care unit are both owned and operated by the public health service provider operating in the region. Patients in their own homes receive specialist palliative care by a publicly funded community palliative care service. Private hospitals in the region also provide inpatient palliative care, but were not accessed by the patients included in this study.

The Acute Hospital

The region's acute hospital has approximately three hundred beds, providing a range of general and specialist health care services. Most oncology, cardiac and renal services are provided on site; however, patients requiring radiotherapy and some highly specialised surgery need to travel outside the region. A consultancy palliative care service provides specialist medical, nursing and pastoral care advice to any hospital patient or staff member. Medical or nursing staff make patient or family referrals. Some proactive referral seeking occurs by the palliative care nurse using the patient register to identify possible palliative care patients. The palliative care nurse then speaks to the nursing staff caring for these patients, offering to assist with any problems such as pain or symptom management and family support. An approach by members of the palliative care service to patients is, by necessity, sensitive to patients' awareness of their conditions, and is generally not undertaken until the treating medical officer has discussed a limited prognosis with the patient. Medical referrals are required to provide the full service to patients.

The Inpatient Palliative Care Unit

The inpatient palliative care unit is a fifteen-bed purpose built public facility that shares a site with rehabilitative and aged care services and a co-located community palliative care service. The unit has only been recently commissioned and the staff were newly employed or redeployed from other areas of the health service. There are varying levels of experience, palliative care knowledge and expertise amongst the nursing staff. As a member of the consultancy service at the acute hospital, and as the medical director of the inpatient unit and the community palliative care service, the doctor provides continuity for patients transferring from one service to another.

In the palliative care unit, patient care team meetings occur on a weekly basis. These meetings, attended by approximately sixteen medical, nursing, physiotherapy, occupational therapy and counselling staff, review and discuss the care plans of each patient in the unit. Although the patient's opinion on issues is often discussed, a member of staff rather than the patient presented this viewpoint. Representatives of the community service's nursing team and the acute hospital's consultancy team also attend the in-patient unit's care team meeting and report on the condition of patients that have been discharged from the unit into their care. During the meeting, the staff review each death by reflecting on issues related to symptom control, the patient and family's emotional state and the family's need for bereavement support. Dialogue is active and involves all attending the meeting. Patient care decision making also occurs during weekly multidisciplinary 'rounds' led by the medical director and attended by the patient's nurse, counsellors and other health professionals.

The patients in this unit are allocated to a different nurse on each shift and although some nurses cared for the same patients over a number of days, this is negotiated among the staff on a day-to-day basis. The medical and allied health staff are allocated patients on a referral basis, with most patients being under the care of the unit medical director.

The Community Palliative Care Service

The community palliative care service is well established, having been the sole specialist community palliative care provider in the region for over fifteen years. This organisation provides services to metropolitan and rural areas and covers a broad

geographic area. The service works closely with the patient's general practitioner, piloting a number of programs to improve the role of these doctors in the service and their palliative care knowledge and expertise. The range of counsellors employed by the service provides an integrated social, psychological and spiritual counselling facility to patients and family members. Counselling is provided by individual appointment and through a number of bereavement groups for adults and children. Specialised palliative nursing care is provided under contract by a community nursing service, working closely with the palliative care service.

The community service also holds patient care team meetings on a weekly basis. These meetings review the care plans of patients cared for in the community in much the same way as the team meetings held in the in-patient unit, and at a similar venue. The nurses who manage the care teams take it in turns to lead the meeting and dialogue is active from all participants without being dominated by any one person. Nurses from the acute hospital consultancy team attend to report on patients admitted to the acute hospital. General practitioners are invited to participate in these team meetings using a system of telephone conferences.

Second Setting

The second setting is an in-patient palliative care unit in Western Australia that has been established for eighteen months and also serviced a predominantly Anglo-Saxon community. This second setting was selected because, although relatively new, has a stable team of staff who have worked there for a period of time. It is an independent organisation situated on the grounds of a large acute, private hospital and consists of twenty in-patient beds and a day respite service catering for approximately two hundred visits from patients and family members in the community, each month.

The daily multidisciplinary care planning meetings are generally chaired by a senior nurse and attended by the medical director, registrar, visiting medical specialists, other supervising nurses or team leaders, the social worker, pastoral carers and any nurses who have specific issues regarding patient care they wished to discuss. Each meeting generally reviews the care plans of ten of the twenty patients on the ward, identifying unaddressed problems and discussing care changes. As is the case with the team meetings identified in setting one, patients are not invited to this meeting, though during the meeting the need to discuss care changes with patients and family members

is often noted. In addition to the patient care review, a number of quality management activities such as the audit of deaths and discharges are regularly conducted, from the perspective of the health care professionals.

The nursing staff of this unit work in discrete teams, each team caring for a section of the unit. Although the team leader remains constant, there are some alterations in staff for each team over different shifts. The medical and allied health staff care for patients across the whole unit.

Third Setting

During the course of the study the researcher was invited to be involved in a teaching program with a translator in Japan. This provided a unique opportunity to explore the patterns of palliative care decision making in Japanese families whose information needs and decision making have been reported as different to western cultures. (Huang, Butow, Meiser, & Goldstein, 1999). The third setting was a palliative care unit at a small private Christian community hospital, built in the 1960s, in Japan. Like many palliative care units in Japan, this unit is privately owned, but has government approval, which secures its ongoing funding. Though the hospital consists of only approximately two hundred beds, thirty-six of those are palliative care beds in two eighteen-bed wards. There is access to generalist home based services, but no day respite services and the average length of stay is approximately fifty days. This situation is representative of palliative care service in Japan, which is dominated by in-patient services. This model of services limited numbers of patients needing palliative care and there are often long waiting lists. Patients spend a significant amount of time after diagnosis in in-patient care because of the difficulties associated with the provision of home-based care. Patients either self refer to this palliative care unit or are referred from a nearby large tertiary treatment centre. It is recognised by the staff that patient and family care is limited by their aging facility and a new facility is being planned.

Multidisciplinary team care decision making meetings are held in a central room that contains medical equipment and is the procedure preparation room and nurses station for writing records. The nursing team leaders seem to lead the meeting and medical staff, physiotherapist, and social work and pastoral staff also attend. Selected cases are reviewed in discussions between the nurse and doctor. Other health professionals, sitting off to the side of the central table respond to direct questions but

otherwise sit silent, listening. Patients and their family members are not included in this meeting though their preferences regarding decisions are noted and recorded in the medical record.

In contrast to the palliative care units in Australia, where the professional dress code results in staff being identifiable only by their identification badges, the staff in this Japanese palliative care unit all wear uniforms that indicate their specific discipline; the nurses in white uniforms, starched white caps and starched pink coloured aprons, the doctors in long white coats, social workers in short blue coats. Some of the staff admit that their uniforms give them the authority to speak to patients about the personal aspects of their lives. Other staff agree that the uniform code reinforces traditional hierarchical structures and might be a barrier to cross-discipline discussions and multidisciplinary teamwork.

A feature of this hospital is that palliative care is considered a major focus and multidisciplinary palliative care education, in the form of seminars and workshops, is a quarterly activity. These education sessions regularly draw hundreds of health care professionals from the region to listen to national and international experts in palliative care.

Participants

Initially, the target population was patients with advanced illness such as cancer and an expected illness trajectory of less than 3-6 months (Table 3.1). Participants also included family members and caregivers and the health care professionals caring for the patient over a period of time, either in hospital, hospice or at home. A purposive method of sampling was used. Purposive sampling is useful to identify subjects that might be typical of a population and therefore would be useful in explaining a phenomenon (Beanland, Schneider, LoBiondo-Wood, & Haber, 1999). Patients with relatively short illness trajectories, were initially selected because it was more likely that they, their family and health care professionals, were to have experienced multiple complex decisions over a short period of time.

Table 3.1
Initial Inclusion Criteria for Patients

Patient Inclusion Criteria
Terminal Illness
Prognosis 3-6 months
Able to speak, read and write English
Able to give an informed consent

Each of the initial patients was recruited early in their palliative phase. However the number of interviews conducted with them, family members and their health professionals was dependent on the period of time before the patient's death and their physical and mental condition. Although each of the patients was described by their doctors as having a three to six month prognosis at the time of recruitment, the reality of their condition was highly variable. The shortest period of time between recruitment and a patient's death was one week and the longest was 11 weeks. The mean period of time between the recruitment of patients in the initial phase of data collection and death of patients was 6.1 weeks (Table 3.2).

Table 3.2
The length of time in weeks between recruitment of initial participating patients and their subsequent deaths.

Patient	Time (weeks)
1	9.5
2	11
3	1
4	2.7
5	6.3
Median period	6.3

The Patients

There were sixteen patient participants in this study with ages ranging from twenty-eight (28) years to ninety-three years (Table 3.3). Participating patients included equal numbers of females and males, similar to the gender balance reported by inpatient palliative care services (Nightingale, Ireland, Whan, Stafford, & Barnes, 1999). The

mean age of patients participating in this study was nearly sixty-three (62.9) years and table 3.4 indicates in summary, a spread of ages typical of patients receiving palliative care. The proportion of patients in the youngest age group participating in the study was substantially greater than the representation of this age group in the general population of patients receiving palliative care. The proportion of participating patients in 55-74 years age group was smaller than the proportion of that age group receiving palliative care. Possible reasons for these differences include age differences in those patients admitted to in-patient units, a statistic not reported by Nightingale et al. (1999) compared to community palliative care services and the willingness of younger patients in this study to participate in research.

Table 3.3
Participant patient profiles.

Age	Gender	Country of Birth	Years in Australia	Marital Status	Education (age at completion)	Occupation
28	Male	N/K	N/K	N/K	N/K	N/K
33	Male	N/K	N/K	N/K	N/K	N/K
43	Male	U.K.	34	Divorced	19	Technician
47	Female	Australia	N/K	2 nd Marriage	16	Receptionist
50	Female	N/K	N/K	N/K	N/K	N/K
50	Female	Japan	N/K	N/K	N/K	N/K
64	Female	Japan	N/K	N/K	N/K	N/K
68	Male	N/K	N/K	N/K	N/K	N/K
68	Male	N/K	N/K	N/K	N/K	N/K
73	Male	Australia	N/K	Married	14	Labourer
77	Male	U.K.	50	Married	15	Bricklayer
77	Female	N/K	N/K	N/K	N/K	N/K
77	Female	N/K	N/K	N/K	N/K	N/K
77	Female	N/K	N/K	N/K	N/K	N/K
78	Female	U.K.	77	Widow	16	Housekeeper
93	Male	N/K	N/K	N/K	N/K	N/K

*N/K = Not Known

Most of the patients participating in the study had been diagnosed with cancer, although two patients had been diagnosed with neurological disorders, one with Acquired Immunodeficiency Syndrome (AIDS) and one with cardiac disease.

Table 3.4

Frequency and percent distribution of patients according to age group compared to most recent National Census Data.

Age Group	Number of participating patients N = 16	% Participating patients 100%	% Palliative Care Deaths in Australia 1998 census* n = 2196
< 55 years	6	37.5	13.95
55 - 74 years	4	25	50
75+ years	6	37.5	36.15

*(Nightingale et al., 1999)

The Family Members

During the initial phase of data collection, patients were asked if their family members could be approached to discuss their involvement in decisions about the patients' care. Four patients nominated at least one family member, one family member refused to participate and another declined further participation after one interview. As the study progressed, family members were invited to participate independently of patients, who had already died. No identifying information was collected about these patients.

In total, nine family members participated in the study, six female and three male. Most family members were considered the primary provider of care for the patient when they were at home and were nominated as next-of-kin while the patient was in hospital. The predominant relationship between the family member and patient was spousal and three family members were children of the patients (Table 3.5).

Table 3.5

Profiles of participating family members

Gender	Relation to Patient	Caring Role
Male	Son	Primary Carer (not Next-of-Kin)
Female	Wife	Secondary Carer (Next-of- Kin)
Female	Daughter	Next-of-Kin (support, but minimal caring role)
Male	Husband	Primary Carer
Female	Wife	Primary Carer
Female	Wife	Primary Carer
Female	Daughter	Primary Carer
Male	Husband	Primary Carer
Female	Wife	Primary Carer

The Health Professionals

Health professionals were initially invited to participate in the study if they were caring for participating patients. Later in the study, health professionals were invited to discuss decision making more broadly. All of the participating health professionals worked specifically in palliative care, in in-patient settings or in the community. At least two of the palliative care physicians and one of the palliative care nurses worked across more than one setting, being employed by different organizations. Therefore, they were responsible for patients in both hospital and community (Table 3.6). None of the patients agreed to the recruitment of their general practitioners to the study, believing they were already very busy and that giving permission for their doctor to be recruited would further impose on the general practitioners' time.

The gender imbalance noted amongst the participating nurses is reflective of the imbalance among the general population of nurses. The Nurses Board of Victoria reports that only eight percent of Registered Nurses in Victoria in 2003 were male (Nurses Board of Victoria, 2004). Although similar data on the gender of Registered Nurses was not available from Western Australia or Japan, numbers of registered male nurses in the United Kingdom is reported as rarely exceeding 10% (Whittock & Leonard, 2003).

Table 3.6
Profiles of participating health professionals

Profiles of participating health professionals				
Discipline	Gender		Role	
	Male	Female		
Medical	3	2	Palliative Care Physician	4
			Trainee Palliative Care Physician	1
Nursing	0	16	Palliative Care Nurse Manager	5
			Palliative Care Nurse Consultant	1
			Palliative Care Nurse	9
			Enrolled Nurse	1
Allied Health	0	3	Pastoral Care Counsellor	2
			Social Worker	1
Total Health Professionals				24

Data Collection and Analysis

Data were collected over a period of three years. Data collection techniques included in-depth and short interviews, field observations and the recording of field

notes. A summary of data collection activities is represented in table 3.7. In addition to the interviews reported in Table 3.7, data collection involved 106 hours of field observation. The initial data collection was specifically described in the research proposal and included description of the patients, their family and health professionals, observing and interviewing related to decision making over a period of time between diagnosis and death. In subsequent data collection, the activities were targeted at specific types of information from particular groups of participants. This process is identified as theoretical sampling by Glaser and Strauss (1967). The targeting of data collection activities, observations, short interviews or longer in-depth interviews, in this way, was necessary to provide additional clarity to the concepts, categories and emerging theory in the study. Consistent with the grounded theory approach, data collection, data analysis and the writing of memos were undertaken simultaneously over a substantial period of the study, until the theory emerged and became established. The patient decision making process emerged slowly from the interviews and observations, where initially there were glimpses and through constant comparison (Glaser & Strauss, 1967) with theoretical sampling, these glimpses became relevant parts of the processes.

Table 3.7
Number of participants and interviews by discipline

	Patients	Family	Doctors	Nurses	Counsellor	Total
Number	16	9	5	16	6	48
Interviewed						
Number of interviews	21	11	5	18	3	58

Constant Comparative Analysis

Constant comparative analysis is referred to by Strauss and Corbin (1990) as a systematic approach of making comparisons and asking questions. Essentially, data is coded initially and then as coding continues, new examples of categories are compared with other examples of the same categories to fully describe them, challenge interpretations and improve their explanatory power.

The focus of early data collected was broad, with little direction other than to ask participants to talk about their palliative care decisions; who made the decisions, what the decisions were, when those decisions were made and how they were made.

Field observations were similarly broad. Each participant's data was coded. As new participants were interviewed, the pieces of data coded similarly were compared and descriptions of the codes were made, delimiting some codes and expanding others to develop categories. Memos were written to describe and challenge these categories.

As the study progressed, data collection was more focused, but constant comparison continued; fleshing out categories and discovering their boundaries by comparing new examples with past examples. Memos questioned the relationships between categories as the theory built. The core problem, conditions and basic social process were developed using this method of analysis.

Theoretical Sampling

As the study developed, data was collected with the emerging theory in mind, when concepts kept appearing repeatedly in the data or were noticeably absent in the data. This process is described as theoretical sampling and involved "sampling on the basis of concepts that have proven theoretical relevance to the evolving theory" (Strauss & Corbin, 1990, p176).

In this current study, the sampling of general decision making processes became more focused on the patients' care decisions, because the centrally important categories, particularly regarding the patients' involvement in decisions, were revealed. Although data continued to be collected from participants other than patients, it was the perspective of the patient that was sought.

Following the emergence of the core problem, the involvement of patients in decision making was explored by asking participants to explain situations where good decisions had been made and examples of situations where there had been poor decisions. These situations illuminated the processes patients used to resolve their problem of lack of involvement in making care decisions.

Data Management Using NUD*IST Vivo @ (Nvivo) Software

Computer assisted qualitative data analysis tools were first developed in the 1990s to assist users in the management of qualitative data. Gibbs (2002) suggested that these computer based systems have replaced the paper and pen, photocopy, card and

filing cabinet systems traditionally used by researchers, before computers, to manage the large quantity of text, memos, codes and notes generated by qualitative research. NVivo was developed from the experiences of researchers with an earlier software package NUD*IST 4 (N4) (Richards, 1999) and uses the advantages of a windows based operating system (Gibbs, 2002). In NVivo, transcripts and documents typed in rich text can be directly imported and then searched and coded on screen. Codes and documents can be linked, ordered and searched for common textual components or attributes. In this way, NVivo might be viewed as assisting in analytical processes by testing hypothesis and building theoretical ideas (Gibbs, 2002).

The researcher noted the concerns expressed by others (Fielding & Lee, 1998; Gibbs, 2002; Glaser, 1998), suggesting that computer assisted qualitative analysis software usage stifles the creativity of researchers by distancing them from the data and by interfering in the development of theoretical sensitivity. To manage these risks inherent in using computers when conducting qualitative research, in this current study the researcher used the features of the software that enabled data management described above and returned intermittently to more traditional means of searching the data. Despite being reasonably comfortable with using the software, the researcher found that reading paper transcripts, re-listening to audio tapes, making memos and diagrams with pen and paper were often a helpful means of clearing blocks in thought processes and moving theorising forward. These notes were kept in a diary of analysis to ensure that a record of both activities was maintained.

Data Collection and Analysis Process

Data collection began with five patients who agreed to participate in the study. The senior nursing and medical staff caring for them identified them as meeting the criteria for the study identified in Table 3.1. They were approached by the nurse manager and asked if they would like to speak to the researcher about a study on decision making. These patients were given written and verbal explanation and provided written consent to be involved in the study. Following an induction interview, the care decisions of the patients were observed and further interviews undertaken over the subsequent period of time until their death. If the patients nominated a family member, who also gave written consented to participate in the study, they were interviewed and observed. Health professionals involved in the care decisions of these patients were

observed unless they indicated they did not wish to be observed. Those health care professionals who participated in interviews gave written and informed consent.

Decision Role Preference Card Sort

In order to gauge some understanding of decision making patterns of participants, they were asked to indicate their preference for different types of decision roles utilising a card sort exercise. The Decision Role Preference Card Sort (Degner & Sloan, 1992) utilises a set of five cards that describe the patient preference for either an active role, a collaborative role or a passive role in decisions about treatment. In this study, the patients were asked to select their preferred role by selecting one of the five cards.

The card sort (Appendix 1) was utilised at the first induction interview with patients and was repeated periodically throughout patients' involvement in the study to check on any change in the preferred decision role. In addition, the card sort was used as a discussion prompt in interviews with health professionals and family members. Family members were asked to identify their preferred role in decisions regarding their own health care and what role they thought their sick relative might prefer. Health professionals were asked what decision role they preferred to take with patients.

Demographic Information

Some demographic information was collected about patients during the induction interview to identify the patient's age, gender, marital status, level of education, occupation and country of birth. The gender and caring role of family members was also recorded, as was the gender and role of health professionals.

Field Observations and Field Notes

During this study, health care teams and patients were observed making care decisions. The observations were unstructured; field notes being used to record various aspects of decisions made, including the nature and context of the decisions, who was involved, explanations and body language and the impact of those decisions on the people involved. The researcher's own inferences and feelings also formed part of the observations noted to ensure the disclosure and accounting of bias. The medical records

of patients were also examined periodically and decisions, dates and decision makers recorded in the field notes. Table 3.8 indicates an example of the field notes recorded during an observation.

Table 3.8

Example of field notes from observation of a family meeting

Family Meeting 3/5 Morris, Wife, Doctor James, Nurse Wendy	
Doctor James and Mrs Morris	Mrs Morris spoke to Doctor James outside of the room and they agreed that Morris would only go home for day leave. Mrs Morris did not want to say in front of Morris that she was not willing to take him home (permanently) as she couldn't manage him. Doctor James agreed to keep Morris in hospital for the moment but that every effort should be made to see if he could go home on day leave with his brother or son there as well as Mrs Morris to provide additional support. They then entered the room.
Doctor James and Morris	<p>Doctor James assessed Morris physically and asked him how he was. Morris denied his condition was deteriorating and said he felt fine.</p> <p>I noted as he was talking to Doctor James that Morris' fine motor co-ordination was poor with his right hand and he seemed slightly confused. Is his competence in question? ...</p>
Morris and Mrs Morris	<p>Doctor James and Nurse Wendy left the room. Morris and Mrs Morris started talking about going home. Morris was saying he wanted to go home the next day. Mrs Morris was saying maybe next week.</p>

The strength of observation as a data collection method lies in the ability of the researcher to discover the difference between how participants say they will behave and how they actually behave (Beanland et al., 1999). However, the technique had some limitations in this study. To some extent the researcher's presence alerted the participants to the scrutiny of their decisions and may have influenced the way that those decisions were made. In a study involving a similar technique to examine life and death decisions in health care, Degner and Beaton (1987) attempted to overcome the problem of the observer influence by sensitising the participants to the observers presence with a process of observing non-patient activity first. In this study, the researcher briefed all the sites and spent some time at the commencement of the study practicing positioning herself unobtrusively. The long history of the researcher's involvement in palliative care settings enabled the identification of situations where it appeared that patterns of health care professional behaviour were changed because of

the researcher presence. For example, observations of clinical care in patient rooms were limited due to concerns that patients were being avoided when the researcher was present. Observations were also conducted in corridors, on clinical rounds, in family meetings and in multidisciplinary team meetings. Because of the limited time patients spent in acute hospitals and the difficulty in recruitment during the acute phase of their illness, negligible time was spent observing decision making in the acute hospital.

Interviews

Two types of interviews were conducted during this study. Patients recruited into the study in the beginning participated in an induction interview, which gave them an opportunity to explain their illness experience from diagnosis and the influences on their decisions. Prior to interviews commencing, introductions were exchanged with patients and any family or friends present and some social pleasantries, about health, weather and surroundings were traded that enabled a level of comfort to be reached prior to a probing interview. With some patients, the induction interview was conducted over two separate occasions, particularly when they had a long history or were too unwell to complete the interview on one occasion. Some family members participated in the patient's induction interview. On other occasions, family members were interviewed separately.

The induction interview was in depth and unstructured. Holloway (1996) suggested that these types of interviews have the capacity to generate the richest data, allowing the flexibility required to follow particular trains of thought or directions. An "aide memoire", identified in table 3.9, provided an agenda for these interviews (Holloway & Wheeler, 1996, p54). The induction interviews generally commenced with the question "Tell me about what happened when you first knew you were not well." Each interview then progressed through patients' experiences of diagnosis and treatment up to the time of interview. The diagnostic and treatment story was often long and involved and though it generated data that was not significant to the study question (Holloway & Wheeler, 1996), understanding patients' stories gave meaning to their later decision making processes. During these interviews, the patient's family structure was also mapped from their description. Interviews were unstructured and questions open ended to generate a range of responses (Beanland et al., 1999).

The other type of interview was shorter and more focused, occurring with participating patients, family members and health professionals. These interviews were opportunistic, to clarify the mental processes of decisions observed or noted in the medical record. The focussed interviews were not standardised and did not result in common outcomes (Holloway & Wheeler, 1996), because each was focussed on particular data emerging from previous collection episodes.

All interviews were audio recorded and later transcribed. All transcriptions were checked against the audio recordings for accuracy.

Table 3.9

Aide memoire for induction interviews

Initial Question: Tell me about what happened when you first knew you were not well.
Prompts:
Health care professionals involved in diagnostic and subsequent treatment phases
Family involved in diagnostic and subsequent treatment phases and how they were involved.
Decisions made and by whom
Patient's role in decisions
Descriptions of feelings and reactions

Open Coding

Initially, the data collection was designed to capture as much information as possible about the making of care decisions. Strauss and Corbin suggest that this type of data collection is "Open Sampling" (1990, p176), most of the activities involving purposeful sampling to gain the broadest picture available of the situations of care decisions. The initial analysis of data consisted mostly of open coding. Open coding is defined by Strauss and Corbin as "[T]he process of breaking down, examining, comparing, conceptualising and categorising data" (1990, p61).

Open coding occurred in three steps. Initially, the data transcripts were examined line by line. Significant ideas or incidents were given a name that represented what was important about what had happened or what had been said that was important. This initial coding was conducted on paper transcripts. The second reading of the transcripts occurred from the computer screen in the Nvivo (Qualitative Solutions & Research, 2001) database, after the transcripts had been uploaded. This second reading

involved coding line-by-line and paragraph-by-paragraph. Thirdly, the shorter interviews and observations were also examined as single events, the researcher focusing on why these particular events were important in relation to categories identified in other, longer interviews. The initial open coding resulted in an extensive list of codes represented in Table 3.10.

Table 3.10
List of categories resulting from initial coding

Accepting decisions	Decision roles	Feeling guilty	Negotiation	Searching for answers
Being realistic	Deferring to experts	Frustration	Novice Decision makers	Security
Big decisions	Did not question	Getting support	Partnership	Sensitive
Bite the bullet	Discussing options	Going with the flow	Personality	Social time
Boundaries	Enduring decisions	Good and bad decisions	Piece it together	Team decisions
Caring	Environment	Important	Pragmatic decisions	Time to talk
Communication	Everyday decisions	Independent	Pro-active role	Too sick to decide
Compliance	Facilitating decisions	Information	Reassurance	Treated like a child
Compromise	Familial	Keeping them safe	Relationship	Trust
Control	Family fractures	Motivation	Responsibility	Understanding
Coping	Family roles	Mutual agreement	Role modelling	Weighing pros and cons

During subsequent data collection, open coding continued line-by-line, paragraph-by-paragraph and incident-by-incident as an initial data analysis exercise. During each episode of open coding, the categories were further developed, their properties and dimensions more fully described. Some categories were collapsed into a single category and others were expanded into further categories. During early data analysis, notes were taken that explained the properties and dimensions of categories. Notes or memos (Strauss & Corbin, 1990) became more theoretical in nature as the analysis proceeded.

Becoming More Theoretical in Data Collection and Analysis

As described earlier, constant comparison of data involves the comparing of data and asking of questions in order to more specifically describe concepts and categories (Strauss & Corbin, 1990). Questions arose from the concepts noted during the collection of initial data. Consistent with theoretical sampling (Strauss & Corbin, 1990), the questions arising from these categories (Table 3.11) guided the subsequent collection of data.

Table 3.11

List of initial categories identified and related questions for focusing interviews and observations

Initial Categories	Questions
<i>Relationship</i> The rapport or connection between individuals. Relationship seems to influence the type and process of decision making.	Patients who do not want to develop a connection - Patients who do not fit in eg: who are depressed and do not offer much to the relationship. How does this affect decision making and how are they approached?
<i>Control</i> The exercise of restraint over oneself or direction for oneself or the exercise of domination or command over others	Areas of potential paternalism - What decisions are being made about safety? Who identifies and who decides what is done? How is family wellbeing protected? What kinds of decisions are made about protection?
<i>Decision roles</i> The part played in making decisions	Decision Role Cards - Which card would be picked after 3 years or 5 years? What influences the difference? Age? Experience? Education? Team Meetings - What are Multidisciplinary meetings like and do they help with decision making?
<i>Pragmatic</i> Focussing on the practical things and their consequences	Which decisions are practical and how do they differ from other decisions.
<i>Everyday decisions</i> Decisions that occur regularly and don't require a lot of energy	Which are these decisions? Who is involved? How? Why do these decisions not require energy?
<i>Big decisions</i> Decisions that require a lot of energy and multiple opinions.	Which are these decisions? Who is involved? How? How is the energy expended?

During a period of two weeks, the researcher spent approximately forty hours observing and recording field notes of daily multidisciplinary care planning meetings and nursing hand-over meetings, medical 'rounds', family meetings and patient care. In

addition, short interviews with health professionals, patients and family members focussed on decision roles, using the decision role card sort explained previously, and decision activities. The format of these data collection activities was as described previously. Participants, who were interviewed during this period, gave informed verbal consent. Patients who were unable to speak or read English or who were unable to give an informed consent were identified by nursing staff at the commencement of each observation period, and were not approached by the researcher.

A small number of in-depth interviews were also conducted in a Japanese palliative care unit to identify the particular way care decisions were made in that environment. The patients and family members who provided a written informed consent to be interviewed, were initially approached by a doctor in the unit who identified them as competent to provide consent and physically and emotionally able to cope with the demands of an interview. The patient and family interviews were conducted in the palliative care unit and involved the use of the role card sort (Degner & Sloan, 1992), described previously, and open ended questions about their experiences of diagnoses, treatments and care decisions throughout their, or their family members' illnesses.

Health professionals interviewed during this stage were also asked to complete the role card sort (Degner & Sloan, 1992), described previously. Their interview consisted of open ended questions about their experience of care decisions related to patients diagnosed with terminal illness. During these interviews, and the interviews with patients and family members, theoretical sampling focused some questions on the nature of important categories already noted. In particular, the researcher sought to explain variations in decision roles and relationships between health professionals, patients and family members. The Japanese palliative care environment was specifically chosen because of the reported difference in decision making processes (Miyata, Tachimori, Takahashi, Saito, & Kai, 2004).

All interviews were conducted in the presence of a translator who translated the researcher's questions into Japanese and the participants' answers into English. The interviews were audio recorded and later transcribed by the researcher. The transcripts were back translated and compared with the audio recordings and their accuracy confirmed.

In addition to the interviews conducted in the third setting, two multidisciplinary patient care planning meetings were observed and field notes recorded.

Memos

During the analysis of these observations and interviews, open coding continued with episodes of particular instances compared with those identified during earlier data collection. In addition to continuing with constant comparison and coding the data, the researcher began making links between categories and theorising about those links in documents called memos. Memos are defined as “[W]ritten records of analysis related to the formulation of theory” (Strauss & Corbin, 1990, p197). The example of memos in table 3.12 illustrates two aspects of memos; theoretical notes, making summaries of inductions and deductions, discussing the relationship of categories discovered to existing theory and operational notes, which served as instructions to the researcher as to further sampling and questions.

Axial Coding

Although open coding and writing of notes and memos continued, an additional data analysis tool, axial coding was used to make connections between categories in new ways (Strauss & Corbin, 1990). The paradigm model suggested by Strauss and Corbin (1990), involving conditions, context action / interactional strategies and consequences was used to identify the central idea or phenomenon around which other categories were related. Table 3.13 represents one of the early paradigm models completed during the analysis of this current project.

Table 3.12

Examples of memos written during the analysis

26/07/02

In developing a relationship, health care professionals take time. In taking time, they seem to go 'the extra mile'. Joan talked about her GP, who she had been with 18 years, who had cared for her dying son some years earlier when he was at home. She said of this doctor "you can't knock him - he was in every day".

In developing the relationship, health care professionals make an effort to find out about the person- more than just about the illness. (Doctor Michelle and Doctor Peter). Patient Henry thought that health care professionals should get to know him through talking with him, as well as care about him.

As the relationship develops, a free flow of talk occurs between patients and health professionals (HCP). Trust and faith (including blind trust) is a feature of the relationship. This does not mean that the patient will always be honest with the HCP (Joan) but does usually lead to more frank disclosure (Nurse Cheryl). Never the less, relationship does not change that patients hear what they want to hear and believe what they want to believe (despite more qualified advice (Joan)).

Patients are protective of HCP with whom they have developed a relationship (don't want them bothered unnecessarily or upset) - Joan, Wayne, Jenny and Harry.

Relationship leads to collaboration in decision-making. It encourages and facilitates patient choices, assisting with interpretation of choices and providing support (Nurse Samantha) (need to cross check relationship and role card sort for patients and HCP. - use matrix) (Joan, Wayne, Doctor Michelle, Doctor Peter, Nurse Lindsay, Nurse Samantha) Nurse Lindsay thought that without a relationship with their HCP, patients have to be more independent in decision making. Perhaps they could also be equally very dependent eg: patients in Japan in acute care and also older patients in Australia. What sort of Relationship is seen here? Caring - Friendship - Therapeutic? Is the relationship a decisional alliance? Or perhaps a partnership between patient and HCP (Doctor Michelle, Doctor Peter and others?)

Valued characteristics of HCP

Linda (Joan's daughter) - Open, helpful, understanding, giving

Bob (Jenny's Spouse) - look me in the eye because then they have to speak to you and you have their attention

Sonia- Tell the truth, sense of humour, conversation, discovers my preferences

Marion - Listen, companionship, connection, trust, reassurance, unconditional love, patience, vigilant, slow to judge

Louise - Slow to judge

-Do good HCP encourage patients to be involved in decision making despite a preference not to be involved? (Crosscheck role preference with observations)

Table 3.13

An example of an axial coding paradigm model used to explore the category of 'Information' as a phenomenon

Causal Conditions – causing the phenomenon	<ul style="list-style-type: none"> • To find meaning and understanding • Expected to ask <p>The sharing of information assists patients, relatives and health care professionals in understanding the context, options and parameters of a decision.</p> <p>Finding meaning and Understanding</p>
Phenomenon – central event/incident/idea	<ul style="list-style-type: none"> • Communication • Gathering Information • HCP Responsibility <p>Sharing Information</p>
Actions and interactions - Strategies used to manage the phenomenon	<p>Facilitating</p> <ul style="list-style-type: none"> • Communication tools - A manner that facilitates communication. Props that facilitate a particular message. Indicates a readiness to share information. • Explaining • Reciprocal sharing - A feature of team work • Repeating information - Although it is necessary that health professionals be prepared to repeat information to a patient, patients find it frustrating when they need to repeat information to different health professionals. • Go between - Major role of nurses to pass information between families, patients and health care professionals. • Important - Knowing what is important to the patient/family member <p>Getting what you want/need</p> <ul style="list-style-type: none"> • Body language
Context – when the phenomenon happens Link to Developing Relationships Getting to know me	<p>Knowing the person</p> <p>Information helps health professionals know the patient better. Gleaning information about the patient from different sources –other health professionals and family members</p>
Intervening Condition – what affects the strategies Linked back to developing relationships	<p>Barriers –constraints</p> <ul style="list-style-type: none"> • Jargon - Using jargon interferes with the sharing of information and understanding. Ultimately it interferes with the patient/family members respect of the health care professionals and their relationship • Timing • Environment • Boundaries
Consequences – Outcomes of actions/interactions	<ul style="list-style-type: none"> • Blunt truth • Withholding information - Keeping information from a particular person or a group is an act of controlling – an indication of power. Whilst the motive might be protection of the patient, ultimately it controls decision making by making the patient a dependent decision maker and in a way nurses and doctors too (the HIV example). <p>Shielding</p>

Selective Coding and Diagramming

At this point in the study, a number of paradigm models had been created, but the coherent story line proved elusive. A number of exercises in unpacking these models and repacking were necessary to identify the central phenomenon. The researcher found herself ‘wallowing’ in pools of perspectives, the patient’s voice lost in the opinions of health professionals and relatives about what the real issues about decision making were. The researcher refocussed on patients’ perspectives in the data and a process of diagramming as a form of memoing and more selective coding proved a successful strategy for identifying the patients’ stories.

The initial step of this refocus was to reread the interview transcripts. Moving away from the computer was important to break the unhelpful patterns of thinking that were clouding patients’ stories. The researcher sat with pen and paper, as suggested by Strauss and Corbin (1990) and wrote about what appeared to be the main problem experienced by patients in making care decisions (Table 3.14). Using this memo, the researcher then returned to the transcripts searching for evidence of these ideas. The evidence from this selective coding appeared in codes identified in italics in Table 3.14.

Using coloured pens and paper, a number of attempts at mapping the concepts associated with the patients’ experiences of making decisions, discovered in this selective coding. A transcribed example of one of these diagrammatic memos appears in Figure 3.1.

Table 3.14
Memos used to guide selective coding

Characteristics of better decision making processes

Where decision processes were described in favourable terms, there is always a level of involvement of the patient in those decisions. There is a flow of information (*kept informed*) between the HCP and the patient, where the patient believes they are informed about what is happening and that they understand why. There is also a *focus on the patients' needs*, as perceived by the patient. Often this is featured in the conversations between HCP and patient where the patient values that they are asked about their issues. Sometimes patients will clearly state what they want and know that the HCP will ensure their decisions are implemented. The final element of these better processes is that the patient has *confidence in the HCP* involved in their decision making.

In this process where the patient believes they are involved, the decision is built in a spiral of the developing rapport, sharing information and deciding. They and the HCP work together in this process. Sometimes the patient's participation is controlling the process, at other times it is more collaborative.

Characteristics of poorer decision making processes

Poor decision processes are characterised by the patient's exclusion from the decision processes. The patient is *not confident in the HCP* and is somewhat bewildered by processes that are not clear to him/her. Patients find that the health professionals *do not listen to them* and are more likely to push their (the HCP's) point of view. Often there are many voices influencing the process, all louder than the patient's voice. Whether the patient is being given information about the decisions and process or not, they experience a *lack of information* about the decisions being made (or not being made) around them. The goals of the health professional do not seem to relate to them.

Decision processes that exclude the patient in this way leave the patient feeling powerless and the goals of their care vague. The patient does not know what is happening to them. Instead of a building spiral, this process inverts the spiral to a vortex over which the patient struggles to exercise control. They are sucked into the vortex, battered around and spat out with the decision outcomes.

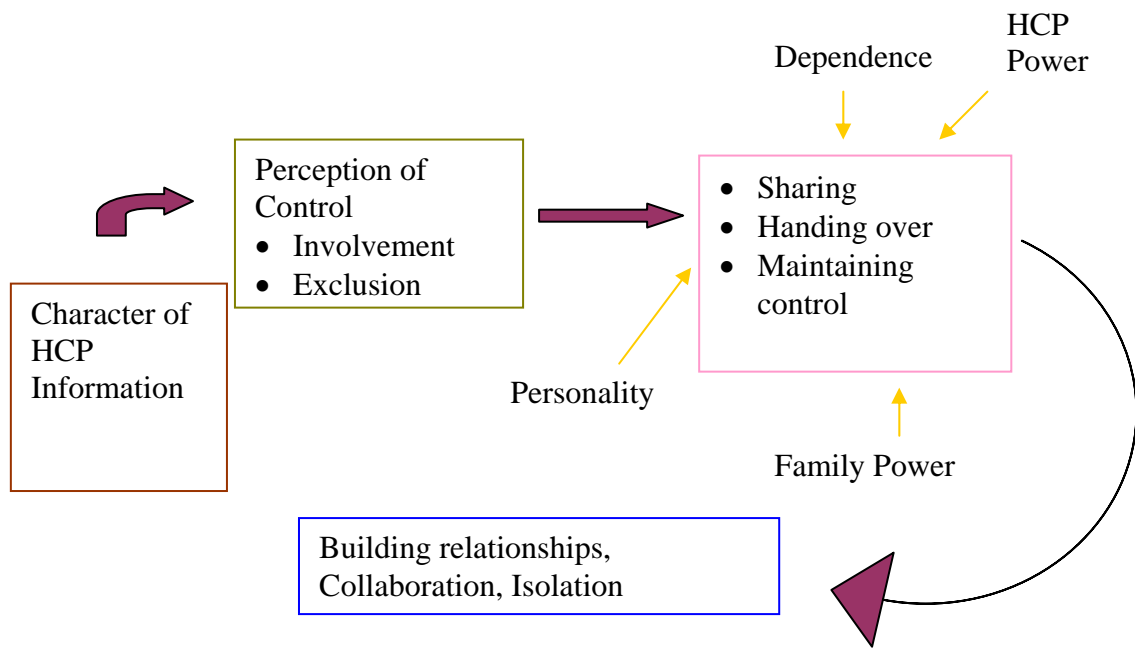


Figure 3.1:
An example of a diagrammatic memo related to analysis when searching for the patients’ story.

Identifying the Basic Social Process

The Basic Social Process was defined by Glaser as, “... fundamental patterned processes in the organization of social behaviours which occur over time and go on irrespective of the conditional variation of place” (1978, p100).

In identifying the Basic Social Process, the first step was to identify the actions or interactional strategies used by participants to manage the core issue or problem. Strauss and Corbin described the properties of these as firstly being “processual” or occurring in a sequence. Secondly being purposeful or goal-oriented. A third property was that failed action or interaction was as important to understanding the process as actual action or interaction that was used. The fourth property was the conditions that intervened to alter the strategy or its outcomes (Strauss & Corbin, 1990). Showing why and how actions change or stay the same or alter in the face of changes in the conditions and with what consequences demonstrated the Basic Social Process.

To identify the actions and interactional strategies in this current study, the researcher asked the following question of the data: ‘What do patients do in response to their concern about being involved in decision making in palliative care?’ The

researcher looked for actions or responses to examples where patients had experienced involvement or exclusion from decision making and distilled these examples in to common strategies used by patients. Examples were selected from the data that demonstrated when these strategies were used and when they were not used. How the strategies changed over time, were cross-referenced with different environments and with different people involved.

Strauss and Corbin suggest the use of a conditional matrix to examine the levels of effect of conditions on particular actions (Strauss & Corbin, 1990). The example illustrated in Figure 3.2 demonstrates this technique to examine how conditions identified affected how people used the strategies; linking conditions, consequences, actions and interactions. Gradually, the nature of the process used by patients emerged.

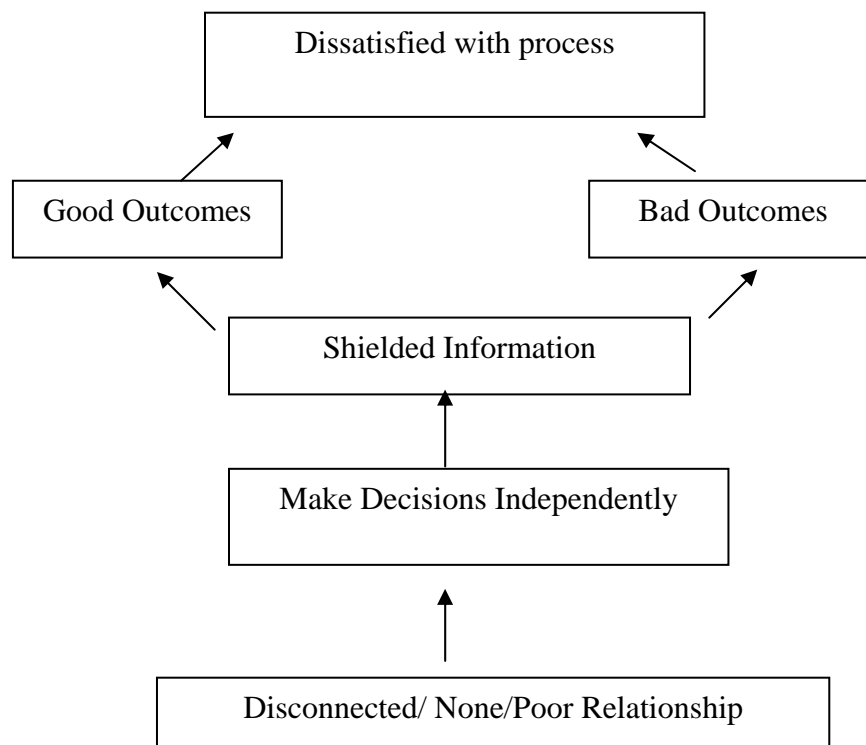


Figure 3.2:
Conditional Matrix – What is the effect of the condition relationship on other conditions, the actions of patients and the outcomes?

As the theory was emerging, the data collected focused on aspects of decision making identified from the central themes of the theory. The purpose was to gather data that “validate the integrative statements of relationship, and fill in ... categories that need further development” (Strauss & Corbin, 1990, 187). In a process identified by

Strauss and Corbin as “discriminate sampling” (1990, 187), the researcher sought participants who had substantial experience in making care decisions in palliative care, as patients, family care givers or as health professionals. Following a briefing discussion in the first setting in-patient unit in which the researcher indicated a desire to discuss experiences of good and bad care decision making, a number of nursing staff volunteered to participate in a single in-depth interview at their residence during their off-duty time. They indicated their willingness to participate by contacting the researcher and leaving their phone number. Prior to the commencement of the interview, each nurse gave a written and informed consent.

The patients interviewed at point in the study were identified and approached by the nurse unit manager using similar criteria to those identified earlier (Table 3.1). These patients also provided written and informed consent. The family members interviewed at this stage of the project contacted the researcher after hearing about the project through other family members, and asked to be interviewed. Each of these family members had experienced the death of their spouse between twelve months and three years previously after protracted terminal illness.

Each of these interviews commenced with the decision role card sort (Degner & Sloan, 1992), identified previously and then participants were asked to identify examples of good and bad decisions in which they had been involved. The interview that followed involved open ended questions focussing on these examples. The focus of the questions was an attempt by the researcher to compare specific aspects of these experiences and examples with the theory that had emerged from previous analysis.

Selective Coding and Theoretical Saturation

At this point during data collection, coding and memos were selective; being related to the validation of relationships between categories and expansion of existing categories, to fully ‘flesh out’ the story of patients’ experiences of care decisions in palliative care. A number of categories were renamed and some were shifted from one component of the story to others.

Data collection and analysis continued until it was apparent that saturation had occurred. Theoretical saturation occurs when the new examples of data fail to deliver new insights into categories (Glaser & Strauss, 1967). Glaser and Strauss (1967)

explained that throughout the study, coding continues until the codes stop contributing to the emerging theory. The constant comparison of data reduces the scope of data to defined categories and guides the focusing of the data collected to the point where no further focus can be achieved. In addition, data collection and analysis must continue until all the paradigm elements of categories are sufficiently described. Data collection continued until these elements were fully described.

Strauss and Corbin (1990) also indicated that theoretical saturation occurs when the theory is well established and validated. This was evident when the stories of participants in the later part of this stage of data collection repeatedly confirmed the elements of the theory as the researcher had described it during analysis.

Use of Literature

The use of literature in grounded theory studies is different to the use of literature in research using other qualitative and quantitative methods. Holloway and Wheeler (1996) indicate that a substantial literature review of all published information “close to the area of the project” (Holloway & Wheeler, 1996, p23) is reviewed in order to articulate what is known about the subject and the gaps in that knowledge, to identify how the research will contribute and to avoid repeating similar work already undertaken. However, in grounded theory, a detailed literature review would risk biasing the researcher to the data collected, resulting in a theory that is contrived and coloured by the researcher’s interpretation of the data through preconceived ideas about how the data should be perceived. Glaser (1978) notes that going outside the area too soon can “kill or dilute the emergence of the basic social process under study, by comparing it to areas where the process is less relevant” (Glaser, 1978, 50-51).

Glaser (1978) suggests that the reading of theoretical literature should be undertaken after the theory has emerged and settled. In their original text, Glaser and Strauss suggested that researchers should enter the field without preconceived ideas and with an open mind, though “alert with all his learning” (1967, p123). However, Strauss and Corbin (1990), suggest that some knowledge of the technical literature related to the field of research can assist the researcher in becoming more theoretically sensitive to the data collected during the research. This approach, discussed in the previous chapter enabled the researcher in this current study to be sensitive to the variety of approaches

to decision making in the data and the contrasts to the common theoretical approaches to decision making

The focus on the substantive area of palliative care decisions enabled theory generation by comparative analysis between groups within the substantive area (Glaser & Strauss, 1967). The substantive theory was well developed and the fit confirmed with experienced palliative care nurses and bereaved family members prior to comparison with other substantive and formal theory drawn from published literature. In order to present the theory as a clear representation of the substantive area from which data was drawn, the relationship between the literature and theory was presented at the end of each chapter of findings.

Trustworthiness of the Findings

Trustworthiness is a term used in qualitative research methodology to describe how credible the study is in relation to the phenomena studied and the depth to which there is evidence demonstrated of the emerging theory in the data gathered.

Trustworthiness in the data collection was demonstrated through the recording of interviews and keeping of detailed field notes. The effects of the researcher were monitored through the use of field notes to analyse interactions of the researcher in the setting (Chenitz & Swanson, 1986). To improve the depth of the evidence sought to underpin a grounded theory, different health care provision environments were included in the study. The use of multiple data collection sites increased the researcher's exposure to different health care practitioners, teams, patients and families. Though it was not possible to include all variations of individuals, some attempt was made to include patients of varying experiences and socioeconomic and cultural backgrounds. Utilising sites in various regions, states and countries, also demonstrated variation in health care practitioner backgrounds.

Chenitz and Swanson also suggested that credibility during data analysis is demonstrated in the way that the grounded theory is reflected in categories generated and "applied readily to the data" (1986 p13) collected. The use of experts in the review of data analysis, for the purposes of this kind of validation, has been criticised by Sandelowski (1998) as being an impossible task. She believes that experts cannot be as immersed in the project as the researcher, able to see all the analytic manoeuvres made

by the researcher and recommends a more judicious use of expertise. In this study, expert health care providers were consulted to clarify the research question and the design of the project. Prior to the commencement of the study independent experts in the field reviewed the credibility of the method and procedures. Credibility was also enhanced by clarifying interpretations of interviews and field notes with the subjects throughout the progress of the study. In particular, the grounded theory was presented to a number of participant nurses and other health professionals, and to two family carers whose relatives had previously died, who affirmed the categories as they were interpreted.

The supervisors of the study, experienced in palliative care and in field research, regularly reviewed the data and coding as the study progressed. Glaser (1998) expressed concern that the taping and transcribing of interviews was unnecessary because it wasted valuable research time and interrupted the constancy of comparison necessary for analysis. Despite this, most interviews were audio-taped and transcribed to allow for the supervisors to also be familiar with the data. To ensure that the context of the interviews was not misinterpreted by only having access to transcripts (Glaser, 1998), field notes were transcribed and included with the interviews.

Ethical Considerations, Challenges and Protection of Participants

The proposal for this study was scrutinised by the Edith Cowan University Human Research Ethics Committee prior to presentation at a number of Australian institutional ethics committees representing the various clinical organisations of which participants were employees, patients or clients or patient or client family members. Formal interviews were required at the Melbourne ethics committees. Three major ethical considerations were a feature of each application for approval of the research: protection of the participants from harm, informed consent and confidentiality. Confidentiality was maintained by the transcribing of all interviews from audio recordings and field notes without identifying information. All participants were assigned a pseudonym and the data collection sites have not been identified. At each of the data collection sites, and stages, the different activities undertaken meant that the procedures for considering informed consent and protection from harm were also different.

In order to proceed with the initial data collection, ethical approval was sought from the acute hospital, the community palliative care service and the community nursing service. The acute hospital approved the study protocol without assessment of family functioning. Patients meeting the recruitment criteria were initially approached by their doctor, or nurse who asked the patient if they would like to speak to a nurse researcher about a decision making study. With this initial permission, the researcher approached the patient with a detailed explanatory statement (Appendix 2) and discussed the study with them. Following the initial discussion between the researcher and patient, most patients were given twenty-four hours to consider their involvement and on the researcher's return those who wished to participate signed a consent form (Appendix 3). On two occasions, the condition of patients recruited deteriorated significantly within the recruitment period of twenty-four hours and their involvement in the study was ceased. The consent signed also involved the patients' permission for the researcher to approach particular family members and their health care providers. All family members and health professionals interviewed were provided with written explanatory statements (Appendix 4) and consent forms (Appendix 5 and 6).

One of the challenges created by the recruitment process was that the oncologist initially involved in the recruitment, after some weeks was unable to identify any suitable participants. Though it may have been possible that there were no patients during this period that met the recruitment criteria, the oncologist may also have been reluctant to identify patients because of the scrutiny of decision making that involvement in the study required. Due to the potential that the study was influencing the referral patterns of the oncologist to palliative care, recruitment to the study was changed so that patients were only approached after their referral.

A further challenge was created by observations in the palliative care in-patient unit. A formal briefing of the unit staff was undertaken across two shifts and explanatory statements distributed. Staff who did not wish to be observed in their work, had the option of informing the nurse-unit manager or the researcher. No such refusals were indicated. Following the informed consent of each patient, the researcher sat in a corner of the patient's room for observations. The unit comprised mostly single patient rooms. After a number of observation periods at different times of the day, it was noted that few staff entered the room during these periods. Observations in patients' rooms

were then limited to periods of care activity due to the researcher's concerns that patient care patterns were being altered by the researcher's presence.

Each day that the researcher was to engage the participating patients in the activities of the research, the patients were asked if they were still willing to participate. On occasions during the study, participating patients indicated they were too unwell or tired to participate in the study activities and on these occasions, the researcher did not persist with these activities. During the end stages of patients' lives, the researcher withdrew from patient observations and did not conduct interviews with the patients or their family members in order to reduce any additional burden on patients and family members that the study would create. During these occasions, decision making activities were monitored through health professional interviews and observations of team meetings.

Though the community palliative care service approved the study protocol without alteration, the community nursing service ethics committee did not permit observations of care visits, expressing concerns about the interference of the development of the nurse-patient relationship. Written informed consent for interviews was obtained from nurses and other health professionals working with participant patients in the community. With the permission of team members, the researcher was invited to observe team meetings that discussed the participating patients.

During the observations and interviews at the second setting, following a staff briefing, a notice (Appendix 7) and explanatory statements (Appendix 8) were located in at the nurses' station of the palliative care in-patient unit to alert staff, patients and family members of the conduct of the study in the unit. Each shift, the nurse in charge identified patients who were either not competent to consent or were too ill to be approached by the researcher. Staff and patients approached for short interviews were given an explanatory sheet and provided verbal consent if they wanted to be interviewed.

In one situation, a patient was identified as competent to consent by the nurse in charge and although he agreed to be interviewed, during the interview he appeared to be unable to participate and the interview was abandoned. The researcher asked the staff to review the patient's condition.

In the third setting, participants were drawn from an in-patient palliative care unit in Japan. The hospital management rather than an ethics committee reviewed the proposal for the study. No concerns were raised regarding the potential ethical issues addressed in the study proposal. The patients and family members interviewed in this phase were invited to participate by a doctor in charge of the palliative care unit. Once identified, the researcher and translator met with the potential participant and provided a written explanatory statement (Appendix 9) and gave opportunity to answer questions. All those invited agreed to participate and provided verbal consent. The potential for coercion of patients and family members created by this recruitment method was considered, however the participants were aware that the researcher would not report their participation or non-participation back to the doctor in charge, nor would their interview be reported to the doctor.

The health professionals recruited in the third setting were all volunteers who made an appointment with the researcher for an interview. They were all provided with a detailed written explanatory statement and gave verbal consent for the interview.

During the later data collection, the researcher returned to the first setting in-patient palliative care unit. Suitable patients were approached by the nurse in charge of the in-patient palliative care unit and asked if they would like to speak to a nurse about a research project on decision making. A number of patients approached by the nurse indicating they would speak to the researcher, after doing so, declined to participate in the study. This recruitment strategy was undertaken on the advice of staff and the ethics committee and had been successful in the initial data collection when involvement in the study was a much greater commitment. Approximately fifty percent of those approached by the researcher on the advice of the nurse manager declined to participate. Although this recruitment issue suggested that patients may have been reluctant to refuse the approach of the nurse-in charge, they felt sufficiently free to refuse the researcher.

Data collection in each organisation was preceded by organisational briefings by the researcher, which gave staff the opportunity to ask questions and make comment on specific issues in their organization affecting the research. Staff were also debriefed at organisational meetings by the researcher, at the conclusion of the data collection, giving them opportunity to comment on the impact of the research on their care and

decision making activities. Despite the concern expressed by a number of ethics committees regarding the effect of the presence of the researcher on decision making, health professionals indicated that their general work pace was such that they did not believe they had time to alter their decision practices because of the researcher's presence.

During data collection, the potential for distress created by discussing difficult decisions was an ethical concern addressed by identifying the counselling resources of each site for staff and patients and providing information to participants about those resources when indicated. This was required on only one occasion where a patient asked the researcher to make a referral on her behalf.

The ethical conduct of this research involved scrutiny by five human research ethics committees, all with different concerns and requirements. The difficulties encountered in the approval process related to the tendency of some committees of viewing dying patients as *prima facie* unable to be involved in palliative care research because of their terminal illness, methodological and other issues in one committee being incongruent with others and a lack of congruence in the interpretation of ethical standards (Lee & Kristjanson, 2003). Initial data collection was significantly delayed by these difficulties and as a result a second Melbourne site was not pursued.

Summary

In summary, grounded theory was used as the design for this study examining the processes of care decisions made in palliative care. The grounded theory method used was based on symbolic interactionism and derived from the method first described by Glaser and Strauss (1967) and later by Strauss and Corbin (1990). Grounded theory was used to develop a substantive theory of patient decision making processes in palliative care verified by constant comparison and theoretical sampling. Data was systematically collected from three different settings and analysed concurrently using the techniques of coding and memoing. The Basic Social Process relating to patients' experiences of making care decisions emerged and the categories describing it were fully explicated before data collection ceased. In total forty-eight (48) participants were interviewed and one hundred and six (106) hours of field observations were recorded (Table 3.7).

The trustworthiness of the findings was demonstrated by using a variety of data collection sites, ensuring a variety of participants. Credibility was sought by expert opinion on the research question and methods, by using the expertise of the supervisors to review transcripts and emerging categories and by verifying the theory with palliative care nurses and family carers.

Substantial recruitment and ethical challenges were noted during the conduct of this study. These challenges reflect the sensitivity of ethics committees to palliative care research as much as the sensitivity of palliative care patients and family members to involvement in palliative care research and have been recorded in the publication by Lee and Kristjanson (2003). The experience of the researcher as a palliative care nurse was a necessary attribute in resolving potential ethical problems.

CHAPTER 3

Core Concern: Patients' Lack of Involvement in Palliative Care Decision Making Processes

Introduction

In any substantive area of study, participants will be driven to a particular pattern of behaviour to resolve their main concern (Glaser, 1998). In a grounded theory study, this main concern or core problem describes the major issue experienced by participants regarding the area under study. A comparison of the positive and negative characteristics of decision making from the perspective of patients revealed a main concern that related to patients' fears of being isolated or excluded from making palliative care decisions, resulting from a lack of involvement in decision making. The Macquarie Dictionary defines the term 'involve' as, "to affect, as something within the scope of operation." (Delbridge, 1986, p324). In this current study, the term 'involvement' refers to the extent to which patients believed they were able to influence decisions related to their palliative care. Involvement in decision making in this study included a range of types of involvement, extending from being merely informed about the decision to being in control of making the decision. In this chapter the type of clinical and life style decisions that form the context of their involvement and the nature of involvement and lack of involvement in palliative care decision making are described.

Involvement, Decisions Type and Magnitude

When participants discussed their involvement in decision making, there was some commonality in their interpretations of how involved they needed to be in different types of decisions and in decisions they regarded as more difficult or of greater

magnitude. These aspects to their decisions were driven by the conditions discussed in the following chapter. Nevertheless, the types of decisions observed and discussed by participants in this study have been broadly summarised as either clinical care or life style decisions. Examples of these types of decisions and patients' interpretations of how difficult these decisions were in terms of their actual and desired involvement, are identified. The palliative care decisions observed where patient involvement was not sought nor discussed by patients are also outlined.

Patient Involvement in Clinical Care Decisions

Decisions that involved the assessment or treatment of patients' disease or symptoms were categorised in the data as a clinical care decisions. Clinical decision making was observed in team meetings, at patients' bedsides and in corridor discussions amongst health care professionals. Patient involvement in, and interpretation of, clinical care decisions are discussed in relation to three categories: *New Treatments, Procedures or Major Treatment Changes, Medication Dose Alterations* and *Admissions and Readmissions to the Inpatient Unit*.

New Treatments or Procedures, Major Treatment Changes

Decisions about new treatments, procedures or major treatment changes were usually a result of a medical problem for which the patient had sought advice, and was often presented as an option to the patient by the doctor as a result of an assessment. Doctor James explained how he would proceed with a decision regarding the administration of a medication to treat Wayne's bone metastases after the nurse had drawn to his attention to Wayne's increasing pain:

... the message I got from the ...[community] nurse, was that there was a bit of an acute pain management problem ... And my response to that was well that needs a medical assessment in terms of whether or not it is a problem relating directly to bone disease, or whether it is related to spinal instability ... So the advice ... was to ask his General Practitioner to review the situation ... if there was any doubt about the assessment, I would expect to be asked to go and assess the patient at home ... if it was determined ultimately that it was time for another infusion, then it should be possible to arrange for that to be done at home. Because ... the possibility of him getting the ... treatment at home ... had been well received by the family, that is by [Wayne] who apparently just wants to stay at home (Doctor James)

Doctor James viewed the option of the treatment as primarily a medical decision regarding its suitability for the resolution of Wayne's pain. However, he acknowledged there were other aspects of the decision that were related to Wayne's preference about having the treatment. Therefore, a resolution could not be made without involving Wayne in the decision. Another example involved the treatment of a patient's fractured hip. In an inpatient setting Doctor Lena sat next to a patient and:

... talked about local hospitals she had been treated at and asked how she would feel about an operation to fix her fractured hip. The patient said "it has to be fixed". Doctor [Lena] said "OK". [The] patient [said] "please keep me informed" [about the plan]. Doctor [Lena] said "I'll let you know". (Team observations)

In this example, Doctor Lena had determined that the patient had fractured her hip and concluded that surgery was most appropriate to treat the fracture. However, whether the patient wanted the surgery and in what hospital she might be comfortable having the surgery, were different aspects of the decision in which the patient also needed to be involved. Further, the patient indicated her desire to be involved by being kept informed.

Similarly, a patient who had ascites and his family met with medical staff to discuss treatment options. The field notes record, *"medical record noted family meeting with patient mum and dad and doctor. Three options (2 drug and 1 surgical) discussed for decreasing ascites. Side effects of each option ... [explained to the patient and his family]. Decision to try two options was documented"* (Team observations). The doctor in this situation presented three options that he considered appropriate medical treatment for the patient's problem. Choosing amongst those options involved the patient and his family considering the effects of each option for this patient and his particular circumstances.

Having, or not having treatments or procedures was often considered by patients to be a significant decision. For example, a patient acknowledged the decision about whether or not to have a recommended treatment as a *"big decision"*. She explained:

But I knew of another new drug. It's a good drug. I did my own research whether this drug will match my disease or not. And I found it was good for me but the doctor said I should use this drug with chemotherapy. But the

chemotherapy has lots of side effects so I had a big decision; whether I will use this drug or not. (Patient Barbara)

In this decision, going against the doctor's advice was one option under consideration. Another patient, Jenny, also found that her decision to go against the advice of her doctor to have chemotherapy was her most difficult decision (Patient Jenny). She had been advised to have chemotherapy to slow the progress of her disease, but the first course had left her questioning the value of further courses. It was this questioning of the doctor's advice and weighing the harms and benefits that she found difficult. Further, she had initially discussed discontinuing the therapy with the nurses administering it and they were not supportive of her proposal not to have the therapy. By the time she saw the doctor again she was adamant she did not want further chemotherapy, *"I was quite sure that I wasn't going to have it any more, it was making me sick and taking away my quality of life, I didn't think that it was doing me any, any benefit at all"* (Patient Jenny).

Patients and health care professionals acknowledged that it was important that patients were involved in decisions about major treatments and major changes to treatment. Joan, for example was asked about her decision regarding further chemotherapy. She said, *"I wanted it [the third course of chemotherapy] as I didn't think two [courses] was a fair trial to see if it works"* (Patient Joan). Health care professionals usually attempted to access the patients' opinions on options before they made decisions about treatment. This was the case expressed in a team meeting when the solution to a patient's urinary incontinence was discussed. *"[The patient] gets very distressed when incontinent. Doctor [Peter] asked if patient has a problem with having an in dwelling catheter. Nurse said 'I don't think so'. Doctor [Peter] said 'she needs to be consulted and probably her husband too' ... "* (Team Observations).

In situations where major treatment changes were under discussion, some staff expressed concern about the decision being correct if they were unable to involve patients or gain insight into patients' perspectives. A nurse described a situation in which she was uncomfortable with a decision regarding the commencement of an intravenous infusion for a patient who was unconscious and dehydrated.

In this example, the patient couldn't decide for himself. The family also said to the health care professionals ... "could you decide". So the health care professionals needed to decide whether to give the intravenous drip or not. So

even though they had a meeting, they felt unsure if it was a good decision ... The feeling continued for some time. (Nurse Samantha)

Medications

Clinical decisions considered by participants to be less significant in terms of involving patients were related to alterations in medication. After an interview in which Doctor Lena was adamant that she shared all decisions with the patient, or their family, she acknowledged that there were more routine clinical decisions that she made without such discussion. In the interview she said:

When the patient can't decide or can't communicate, I look to the team and the family for what he would have wanted, because assumptions about a person's quality of life can be very subjective ... It would not be just me, [making the decisions] decisions are shared. (Doctor Lena)

After the interview, the field observations recorded

"Doctor [Lena] passed me in the corridor after this interview and jokingly said, "I just made a decision [for a confused patient] without informing the relatives! The patient wasn't drinking so I added some more fluids [to the intravenous orders; the patient already had an intravenous infusion which had been discussed with the relatives]."(Doctor Lena)

In many of the situations observed and discussed, when alterations to medication dose decisions or decisions to take 'as necessary medications', patients would initially report their symptoms to a health care professional. The professional would then advise the patient and the patient would make a decision about that advice by either agreeing or discussing alternatives. Wayne's son John explained how he and his father made decisions about his medications with the nurse who visited them at home:

the ... Nurse came and he'd [Wayne] had a few days of pain with the shoulder and that was the worst of it so I've been using extra breakthroughs ... [the nurse] and I talked about it and she suggested, you know a change ... and she gave him the [choice] and ... he was ... agreeable ... we debated over the dose ... and Dad was happy with that (Patient Wayne and Family John)

When the nurse or doctor was making suggestions and writing orders for medications, some patients did not believe they were in control of the decision. However, like Jenny in this next example, these patients were often still involved in

some way in the decision process. Jenny was asked how she was involved in decisions with the nursing staff and replied, “... *I find that they’re very helpful ... we don’t actually make decisions between us ... but if we come up with some sort of an idea, the nurses will go back to the Doctor ...and speak to him about it*” (Patient Jenny).

Despite the fact that patients did not acknowledge decisions about ‘as necessary’ medication or medication doses as significant or difficult decisions, these were decisions in which many patients wanted to be involved. Both Jenny and Joan were identified as patients who wanted to stay in control of their medications. Jenny in particular worried about how she might balance the severity of pain she tolerated against the sedation effects of increasing doses of medication, her medical record noting she “*was still very in control of [as necessary] medications*” (Patient Jenny Observations). Though she did not claim this decision as one that was difficult, Joan explained why controlling her medications was important to her. The field observations record her conversation:

... she was trying to cut back the pain tablets as she felt she was walking round in a daze. She had to find the balance between the pain and drowsiness. She indicated that during the drowsy times, she felt very busy with a lot going on in her head but it was all hazy ... to be without pain, [she felt like] a zombie and she had to find the balance because " you will do some damage cause you won't know what you are doing. You have to be clear minded enough to look after yourself and pain free enough to live a life again". (Patient Joan Observations)

Refusing analgesia was identified as a more significant problem for one patient whose pain was likely to escalate. She had expressed on a number of occasions that she did not want to take narcotic analgesia. Nora had experienced an episode of the condition hypercalcaemia. The field notes record a team meeting discussion of her experience and resulting decision:

[Nora] is stoic and fiercely in control. She refuses analgesia as it makes her confused and nauseous. This was noted as a potential problem at home. Doctor [Peter] explained that she was given narcotics during an admission for hypercalcaemia. They compounded her confusion. (Team Observations)

Nora maintained her refusal of narcotic analgesics in a family meeting to plan her discharge some days later. In front of her family and other health care professionals, Doctor Lena reassured Nora that the health care team would:

... respect ... her wishes on this now but asked her to keep an open mind and consider analgesics for her future quality of life. Doctor [Lena] explained that the previous combination of raised serum calcium and morphine might have contributed to prior confusion. [Doctor Lena] explained that a future situation would be different. (Team Observations)

At home, the taking of medications could also involve more difficult decisions. Joan said the list of tablets “bamboozled” her daughter and her. The solution to use a packaging system that metered out doses of tablet four times per day was a relief. She explained, “*I just take whatever is put in front of me. You put them in a jar and I shove them down*” (Patient Joan). However, for family member John, a Registered Nurse who took on the responsibility of decisions regarding when to administer as necessary parenteral medications when his father was dying, he described those decisions as burdensome:

... giving him some of the drugs towards the end ... whether is it too much ... I knew his death was inevitable but ... we’ve all had thoughts if you’ve been in that situation ... that last dose, was that last increase the cause of someone’s death. And perhaps it was and ... I can rationalise and justify and say, well if it was then it’s a blessing (Family John re Patient Wayne)

Admission and Readmission to the Inpatient Unit

A further group of decisions that patients felt were generally easier were decisions to be admitted or readmitted to the in-patient palliative care unit. Jenny had looked forward to being at home over Mother’s Day, but was readmitted to the palliative care unit with an exacerbation of her pain. She was asked whether this was a big decision and replied that “*didn't think that was as hard because when you are in pain, you don't control decision making*” (Patient Jenny). Joan also viewed the decision to return to the palliative care unit as fairly straight forward. The field notes included the following note:

She described her stay at home as a dismal failure though she had got done the things that she wanted to ... I asked about the decision to come back into the in patient unit. [Joan] indicated that it was everyone’s [decision]. She said “I listened to everyone and then agreed to come in”. (Patient Joan)

However, although patients might have believed that the decision to be readmitted had been easy because it was clear or obvious, for family members, it was a more difficult a decision. Some family members found the decision difficult because the

action appeared to violate prior agreements with the patient to care for them at home. One of the nurses caring for Wayne at home reflected on the decisions his wife found more difficult:

... the initial difficult decisions for her would have been to put [Wayne] in hospital when she got the shingles early on and stay at home, I think that would have been a difficult decision for her because she didn't really want to do it. And [Wayne] didn't want to go, but that was the necessity then. (Nurse Kim)

Health care professionals were also conscious that sometimes decisions about readmission to hospital or the palliative care unit were difficult because they were usually not what the patient had originally wanted. In discussing the decision for Joan to return to the palliative care unit, Kim acknowledged that:

... it was a hard decision, but it was a good decision on our part ... she went happily, and ... I think they know towards the end that they (a) can't manage and (b) need more help. So they're happy to accept most of them ... But it is ... difficult when you get people that you're stuck between a rock and a hard place, because ... they want to be home, it's their home, but you know that they'd be better off somewhere else. Sometimes you've just got to step back ... But with [Joan] I think she was quite comfortable with the decision she made, she actually had enough of being home, she was finding it more difficult and then realised she couldn't manage. (Nurse Kim)

Patient Involvement in Decisions that Shape Remaining Life

Decisions described by patients as requiring their significant involvement were decisions that shaped their remaining life. These were decisions that influenced the way that patients lived the remainder of their lives and involved how to use their time, energy and resources. These were decisions critical to the patient's quality of life.

Decisions that shaped remaining life were grouped into three categories; activities of daily living, going home and planning for death.

Activities of Daily Living

There were numerous decisions regarding daily life that were made in relation to the care of patients. Ensuring that they were shaping the quality of their remaining days meant that they had to plan every minute of the day, including their activities of daily living. Activities of daily living include decisions about hygiene, eating and drinking,

moving around, sleeping and going to the toilet. Some patients described these everyday decisions like “*having a cup of tea*” (Patient Nora) as easy decisions. However, for Henry, the combined burden of all his daily living activity decisions was difficult when he was diagnosed. He stated that his, “... *most difficult decisions have been related to holding his life together when he was diagnosed*” (Patient Henry).

Occasionally there was a difference in the perceived significance of decisions related to activities of daily living between patients and health professionals. In a team meeting, the nursing staff expressed considerable concern that a patient who had difficulty swallowing had refused thickened fluids, which he could safely have without choking. In a team meeting the nurses explained,

... the staff had been quite distressed on Saturday when the patient had choked and [queried if he had] aspirated on a drink. He was quite ‘moist’ after so was given [medication] and became completely unresponsive. When he roused some hours later he was dysarthric and hemiplegic. Later Sunday morning these symptoms disappeared. ... no-one wanted to give him [the medication] again despite no indication that this was the cause of his ‘event’. (Team Observations)

The incident left the nurses concerned that the patient’s decision to refuse thickened fluids was appropriate, though their concern and the incident did not sway the patient’s decision. Later in the week the nursing staff asked for further clarification on how to treat the patient’s refusal of the recommended thickened fluids. “*Doctor [Peter] said if we counsel him about the risks and he accepts the risks then it is OK*” (Team Observations).

Some of the activities of living decisions, such as personal hygiene activities, related to the amount of energy and how practical it might be to carry out those activities. Nurse Cheryl described the complexity of the decision that was required for Joan to have a wash:

... she was just sitting there, on the couch and I said what would you like me to do, can I give you a wash here in the lounge room or would you like me to get the wheelchair? ... we found the wheelchair out in the shed, so that was brought in and I’ve got her in the wheelchair and took her to the bathroom. I’d brought in an over-toilet seat, got her to the toilet and I gave her a full sponge, just sitting ... on the chair ... she’d walked because there wasn’t enough room to manoeuvre in the wheelchair, and she’d actually walked reasonably well, but very very slow. (Nurse Cheryl re Patient Joan)

Another patient also had to consider the amount of pain moving around to conduct activities of daily living would cause her. She discussed how she was “*learning her limitations – learning how much she can do like walking before it causes too much pain*” (Patient Jenny).

Nurses visiting Joan at home often impressed decisions upon her such as wearing her personal alarm at all times; and not smoking in their presence, an occupational health issue. Although Joan agreed to their decisions, she reminded them that she was capable of making these decisions herself when she confided that “*I’m trying very hard to do everything everybody told me not to do*” (Patient Joan).

Going Home

Being at home, surrounded by their loved ones and their familiar things was also important to patients in shaping their remaining life. The decision to go home often was described by patients, family members and health care professionals as a big decision, not just because going home was important to patients, but also because of the complexity of the decision itself. Nora indicated that the decision to go home was particularly important to her when she said that the “*hard decisions are when others make decisions for her, like telling her she can’t go home*” (Patient Nora). Patients frequently needed to rely on others to facilitate the outcome of their decisions about going home and this was often complex. For example, Joan’s comment related to her daughter being concerned that she was unable to cope at home. Joan also had to assure the community nursing staff that she would manage and needed to decide how much support she needed to stay at home from various community services (Patient Joan 1 Observations). Nurse Kim thought that Joan found “*her hardest decision ...[was] going home*” (Nurse Kim).

The patient Jenny needed to establish how she would manage returning to the hospital for weekly hydrotherapy after she went home (Patient Jenny). She also needed alterations made to her house to make it safer for her to manage with limited mobility (Patient Jenny).

In another situation, Wayne’s desire to go home could only be facilitated by his son John taking leave from his job and own family to care for Wayne at home. After discussion between the medical staff, Wayne and his family, John summarised the

options for Wayne, “... *I said well dad, basically our options are that you stay here, and you’ll die here, or ... I take some leave and we bring you home, and ... he was unequivocal in saying [he would go home]*” (Family John re Patient Wayne).

The decision to go home often included the resolution of problems related to accomplishing activities of daily living. For example, the nurse Kim believed that Joan’s decision to go home was made more difficult for her because of her concerns at night. Kim explained that:

... being alone at night, was she going to be able to manage ... that was her biggest ... fear ... being on her own at night ... she did wonder how she would manage getting to her bed. (Nurse Kim)

It took some time for Joan to convince herself that she would manage at home. She was asked at the end of the first week of a readmission to the inpatient palliative care unit when she would like to go home and she stated “*I am not ready yet*” (Patient Joan 1). In the subsequent three weeks, she had physiotherapy and encouragement to care for herself and eventually went home after agreeing to further at home meals and personal care support. Just prior to her discharge, Doctor James said, “*I think she is scared of going home. She has agreed to all services*” (Patient Joan Observations).

Nurse Maoki believed that when patients knew that the decision to go home was being made, their need for information and involvement in other decisions increased. She said “...[when] *they know they are going home ... then they want to know everything about their medication, because they’re nervous about it*” (Nurse Maoki).

Getting a hospital bed installed at home helped in the decision to keep Wayne at home when his primary carer John had to return to his own home for four days, leaving Wayne’s wife Kerry to care for him. Nurse Kim explained that despite this in her opinion, the decision left to Kerry was a difficult one:

I think [Kerry] would have ... made the hard decision to keep [Wayne] at home when [John] went back [home], that would have been a difficult decision for her, she would have wanted it, it’s not that she didn’t want it, but I think it would have been a difficult decision for her because of her wondering whether she would manage. (Nurse Kim)

Not being able to fulfil a patient's wish to go home was particularly difficult for relatives. Although Jenny had previously wanted to go home, as her condition deteriorated she was more preoccupied with the issues surrounding her impending death and funeral. However, her husband Bob continued to discuss the possibility of Jenny returning home and was disappointed when she died without going home. Doctor James tried to explain to Bob how difficult it was going to be to achieve Jenny's discharge. He explained that, "[s]he couldn't go home without a lot of support. Doctor James said he wants her to go home but would require 2 visits per day from the community service, which they are unable to provide regularly ..." (Patient Jenny Observations).

Planning for Death

Towards the end of their lives, some patients reflected on their death and decisions such as their funerals, what they wanted to happen to them after death and wanting to die. These plans were important to patients who wanted to feel that they had done their best to support their family members in shaping what was also their family's quality of life. Although they did not discuss these decisions in interviews, staff noted the patients' preoccupation with these issues in team meetings and patient records.

In the last two weeks of her life, Jenny declined to be interviewed. Over this period, the staff caring for her wrote in her record that "[Jenny] *is starting to become more aware of deteriorating and [her] terminal condition. She is starting to make decisions about her funeral ... and where she wants to die. She is quite distressed and preoccupied*" (Patient Jenny Observations).

Another planning for death decision that was reported to the staff by a patient's family, occupied a significant amount of time in a nurses' meeting. The situation was summarised in the observations:

The patient's last wish is to have his brother carry his body in his arms, into the sunshine and sit with him in his arms. The problem is that there is a lack of privacy in the courtyards, which may cause distress to other patients. The nurses discussed how they might facilitate this last wish, including options that would ... create privacy. (Team Observations)

Although the significance of the decision to the patient is unknown, his family and the nurses considered it significant enough to go to considerable trouble to ensure that as a last wish, it was carried out.

There was also evidence that in planning for the circumstances of their death, when the dying does not proceed according to their expectations, patients alter other decisions. An example was reported in a team meeting where staff discussed offering the patient sedation as an option to relieve her distress at finding she is still alive. *“This patient expected to die over a week ago. She is now refusing all medications and is very unhappy and irritable. [The doctors] agreed to speak to her and identified the possibility of prescribing [sedation]”* (Team Observations).

Decisions Made Without Patient Involvement

The data also revealed decisions that were made by health care professionals and family members where no attempt was made to involve the patient and where the patient was unable to indicate their preference for being involved. Many of these decisions were made while the patient was in a confused or unconscious state. For example, a confused and agitated patient was given sedatives without involving him in the decision. The record of the observations noted that “ [The nurse said that the patient] *needs a [Computerised Axial Tomography] scan of the head. She asked Doctor [Lena] if she could give him some sedation to stop him climbing out of bed. Doctor [Lena] agreed and wrote an order ...*” (Team Observations). However, one of the doctors asked about when he would make decisions without involving patients explained that even in decisions involving sedation when patients are confused, some attempt should be made to discover what the patient would have wanted in those circumstances:

... the decisions about patient sedation and confusion are often paternalistic, but it would be rare for a individual health care professional to make a decision without consultation ... they would consult with family, even by phone both to ensure the family are comfortable about the intervention and also to ascertain what the patient would have wanted in these circumstances. When there is no direction from the patient, or vicariously through the family, it would still be a team decision, rarely a decision on one’s own. (Doctor Peter)

On a number of occasions when patients were unable to be involved in decisions, there was an attempt to find out how they might have wanted the decision to

be made if they had been able to, by asking close family members or friends. In a situation where a patient's wife wanted her dysarthric husband's medications ceased, there was concern that she was not reflecting what the patient would have wanted in those circumstances. This concern was enhanced when the patient's wife refused to have other relatives contacted about the patient's condition. The team meeting discussed how they might obtain another opinion regarding the patient's likely wishes in his current circumstances:

[His] wife doesn't want patient's family contacted in Germany as they can't communicate with each other and it will be too difficult for them to come and stay with her. She says the German family know the patient is ill, but that is all. It is unclear what the patient would want in these circumstances, as he is dysarthric [unable to speak]. Doctor [Peter] will contact his [the patient's] General Practitioner and the Doctor from his previous admission to hospital to see if they can shed light on what the patient would have wanted. (Team Observations)

However, there was also an example of a decision made about a patient's discharge made without the patient's involvement due to his confusion and also without apparent involvement of the patient's family. The field observations recorded a discussion in a team meeting where a decision was made on the basis of what staff thought was in his best interests:

... [the] patient seemed stable and therefore should be considered for moving to nursing home. Nurses [stated that they were] very fond of patient. Round table [discussion and] all agreed that considerable work had gone into understanding his complex psychological issues; despite not getting much [feed] back [from] the patient [who] is dysarthric. All staff think patient is "gorgeous" and that he might find the transition to other care difficult ... it might be cruel to send him to another environment. Doctor [Michael] suggested that there are some patients that we have to keep that are "our lot" (Team Observations)

There is a myriad of decisions made regarding patient care during palliative care. During observations and interviews in this study, participants identified patient involvement or lack of involvement in both clinical decisions and decisions that shaped their remaining time. Although there was some variation regarding the types of clinical decisions that were more significant, most patients found decisions that affected their quality of life about discharge home and planning for death both energy and time consuming.

Involvement

When participants described palliative care decision making in favourable terms, involvement in those decisions was apparent. There was a flow of information between the health care professional and the patient, where the patient believed he or she was informed about what was happening and that he or she understood the reasons for health care professional's actions and decisions. Involvement in decision making was also characterised by the health care professional's focus on the patient's needs, as perceived by the patient. Often the focus on the patient's needs was featured in conversations between the health care professional and the patient, where the patient was being asked about his or her concerns. Some patients clearly stated their needs and knew that the health care professional would ensure that his or her decisions were implemented. Participants who talked positively about their involvement in decision making in palliative care also identified confidence in the health care professional as a contributing factor to their positive experiences.

The situations in which patients felt that they were involved in the decision being made were described as making them feel "*comfortable*"(Jenny), "*practical*" (June, Andrew), "*clear*" (Wayne, David), "*free*"(Louise) and "*happy to go along with*" (Joan, June). The involvement of patients in these situations did not always include the patients controlling the decisions themselves. However, sufficient involvement was perceived when patients felt informed by a health professional, when they liked their manner and when they believed that the decision reflected their individual concerns.

For example, Sonia described her husband's involvement in decision making as a preference for being in control of making decisions. He had valued debating treatment options with his health professionals and had developed a rapport that enabled him to talk freely about what he wanted. In these discussions, Sonia's husband had ensured that the health professionals would continue his choices when his condition deteriorated and he could no longer voice them. Sonia said:

He told these things to the doctor and other health care professionals very clearly. They had open discussions about it. So when he was in the bed and struggling to breathe, I asked the nurse "do we need to use oxygen?" She went back to the nurses station and checked his chart and came back and said "no, we won't". And I remembered, yes he said that. (Family Sonia)

This group of decisions about Sonia's husband's care reflected a level of involvement in decisions about his care that included control of decisions. For other patients though, there was evidence that they perceived sufficient involvement in decision making even though there were different levels of control in different decision situations.

Jenny, for example, preferred to be involved as a partner in making decisions about her health care. Though she often developed trusting relationships with health professionals and was involved in making decisions with them, her preference for working in partnership with health professionals was one she would exercise on meeting new health professionals. Nevertheless, the example she gave of working in partnership related to how she and her general practitioner, with whom she had an established relationship, worked to make decisions:

With my own doctor, with this palsy on my face ... we discussed that and sort of tried to think of the best way that we could tackle that ... he came up with a suggestion of ... doing acupuncture on my face, to try and help that. So that was like a joint decision that we made. (Patient Jenny)

However, in another decision situation with a different health professional, with whom Jenny had also established a trusting rapport, Jenny still felt involved in the decision made, when she was not in control of the decision itself, because she understood the decision: "*Doctor [James's] been doing the decision making for the last few days, he's been telling me what we're actually going to be doing ... quite happy [about these decisions] ... it's been explained ...*" (Patient Jenny).

A third example of decision making involvement was illustrated by Louise who gave an example of how the nurses caring for her encouraged her to be involved in decision making:

I think we have a real relationship now with my health care professionals and so I am happy ... When nurses come they ask something - whether I want to have a bath or whether I want to have the drip now or later. So I have a choice and I can discuss with the nurses what I will do next. (Patient Louise)

When patients believed that they were sufficiently involved in decisions, the decisions had occurred when valued relationships evolved between health professionals and patients in which the sharing of information occurred. The patients and the health

care professionals worked together to make decisions. Sometimes the patient's participation was in controlling the decisions, sometimes he or she allowed the health professional to make the decisions and at other times decisions were arrived at collaboratively.

Lack of Involvement

In contrast, poor decision making was characterised by patients feeling excluded from the decisions being made. In these situations patients were not confident in the health care professionals and were somewhat bewildered by decisions that were not clear to them. Patients did not feel involved in the decisions made when they experienced a health professional who had not listened to them, had felt that the health professional had pushed his or her own (the health care professional's) point of view. These patients did not believe they had developed a trusting relationship with the health care professional. Whether the patient was being given information about the decisions or not, he or she experienced a lack of information about the decisions being made (or not being made) around them. The goals of the health professional did not seem to relate to the patient's needs or preferences.

For example, David was confronted by a demanding nurse who left him feeling excluded from decision making and wondering if the hospital staff would care for his needs at all. He explained how he reacted: *"... she was very, very domineering. You take this. You take that ... You respond to them in the same way. Because it causes friction which is no good ... it made me feel what sort of a hospital have I come to?"* (Patient David). Another patient, Louise, was excluded from treatment decision making by a doctor who she felt had unfairly criticised her and her family. She doubted this doctor's ability to advise her because he had behaved as if he did not care about her. As a result, she was unable to be involved in a discussion about her treatment options, feeling that she could only listen to what he had to say. She called this experience a *"300% bad experience"* and explained:

... When I heard my diagnosis from the doctor, the doctor said many bad things like "you shouldn't listen to the diagnosis by yourself", "your family need to come", "your family aren't so good", and things like that. But now I think that doctor, not all doctors, just that doctor, didn't show his humanity at that time. (Patient Louise)

Decision making that excluded patients in this way left them feeling powerless and the goals of their care vague. These patients said that they did not know what was happening to them. The data indicated that poor decision making became a downward spiral of ignorance and isolation over which patients struggled to exercise control. Under these conditions, patients took control by refusing to engage in decision processes with the health professionals, by using passive resistance or more overt behaviour to regain a sense of involvement in decision making.

All of the patients in this study were found at some time to have experienced feelings of frustration about their ability to be involved in palliative care decision making. For patients in this study, their perception of involvement in decision making was related to their interpretation of the decision making process used by others, particularly health care professionals. Patients' perceptions of involvement in decision making were not related to whether they had actually made the decision, but rather to how they felt about the approach of health care professionals, and the way in which health care professionals shared information and managed decision making.

When patients perceived a lack of involvement in decision making situations, they described feeling isolated or excluded from decision making and used terms such as feeling "*bulldozed*"(June), "*anxious*"(Andrew), "*pushed around*"(Andrew, Joan), "*dominated*"(David) and "*bossed*"(David). In these situations, patients described occasions when health professionals who were not well known to the patients and were telling them what to do, had excluded them from decision making. For example, the patient Joan, became very angry when the community nurses made arrangements with her daughter to have old medication removed from her home. The nurse had convinced Joan's daughter that the medications would confuse Joan and might be dangerous, but neither the nurse nor Joan's daughter had discussed the matter with Joan. She had been excluded from the decision to remove the medication. Later on, at home Joan explained that she had been annoyed with the same nurse who had criticised her for having a cigarette. Telling her what to do made her feel as if she had no choice; as if she were again being excluded from decision making. She said:

... I am so sick and tired of people telling me [what to do] ... I don't mind people asking me to do something, but telling me to do something just goes the wrong way ... [it is as if they are treating me like] an imbecile ... as though I am a ratbag (Patient Joan)

Joan's experience of the health professional's negative attention caused her to feel isolated or excluded from decision making. Similarly, another patient's feeling of isolation was experienced as a result of being ignored by health professionals. Harry described a sense of abandonment when "*... no one would make a decision ... so I was just parked ... I went there for 6 hours and stayed there for 8 days*" (Patient Harry). He was unable to be involved in decision making because the health care professionals were not giving him information or initiating discussions about decisions. Harry's explanation of trying to walk with a mobile intravenous pole that he could not control was a metaphor for the frustration he experienced with his lack of information about his care. The lack of information and attention to his needs by health professionals meant that Harry was unable to make decisions on his own or with health professionals. This situation effectively excluded him from decision making:

It was obvious to me that ... I was going nowhere at [Hospital], except going lying in a rotten hard bed, no information, very little in the way of treatment going on. I mean, just hanging around all day on a bloody saline drip, it's just stupid ... you're tied to the spot. (Patient Harry)

Control and Involvement in the Decision Making Process

The examples of involvement and lack of involvement in decision making above illustrate that control of the decision was not a critical aspect of patient satisfaction related to their involvement in decision making. What patients valued in good decision making was their involvement in the process leading to the making of the decision. The patient Wayne often seemed to simply agree with decisions made by health care professionals and his son, but he was confident that the right decisions were being made. However, he did not believe that this was just a passive agreement. He was involved in a discussion about the decisions and understood the reasons for the decisions being made. He denied he was handing over decision making saying "*It's not shovelling over ... all I hear is sane reasoning*" (Patient Wayne and Family John).

Jenny was extremely confident in the way that decisions were being made and often noted how she liked to be involved in decision making. She was not in control of the actual decision made by her doctor in prescribing medication. However, she felt involved because Doctor James, who she liked and trusted, had explained the decision and she understood that explanation:

... I've improved now, but ... with the infusions, it should have taken a much shorter time. So if the infusion was going to work, it would have been a couple of days ago, that's why he [Doctor James] doesn't think it's worked, that's why he doesn't want to give me any more, because he doesn't think they're working. So, ... I think it's not coincidence, I think the Morphine and other drugs ... the other patch that he's increased has really helped ... [Doctor James] decided that ... we'll put another patch tomorrow and ... see how that one goes as well. Quite, quite happy, quite happy, yes. [with the way that those decisions are being made] ... Yes [it's been explained] ... I do [feel like I understand the decision] (Patient Jenny)

However, in situations where patients were in control of making the decision but not satisfied or confident in the decision that was made, they often described their isolation or exclusion from the decision making process. Barbara described how a doctor had taken no interest in her as an individual and had dismissed the research she had done on her illness herself. She explained that as a result of the way he treated her during the process of making a decision about her treatment resulted in her having to make a decision by herself:

The doctor didn't see me as a whole person. He wanted to do his research using my body. He experimented with drugs and said we can try this, and this and this. But he already knew the drugs were very strong and had many side effects. But I knew of another new drug. It's a good drug. I did my own research whether this drug will match my disease or not. And I found it was good for me but the doctor said I should use this drug with chemotherapy. But the chemotherapy has lots of side effects so I had a big decision; whether I will use this drug or not. I decided not to have it, as I prefer to have a good quality of life, so I chose to come here. (Patient Barbara)

The patient Harry had a preference for making decisions about his care independently, and remained firmly in control of decision making until close to the end of his life. However, he also complained about decision processes, particularly when he was unable to get information related to the decisions he wanted to make. He compared what he thought was happening in good decision making processes at one hospital with his poor experience at another hospital:

... the doctors I saw there [Hospital 1] were mainly specialists in whatever they did, and they would generally be around every day, without fail, at a certain time, telling you what your status was. Now, as far as I'm concerned that's the way it should be. Now, that may happen at [Hospital 2] on a good week, [but it] didn't happen while I was there. (Patient Harry)

Harry was conscious that although he was in control of decisions being made, the decisions he made when the process had not included what he expected in relation to information about his condition and treatment, those decisions were a reaction to the process that left him feeling excluded and not in response to what he thought was best for him.

... I started making noises about discharging myself, ... all that did was get some of them visibly annoyed. "How dare you". And other people a bit frantic because of course I had the power to discharge myself, I could just get out and walk whenever I wanted. [I was] getting quite annoyed (Patient Harry).

Control over the decision sometimes was associated with situations where patients experienced lack of involvement in decision making. However, control of decisions was also associated with situations where patients were involved and confident in decision making. In these situations, patients were often encouraged to be in control of making decisions. Sonia described a good rapport between her husband and his health care professionals and his confidence in decision making. As identified earlier, despite the fact that he liked to make decisions himself, he and the hospice staff often discussed his decisions and he was encouraged in his control of those decisions by the recording of them in his medical record.

Involvement in the making of decisions has been associated with satisfaction with the process of making the decision but not with control of the decision itself. In many situations a lack of involvement in decisions was associated with patients taking control of the end decision. However, in other situations where patients were involved in making decisions, they were sometimes encouraged by their trusting relationship with the health professional and the information they had, to remain in control of the end decision.

Reflections on Related Literature

The types of involvement patients expected in making decisions in palliative care in this study were related to the type and magnitude of the decision. The literature was explored in relation to involvement, lack of involvement and the different approach patients may take to different decisions.

Decision Type and Magnitude

In this study issues arose regarding patient involvement or lack of involvement in both clinical decisions and decisions that shaped how they spent their remaining time. Although there was some variation regarding the types of clinical decisions that were more difficult, most patients found decisions about discharge home and planning for death consumed their time and energy.

Decisions in palliative care that are described in the literature as ‘difficult’ often refer to those related to the end of life, such as withdrawal of drug or other life support treatment (Finlay, 1996; Scanlon, 1998; Slomka, 1992; Taube & Bruera, 1999). The perspective taken in these articles is often from that of the health care professional concerned about the ethical issues associated with these decisions. In contrast, the patients’ perspectives in this current study indicated difficulty in the decisions related to their plans about how and where they spent their remaining life. Finlay (1996) suggested that an ethical framework involving the principles of autonomy, beneficence and justice must underpin difficult decisions in palliative care. However, she goes on to describe the resolution of decisions regarding metabolic disturbances, the care process, drug treatment, emergencies in care and treatment cessation with scant reference to patients’ involvement in these decisions, and a focus on balancing treatment burden and benefit from the clinician’s perspective. Only in the discussion regarding decisions of place of care and treatment refusals does she urge the reader to acknowledge patients’ wishes (Finlay, 1996). However, this current study indicates that patients expect to be involved in some way in all decisions regarding their care.

Agich (1995) argues that respect for the principle of autonomy is as important in everyday decision making as well as the more commonly acknowledged ethical decisions suggested by Finlay (1996) above. Agich identifies two types of ethical decisions made in long term care that provide some insight into the distinction between ethical decisions viewed as difficult in the literature and those decisions viewed by patients in this current study as difficult. Agich viewed “Nodal decision making” (1995, p114) as decisions where clear alternatives were present; where weighing cost and benefit was relevant; and where coercion was possible because of power differences between parties in the decision. The everyday decisions that lacked conflict, that often seemed not to be explicit decisions because they seem to just happen, were termed as

“interstitial decision making” (Agich, 1995, p114). These decisions are significant to the person because they are evidence of the “ideals, beliefs or values that are not just held or asserted in the course of disagreement, but are personally held and lived every day” (Agich, 1995, p114). Patients in this current study found many everyday decisions difficult because, in their rapidly changing personal circumstances, maintaining their sense of self during “typical events of every day care” (Agich, 1995, p115) was challenging.

Other articles focus on the family perspective of making difficult care and treatment decisions when the patient is incapacitated (Forbes, Bern-Klug, & Gessert, 2000; Norton, Tilden, Tolle, Nelson, & Eggman, 2003; Panke & Volicer, 2002). Forbes et al. (2000) sought to describe family decision making processes regarding end of life treatments for nursing home residents with severe dementia. In the focus groups for this study, the family members were asked about the decisions they found difficult. However, the results were reported in terms of the decision making experience in general rather than related to particular decisions. Nevertheless, the article notes some individual reports of difficult decisions as the instigation of particular medication treatments for infection, artificial feeding, and hospitalisation. Though not specifically acknowledged, it was implied that the decision not to undertake cardiopulmonary resuscitation was a less difficult decision. In a description of the perceptions of family members regarding the dying trajectory, one participant described how the issue of resuscitation was a clearer decision than other treatment decisions, “ ... if there is a treatable anything, she’s okay, but not for any blue light specials [resuscitation]” (Forbes et al., 2000, p255).

One significant study focused on decisions that are not obvious causes of medical conflict, but were related to the every-day decisions undertaken by patients related to personal and nursing care (Bottorff, Steele, Davies, Garossino, Porterfield and Shaw, 1998). This grounded theory study used field observations, informal conversations and interviews to examine the experiences of palliative care patients in “making choices related to their personal and nursing care routines on a palliative care unit” (Bottorff, Steele, Davies, Garossino, Porterfield, & Shaw, 1998, p8). They found a wide variety of decisions had individual responses in terms of choices made by patients. Similarly to this current study, Bottorff et al. (1998), found that on superficial

examination, decisions such as personal care routines and medication regimens, seemed “mundane” but held significant meaning for patients.

In another study using grounded theory methods, eleven palliative care patients were asked to identify two decisions they had made within six months, involving nursing staff (Clover, Browne, McErlain, & Vandenberg, 2004). The decisions these patients chose to talk about were not identified in this study as difficult. However, because patients selected two particular decisions, it is reasonable to assume the decisions held some significance to the patients involved. As in this current study, decisions shaping remaining life also featured as significant. Clover et al. (2004), reports that the decisions talked about “related to nutrition preferences, euthanasia issues, advance directives, compliance with nursing practices such as medication regimes, choice in venue of palliation, hygiene practices and choosing not to make a decision” (Clover et al., 2004, p336).

A qualitative study by Saino, Lauri and Eriksson (2001) involving 34 hospitalised cancer patients in Finland in interviews regarding participation in decisions about their care found that patients were more likely to participate in everyday care decisions than medical decisions. The authors concluded that participation in everyday decisions was easier because they involved concepts related to the patients’ everyday life and were therefore easier to understand than medical decisions (Saino et al., 2001). How they arrived at this conclusion is not explored and a lack of clear examples in the report makes this conclusion difficult to substantiate. There was no evidence to support this view in the findings of this current study.

Involvement and Lack of Involvement

The core concern in this current study was identified as a lack of involvement in palliative care decision making processes. In their description of their lack of involvement, patients described how health professionals failed to create a rapport that invited them to be involved and how they failed to give the information critical to their involvement. In an analysis of patient participation in the context of caring, Ashworth, Longmate and Morrison (1992) identified three aspects of patient participation as a social interaction, which were critical for nurses to understand. The first was that for patients to participate in care decisions, there needed to be emotional and motivational attunement between the nurse and patient towards each other’s concerns. This equates

to the patients in this current study finding that for them to be involved in decisions, the health care professional had to be nice and friendly and focussed on them and their needs. The second aspect of patient participation identified by Ashworth et al. (1992) was that patients and nurses felt they had worthy contributions to the decision making process. Similarly, in this current study, patients only felt they could be involved in decision making if the health professional was willing to listen to them and valued what they had to say. Ashworth et al. (1992) identified the third aspect of participation as “a firm sense of personal identity” (p1436). In this current study, health professionals identified patients with whom they could not develop a rapport, in terms of their inability to find common ground. Their inability to identify with those patients resulted in the health professionals finding it difficult to involve them in decision making.

In this current study, despite the type of decision and its magnitude in the lives of those making the decision, palliative care decisions that were described as good were related to patients’ involvement in making those decisions. In contrast, when patients were not involved in making palliative care decisions, those decisions were described as less satisfactory. This finding is strongly supported by research involving other hospitalised patients and in research involving other palliative care patients (Backhouse & Brown, 2000; Brody, Miller, Lerman, Smith, & Caputo, 1989; Brown, 1994; Fallowfield, 1997; Rothenbacher, Lutz, & Porzsolt, 1997).

The literature revealed an association between patient satisfaction with care in a range of specialist areas such as maternity care and rehabilitation, and involvement in making care decisions (Backhouse & Brown, 2000; Brown, 1994). One of these studies indicated “one of the most powerful themes to emerge from the comments sections ... was the respondents frustration with staff who did not spontaneously involve them in decisions about care” (Backhouse & Brown, 2000, p34). Further, a study examining decision control interactions between nurses and terminally ill patients found that when an offer of relationships regarding decision control was ignored, it was damaging because it dehumanised the person offering the relationship (Peplar & Lynch, 1991).

One study examined the relationship between patients’ perceptions of decision roles during medical consultations and their perceptions of improvement in their medical problems a week later (Brody et al., 1989). As in this current study, Brody et al. (1989) found a positive association between decision involvement and satisfaction

with decisions. Adult patients (n = 117) showing new or worsening symptoms were given a questionnaire prior to their medical visit and followed up by phone interview one day and one week later. Questions related to the roles they wanted to play, their attitudes towards their illness, illness outcomes, their perceived role and their satisfaction. The patient's physician also completed a questionnaire after the visit, giving a rating of the seriousness of the patient's medical problem expected discomfort and expected dysfunction. Patients who perceived they had been actively involved in decisions during the consultation reported less illness concern, discomfort and dysfunction, a greater sense of personal control and more satisfaction than those patients who reported a passive role (Brody et al., 1989).

Two studies (Gattellari, Butow, & Tattersall, 2001; Rothenbacher et al., 1997) used role preference statements similar to those used in this study (Davison & Degner, 1998) to analyse patients' preferences for involvement in decision making. Rothenbacher et al. (1997) evaluated the extent to which 59 hospitalised palliative cancer patients in Germany, preferred to be involved in making treatment decisions and the degree to which their doctors were aware of the preferences of their patients. A comparison group of patients with chronic conditions other than cancer and a control group of non-hospitalised persons was also surveyed. In addition to the finding that in 54% cases, doctors were consistently inaccurate in their knowledge of the cancer patients' preference for involvement in treatment decisions, they also found that only 20% of patients preferred a passive role in making treatment decisions.

Similarly, a study conducted in Australia, examined the preference for particular roles in decision making, but compared the effect of achieving their preferred role on patient anxiety, recall of information and satisfaction (Gattellari et al., 2001). The 335 patients recruited for this study were attending an initial consultation at an outpatient cancer treatment clinic and although some may have had palliative goals of treatment, this was not specified in all fields of the findings. Gattellari et al. (2001), reported that 45% of patients had a role preference for sharing decision making and yet only one third of these patients achieved their preferred role. The authors also found that when patients' preferred role and their perception of their actual role during the consultation matched, higher levels of patient satisfaction were achieved. Mismatch between the health professional assumption of the decision roles they expected patients to take and the roles patients preferred was related to anxiety and matching of the perceived role of

the patient by the health professional was more strongly related to satisfaction in the consultation.

The distinction between decision involvement and decision control found in this current study is not discussed in the literature. However, Bottorff et al. (1998) describe the involvement of patients in making everyday choices also including the choice to surrender control of the decision. In this current study, relinquishing control was not indicative of the patients' lack of involvement. Similar to the findings of this current study, Bottorff et al. explained that the "choice to let go was an active choice often made to conserve energy rather than a reflection of patient apathy" (Bottorff et al., 1998, p11). In addition, the distinction discussed earlier between 'nodal' and 'interstitial' decisions asserted by Agich (1995), suggests that everyday decisions do not always have clearly defined alternatives and because there is no choice to make, patients may view control in these circumstances as irrelevant.

Summary

In summary, this current study found that the core concern of patients was their lack of involvement in the palliative care decision making process. Patients experienced a range of levels of involvement in decisions regarding their clinical care and their remaining life choices. Although new treatments or major treatment changes were often considered significant decisions by patients, decisions regarding ongoing treatments such as alterations in medications and admission to hospice or hospital, were often of less significance than were decisions about their remaining days and how these were to be spent. For example, decisions about whether or not to return home and decisions about planning for death were difficult for patients. The literature supports that decision that may appear on the surface to be mundane to health professionals, like everyday care decisions, may be more important to patients because they represent the ways patients live out their personal values (Agich, 1995; Bottorff et al., 1998)

In decisions that patients described in favourable terms, they were involved and participated in decision making. Patients who were involved in decision making were confident that satisfactory decisions had been made, despite the fact that they may not have felt that they were in control of the decisions. In contrast, when patients described poor decision making, they felt excluded from decision making and were not confident in their health professionals or in the decisions made. Despite sometimes taking control

of decisions, those patients who perceived a lack of involvement remained unhappy. Evidence was found in the literature to substantiate the importance of patient involvement and participation in decision making in improving satisfaction with care (Backhouse & Brown, 2000; Brody et al., 1989; Brown, 1994; Fallowfield, 1997; Rothenbacher et al., 1997).

CHAPTER 4

Conditions Affecting Involvement in Making Decisions

Introduction

The term 'condition' refers to "a restricting, limiting or modifying circumstance" (Delbridge, 1986, p.122). In a grounded theory study, conditions are defined as either causal or intervening. Causal conditions are "events, incidents, happenings that lead to the occurrence or development of a phenomenon" (Strauss & Corbin, 1990, p.96). Intervening conditions facilitate or constrain the strategies used by participants to respond to the core problem or phenomenon (ibid.). In this study, patients' perceptions of their involvement in making decisions and how they responded to their involvement or lack of involvement were affected by causal and intervening conditions. Because decision making reoccurred in different health environments and with different health professionals, patients' experiences of involvement were influenced by both causal and intervening conditions. These conditions also affected patients' responses to their concerns about involvement. This chapter discusses the causal and intervening elements of a range of conditions of involvement in making decisions. The conditions related to the experience of involvement in making decisions about palliative care include the relationship developed between patients and their health care professionals, the information possessed by the patient and power differences among patients, their health professionals and family members. Patients' personalities and their level of dependence also affected their involvement in making decisions.

Relationship with the Health Professional

From the perspective of the participants in this study, particularly health professionals, the development of relationships was found to be a central influence on patients' capacities to be involved in making decisions about their palliative care. The term 'relationship' is defined by Delbridge, (1986), as "a particular connection" (p.520).

In this study, various terms were used to qualify the type of relationship activity engaged in by participants. Participants described the particular connection in relationships that were valued by terms such as '*real*', '*good*', '*close*' and '*established*'. Relationships have variously been described in this study as the "*core*" of one's job (Counsellor Marion), and as essential to understanding patients (Counsellor Jill re Patient Jenny, Nurse Samantha). Relationships were also described as providing direction to decision making (Doctor Lena) and were an important influence on the roles patients chose in decision making (Nurse Lindsay). They also provided a forum for health care professionals to show their humanity and therefore engage patients' trust and for patients to be able to express their fears and desires (Patient Louise, Patient Barbara).

Interactions with health professionals in which patients did not feel involved in decision making, or when health professionals had not engaged in behaviour indicating a desire to develop a connection or rapport, resulted in distance between the patient and the health professional. The Macquarie Dictionary defines distance as "reserve or aloofness" (Delbridge, 1986, p.226). The sense of distance between health professional and patient was characterised by discrepancies in what a decision might mean to a patient; as though decisions were being made from a viewpoint that was remote from the patient's particular and individual circumstances. Health care professionals were perceived as aloof, uncaring and disinterested in the person and entirely focused on the disease, on organisational or professional rules and protocols.

Although participants in this study acknowledged that failure to develop relationships between health professionals and patients occurred rarely in palliative care, some situations were observed or discussed where the relationship health care professionals wanted to have with patients were at odds with the type of relationship patients desired to have with health professionals. The patient, Harry, was described as someone with whom staff had found they could not develop a relationship. Two of the participants identified their relationship with some health professionals involved in their initial diagnosis and treatment, as not satisfactory because the health professional was unable to appreciate their individual way that they wanted or needed to cope with illness and treatment (Patient Barbara and Family Betty).

The type of relationship developed between patients and health professionals constrains or facilitates patients' abilities to be involved in making decisions and was largely initiated and controlled by factors related to the health care professionals and the ways that they worked. These factors that were critical to the relationship included the manner and focus of health professionals, trustworthiness, the culture of the health care environment and taking time. These are discussed in detail below.

The Manner of the Health Professional

The term, 'manner' is defined in the Macquarie dictionary as " a person's outward bearing; way of addressing and treating others" (Delbridge, 1986, p.377) and in this study referred to the ways that health care professionals approached patients. When patients were confident about decisions being made and felt that they were involved in decisions, they identified a particular manner or approach of the health professionals involved in their care. This manner was described as enabling or inviting patients to participate in making decisions. However, patients described a different manner or approach by health professionals when they were not involved in decisions. This manner made them feel distanced from the health care professional and unable to be involved in decisions.

A number of patients identified health professionals that they had valued when a palliative care decision had been made. David, a patient, said "... *I like people to be nice and kind*" (Patient David). Wayne's son also discussed the quality of decisions made by particular health professionals by first identifying that they were nice "... *the consultant was really good. She was a really nice person ...*" (Patient Wayne).

Being 'nice' is an interpretation of a range of behaviours that patients often struggled to describe. Andrew talked about the caring and gentleness of the nursing staff he valued as a kind of "... *sweetness in the way they talk to you ...*" (Patient Andrew). June referred to niceness as having a "... *pleasant manner and [being] helpful ...*" (Patient June). She qualified this by explaining that her nurses did more than she expected of them:

They all seem to be nice and they'd do anything for you. Like if I want anything, its there ... when I first went home they said is there anything you want, like in your bathroom that sort of thing. And I said, "no, the only thing I

want is ... a higher seat on the toilet". It was there in half an hour. So that's how they work. They just help you any way they can. (Patient June)

The first meeting between patients and health professionals was found to have an impact on how involved in decisions patients perceived themselves to be. Patients assessed fairly quickly whether the health professional was the sort of person that they liked and therefore was also the sort of person with whom they wanted to be involved in making decisions. One patient, David, described his visits to his General Practitioner: *"Well it's a real friendly welcome with her and before we get down to medical treatment, we have a nicely little homely chat and then we get down to business"* (Patient David). The friendliness of the doctor's manner in welcoming David to consultations was said to have continued throughout their relationship.

David identified the good manners of health professionals as being critical to the rapport he initially developed with them as well as to his decision making. He believed that the good manners displayed by his health professionals made him feel that he was welcome to participate in making decisions. A number of the nurses interviewed and observed were also conscious that the initial approach to a patient was critical in making the patient feel comfortable in making care decisions with them. These nurses also indicated that the initial approach needed to contain elements of good manners, kindness and gentleness. Two of the nurses interviewed described their initial approach to patients involving introducing themselves and explaining their role (Nurse Maoki, Nurse Siu). Nurse Maoki linked her introductory behaviour to her potential control over decision making by suggesting that patients needed to understand how she worked:

I go and introduce myself to them, show them my name tag and I'll often shake hands with them and invite them each shift to ring the bell if I'm not available in the room and they need me for something. And not to lie there thinking, "gee I hope she's coming soon". (Nurse Maoki)

A number of the doctors interviewed also identified their initial approach as important in the development of a *"connection"* or *"rapport"*. Doctor Thomas described how he tried to find some interest in common with each patient, such as a book the patient was reading, as *"keeping the door ajar"* as an ongoing invitation to the patient to be involved in decision making; to allow discussion about symptom management as well as helping him to understand the patient (Doctor Thomas).

When patients did not like health care professionals, invariably it was because they had been insensitive to the patient. David described one nurse who he had not wanted to be involved in decisions about his care as “*aggressive*” and “*domineering*”. She had, he thought, abandoned any attempt to be nice and just told him, “*You take this. You take that.*” (Patient David). She had, he summarised “... *neither manners nor kindness*” (Patient David). Patients tended to assess manner early in their relationship with a health professional and this assessment affected their ongoing relationship. June explained that this was a general life rule, “... *you have to find out if they’re a nice man or if they’re not a nice man you don’t trust them do you? That’s something you learn in life*” (Patient June).

Although some patients would make the judgement that the health care professional was not nice because of their domineering initial approach or manner during their first meeting, and allow that judgement to influence their decision making behaviour, one family member described how his wife tried to put up with their doctor’s general lack of niceness, because of his expertise:

I thought he was a very good diagnostician but his manner to her was quite brutal ... She said physically he moves me and grabs me and his touch isn’t gentle. He says things to me ... they weren’t offensive other than they were direct and brutal. He didn’t try to put things gently. He just said you’ve got to have the leg off. She didn’t mind being told what she had to do but she would have liked to have it put to her fairly gently. (Family Joe)

The strain of putting up with this health professional’s lack of kindness, gentleness and sensitivity had a profound effect on Joe’s wife and her sense of involvement in consultations:

... she came home, she’d be furious. She said “I hate that man”... I thought they were minor things, but she’d be trembling furious ... in fact we discussed this and that’s why we stayed there because he was such a good doctor. Technically a good doctor, but socially a very cruel one. (Family Joe)

Although Joe, who also consulted this doctor, was able to appreciate the technical expertise of this doctor and still feel a sense of involvement in decision making, the “*trembling furious*” reaction of his wife to this doctor reflected the lack of control and involvement she felt in decision making. She did not like his manner and found his care impersonal. Joe believed this doctor’s manner of handling his wife was

cruel and indifferent, affecting his wife's ability to be involved in making decisions and leaving her dissatisfied with the way the doctor made decisions. Other participants identified that indifference and brief efficiency were also an influence on the relationship developed between patients and health professionals. In addition to appreciating the health professionals' manner, patients indicated that liking them and believing they were competent was linked to a sense of the health professionals' interest in the patient.

The Focus of the Health Professional

Patients perceived more involvement in making health care decisions when they were sure that the health professionals involved were focused on them as individuals and on their particular issues and needs. When health care professionals focused on patients as individuals, they were perceived to be putting the patient central to their concerns when they were with them. Patients assessed the health professionals' interest in and focus on them through the health professionals' use of humour, supportive behaviour and touch.

One of the patients, Joan, talked about the approach of one of the doctors as being supportive which indicated to her that the doctor cared for her:

He's got such a lovely way with him, hasn't he? He really has, I don't know how anybody couldn't get on with him ... he's just got such a lovely way of speaking, and he's a toucher, have you noticed that? And for some reason, they've got, to me, they've got more depth in them ... there's a lot of people can't go anywhere near anybody, but he's not, he can put his hand on you, I don't say you feel blessed, but you feel cared for. (Patient Joan)

During her inpatient stay, Joan was comfortable talking about her needs and wishes with this doctor in sharp contrast to her response to other doctors who made less of an attempt to use humour and touch. With one other such doctor she was evasive when questioned about particular problems. He had approached her medical needs without attempting to introduce himself and displayed no interest in her personal circumstances (Patient Joan Observations). In this situation the doctor conducted his medical examination by touching Joan roughly and dismissed her attempts to explain her situation. His lack of good humour and impersonal touch failed to acknowledge her as an individual and effectively excluded her from the decisions he made.

A number of the patients and health professionals talked about being able to laugh with each other. A patient talked about feeling involved in making decisions with nurses who involved her in “... *good conversations and sometimes some humour*” (Patient Louise). It was also noted during the field observations that when health professionals used touch and humour, patients would engage in conversation and reveal information about their lives and their health needs. In unspoken terms, touch and humour indicated to patients that they had the health professionals’ attention.

Patients and family members also reported body language of health professionals that left them feeling excluded from decisions. When health care professionals were seen by patients and family members to be busy, they felt unable to approach them about making decisions. When his wife was in hospital, Bob and his wife felt unable to talk to health professionals, “... *because the nursing staff are usually that bloody busy, they haven’t got time to spend and they’re run off their bloody feet ... and I mean basically there was nobody to see ... we were left high and dry*” (Family Bob re Patient Jenny).

Harry, a patient, also indicated that he did not feel involved in decisions when the staff caring for him were too busy; “... and to get access to people ... because they’re so rushed off their feet, you just wait, and you wait and you wait and you wait” (Patient Harry). There was also some evidence from nurses that they were aware that when they appeared busy, patients would avoid interrupting them. One of the nurses said, “... I don’t remember what we discussed at the time but maybe the patient thought ‘she is not busy now’ that is why the patient started talking” (Nurse Niki).

Busy body language was contrasted again with the way patients noticed when extra time was spent with them. When they felt that the health professional spent extra time with them, they felt supported in being involved in decisions. Patients noted when health professionals had frequent conversations or visits with them, that the health professionals knew them and were committed to helping them and their family. Joan said of her doctor “*you can’t knock him – he was in every day*” (Patient Joan). One of the health care professionals also felt that frequent conversations also help patients to feel supported in their involvement in making decisions:

... the patient was so independent, she wanted to decide everything by herself. She rejected family support. So the family needed to understand lots of things ...

I needed to talk with the patient many times until she felt supported in her decision. (Counsellor Anna)

Patients also acknowledged that the length of the relationship with their health care professionals was a factor in fostering trust. One of the patients, Joan, talked about her trusted family doctor with whom she had been for 18 years. He had cared for her dying son at home some years earlier. Joan felt that over this long period, this doctor had gotten to know Joan and her family: they had a history of making decisions together that facilitated her involvement. One of the doctors interviewed noted how a lack of time to develop a relationship limited the involvement of patients in decisions:

... but that is assuming that we have had the chance and time to get to know these patients, but sometimes with patients who are admitted in extreme situations we have no prior knowledge ... then you just ... provide the treatment required (Doctor James)

Although some relationships developed over long periods of a person's life as was the case for Joan, it was not always so with other patients. Patients felt encouraged to be involved in decisions when health care professionals were willing to slow down consultations and decision making to develop rapport with them. Field notes recorded "*Doctor Lena sitting close to patient holding hand and allowing patient to lead the conversation [about scones, bingo, how well she looks and feels, physiotherapy visit]*" (Team Observations). In this way, the extra time was devoted to getting to know the patient and their needs and showing the patient they cared.

Patients judged health professionals' by the way that they focused on them as individuals and by the way they appeared to understand the patient's personal perspective, background and desires for the future. When the options that health professionals presented reflected patients' own concerns, patients felt that they were influencing the decisions that were made. For example, Harry had only been in the palliative care unit for a short period of time when he was interviewed. He said of the doctor that he had met there that, "*... he seems great, he seems to want to know, he wants to know what he's dealing with*" (Patient Harry). Harry was positive about his new environment and used this doctor's interest as an indication that he could now influence decisions in a way that was in his interests. For Harry, this situation was a distinct contrast to his previous hospital admission where he had experienced a lack of interest in his personal circumstances, and an associated lack of involvement in making decisions with health care professionals.

One of the patients talked about preferring to consult a single health professional who was interested in, and knew about her as an individual rather than consult one of several professionals who might not know her:

They are sort of interested in you ... they get to know you ... what's wrong with you and that sort of thing ... it gives you confidence. You go to these ... [clinics]. There's so many sprung up now and you get so many different doctors. Well, how can you have confidence in them if they don't know you and you don't know them? (Patient June)

When Wayne's condition suddenly deteriorated at home one weekend, his son phoned the community nurse for advice about how he could move Wayne without causing pain. He explained, "... *I rang whoever was on call, and she was kind of unhelpful. She said I can't do anything until the physio gets there on the Tuesday. And I said well I can't move him ...*" (Family John re Patient Wayne). John tried to understand why she had been less than helpful that day and suggested that it was because she did not know the family well; he had only ever met her once. He also indicated this with a sense of relief, as if he were glad that this nurse was not visiting more regularly. His perception was not only that she had not enough contact with them to get to know their circumstances, but also that, even with more contact, she still would not have come to know them.

A focus on the patient's individual circumstances was a measure of the quality of one group of health professionals caring for Joe's wife: "*They knew what she was going through*" (Family Joe). This was because they seemed to be focused on his wife's issues and needs. In this situation, Joe and his wife were satisfied that they did not need to make any decisions by themselves, but Joe believed that his wife was involved in decision making. Patients also felt that health care professionals know their circumstances when they indicated that their record had been read and had changes recorded in it. June said it was part of the test she used to make sure a health professional was focused on her:

And mind you they have big screed [health care record] on them, they got a folio there [medical and nursing charts kept at the bedside] and then they write everything down as one finds ... because they keep up that one for the next one that comes and if there's any change that they suggest in the medication, well it's all recorded. (Patient June)

In contrast to these examples where a focus on the patient enabled a sense of involvement in decisions, the patient Joan felt impotent about the decisions regarding her care at home. Joan stated that a number of nurses failed to acknowledge her personal situation and made judgements that were inaccurate. On several occasions, the community nurses expressed concern that Joan would not be safe at home because of the risk of her small dogs tripping her. A test visit home with her doctor demonstrated, as she had said, that the dogs moved out of her way; *“the dogs know I am coming”* (Patient Joan). In the situation explained earlier, where the same nurses expressed concern about Joan’s safe use of her medications at home, they excluded her from decision making when they negotiated with her daughter to have all but current medications removed from the house. The data suggested that if they had understood more about Joan’s personal circumstances, they may have been aware that Joan was fiercely trying to remain involved and in control of decision making (Doctor James).

One of the patients described her decision not to follow her doctor’s advice because he “... didn’t see [me] as a whole person ... because he prepared a package of treatment and just wanted to put me in it, regardless of me as a person” (Patient Barbara). Another patient, Louise, also talked about the importance of health care professionals understanding her as an individual. She lamented that the doctor who had advised her of her diagnosis and was critical of her independence from her family was unable to understand the needs of patients like her (Patient Louise).

When health professionals approached patients with the manner that patients appreciated and spent time focused on the patients’ needs, patients were able to develop a sense of trust in the health care professional.

Trust in the Health Professional

The concept of ‘trust’ was defined in this study as having faith in a person’s advice. When patients felt that the health professional was someone that they could trust, they were able to be involved in decisions. In trusting the health care professional, patients would have confidence in decisions made by the health care professional. When patients trusted their health professional, they believed that the health professional could be relied upon to give good advice, make good decisions and to care for them. The patient Harry was adamant about feeling involved and in control of decisions made about his care. In affirming his opinion of one of his surgeons, Harry stated, *“If I know*

a doctor well and trust his ... talents ... I will accept without question what he says ..." (Patient Harry). When Harry felt that he could trust his surgeon, he was able to work with the surgeon, discussing his symptoms and asking about various options. Harry's acceptance was not related simply to allowing the surgeon to control decisions, but rather was an acceptance of the advice this particular surgeon gave that enabled Harry to engage in discussion about decisions with this surgeon. Harry was less likely to take the advice of health professionals he did not trust, without doing his own research. Harry's assertion that it was the surgeon's talent that led to his trust was not repeated in his other relations with health care professionals, despite their medical and nursing expertise. Notwithstanding his acknowledgment that the doctor and nurses in the palliative care unit seemed competent (Patient Harry), he was reluctant to talk to them about what he wanted to do in relation to his ongoing care.

Trust was found to have developed when health professionals approached patients with a manner that patients believed was sensitive to their needs. Trust was also engendered when health professionals kept patients informed. The health professionals' invitation to patients to engage with them in making decisions also fostered patients' trust. For example, David articulated this in his comparison between the two doctors he had caring for him and explained why he trusted one doctor more than the other. The lack of an invitation to participate in the decision, by Doctor James asking David his opinion, left David less trusting of Doctor James's advice:

He's not bossy in any way, but he's firm. Now Doctor GP, she makes her decisions then what do you think of it [David]? Do you think you could manage? Or can't you? ... Doctor James would say you've got to do this, she'd say I would like you. Which makes a world of difference ... Is he [Doctor James] right or is he wrong. (Patient David)

However, for other patients and families, this firmness of opinion was a characteristic that they trusted. Nurse Riki described a situation where a relative did not trust a visiting doctor's opinion because he seemed reluctant to order medications. When Doctor James, the regular doctor who knew the patient, returned to the ward, the patient's husband was relieved. Indicating Doctor James, the husband stated "... *thank god there is someone who knows what he is doing*" (Nurse Riki).

Trust also developed when patients perceived that health professionals had formed their opinions based on accurate assessment of patients' views of themselves

and their personal circumstances. When patients felt that health professionals had misjudged what was important to them, patients would not trust the advice given by the health care professionals and could not be involved with those health professionals in decision making. Barbara articulated this clearly in talking about the doctor who encouraged her to undertake debilitating chemotherapy, which he had described, would only offer a small chance of success in curing her disease. She said, “... *I doubted his opinion, also his attitude because he prepared a package of treatment and just wanted to put me in it, regardless of me as a person*” (Patient Barbara). He had suggested to Barbara that she distance herself from the emotional experience of having chemotherapy. Barbara felt this advice was contrary to her particular personality and abilities. From her perspective, Barbara’s physician had made no effort to understand the importance of her emotional and spiritual needs and had not listened to her ideas about the way she wanted to live her life. She felt unable to participate in decision making because she did not trust the way that he was advising her.

Trust in a health care professional was associated with patients taking the health professional’s advice. The example used earlier indicated the value Harry placed in trust in ensuring he felt involved in decision making and able to take the doctor’s advice; however, Harry maintained he was in control of the decisions made. In contrast, Joan acknowledged that her trust in her General Practitioner meant that she would follow his instructions, even if she did not believe his advice would help; “*I mean when you’ve got a lot of faith in somebody, you sort of go along with it*” (Patient Joan). Joan’s trust in her General Practitioner included his advice about her prognosis. She was more inclined to believe his more optimistic prediction than the prediction of her specialist oncologist.

Doctor James was conscious of the responsibility placed on health care professionals whose advice patients trust with such faith:

The patients place such enormous trust in professionals, especially doctors and nurses that you can do almost anything to them and they will agree with it. And I am very concerned about trying to ensure that the autonomy we like to think we allow patients to have isn’t overly influenced by our words and actions and nonverbal communication. (Doctor James)

Trust in a health care professional’s advice about changes to care regimens extended to nurses and other allied health staff. One patient, Jenny, had particular

confidence in the advice of community nurses because she felt they were experts. She said:

... well they just seem to be on the ball, they just seem to come up with great ideas ... That's how I actually got in here ... one of them just rang up the doctor here ... the next thing I was in here ... they seem to just know what they're talking about. (Patient Jenny)

However, patients' perceptions of expertise were not based merely on knowing or admiring health care professional's qualifications. Patients trusted that health care professionals were expert when they had experienced the advice and support of health professionals whose manners they liked. For example, Joe was interviewed about his wife's care decisions and talked about his wife being unable to continue consulting a doctor she did not like. As discussed earlier, despite Joe suggesting he and his wife recognised the doctor's clinical expertise, Joe's wife did not like his manner. She was unable to trust that his clinical expertise would compensate for his rough manner in the decisions made and though she tried to endure his care, she eventually sought other medical support (Family Joe).

Joe's wife in the above example allowed a testing period with her doctor to see if her trust in him would improve over her experience of his care. Testing for trustworthiness was discussed by a number of patients and health professionals. Jenny acknowledged that she would test any health care professional she met for the first time until she trusted them. Jenny's test included being wary of advice given by health care professionals until she could check its veracity with a health professional that she did trust. One of the nurses explained patients often tested her by asking her to resolve problems other health care professionals had been unable to address (Nurse Siu). Another patient, June, acknowledged that she tested the nursing staff "... *automatically* ..." (Patient June). June's test involved making sure the health care professional's manner was consistently nice each time he or she visited her.

The development of trust in a relationship occurs as a dynamic process. Two of the nurses interviewed described how the development and maintenance of trust in a relationship was ongoing. Nurse Siu described that trust could be lost by failing to do what you have indicated you would do. Nurse Maoki acknowledged that if she had lost the patient's trust in this way, she would have to work hard to regain it.

The case of the patient, Jenny, illustrated how dynamic the development of trust is in health care relationships, and how trust influences involvement in making decisions. In Jenny's earlier experience with her health care professionals, at the point of her diagnosis, her trust in her doctor was absolute. Jenny said she just went along with their suggestions, believing that answers to her problems would be forthcoming. As Jenny's condition deteriorated and she found out more about her disease, she became more distrustful that their answers would provide her with the improvements they had promised. This loss of trust led her to turn away from the treatment options they offered; her sense of control changed and she felt less involved. She reconstructed her trust and relationships with health professionals by exercising more control over her involvement in decisions and the decisions themselves, on a more informed basis, and was more guarded in the health care to which she would agree. What reaffirmed her trust in health professionals was when her general practitioner listened to her when she explained the issues with her illness, acknowledged her experience and made open attempts to present her with options and then trusted her enough to allow her to make a decision.

Jenny's later experience of how her trust in her health professionals, who respected her opinions and asked her about her wishes, facilitated a greater perception of involvement in making decisions, was similar to the experience of Barbara discussed above. Barbara felt her previous doctor had not listened to her and therefore she did not trust his advice. Earlier in the interview she had explained her preference for the "... *real* ..." (Patient Barbara 3~1, Section 1.8, Paragraph 21) relationship she enjoyed with her current care providers where she listened to their advice and they listened to what she wanted from her life.

In summary, trust developed in a relationship between health care professionals and patients when health care professionals demonstrated to patients in their approach that they cared, they listened and understood patients' circumstances. However, the development of trusting rapport between patients and health professionals was also affected by the organisations that governed the work practices of health professionals. The work place culture of some health care organisations did not encourage the activities that health professionals needed to undertake to demonstrate their trustworthiness to patients. This is described in greater detail below.

Culture of the Health Care Organisation

In this study, involvement in the making of decisions was dependent on the relationships that developed between patients and health professionals. The way that relationships developed was dependent on patients' perceptions of the health professionals' manner and focus on them. A further influence on the ability of patients to develop a rapport that facilitated involvement in decisions was the culture of the organisation in which the health professional worked and within which patients received care. The term 'culture' is defined in sociological terms as "the sum total of ways of living built up by a group of human beings, which is transmitted from one generation to another" (Delbridge, 1986, p.146). In this study, the culture of a health care organisation was found to consist of the rules and regulations, both written and unwritten, that influenced the work practices of health professionals. Patients, families and health professionals identified the culture of the health care organisations as particular decision making environments that facilitated their involvement or militated against it by the way in which health professionals approached decision making. This approach was related to the general attitudes of health professionals, towards involving patients in decision making by taking time to listen to them, working collaboratively and making decisions that might have been considered unusual.

Many patients interviewed and observed in this study, despite their preference for other decision roles, were found to have adjusted their own behaviour to fit the culture of the health care service in which they were admitted. For example, in busy environments discussed earlier, where staff appeared not to have time to talk to patients, the patients and their families spoke in general about their inability to ask questions because of the busyness of the staff (Patient Harry, Family Bob). These busy environments were often the acute hospitals where patients had undergone diagnostic procedures and treatment for their disease. Participants often contrasted the environment of acute hospitals with the palliative care environment.

Betty and her husband compared their experiences of the culture in an acute hospital with the decision making culture of the palliative care unit where they were encouraged to discuss their prognosis and future health care needs, "*My husband and I could discuss many interesting things. Our lives had changed. The health care professionals attitudes are very important. It supports us in how to live and how to die*"

(Family Betty). Their perception was that they had been given permission in the palliative care culture, to converse freely about life and death and then could be more involved in making decisions.

One of the nurses interviewed acknowledged that different workplace environments encouraged staff and patients to work together in decision making. Nurse Justine's analysis of her team's collaborative approach highlights that other work environments do not practice decision making the same way, *"This type of teamwork improves job satisfaction. It is collaborative ... [I've] never worked anywhere else so collaborative. That is probably why I stayed so long [3 years]"* (Nurse Justine).

One of the nurses interviewed was explicit in her description of how her everyday decision making changed in different working environments, altering her ability to involve patients in decision making:

When I worked in the general ward, there was a routine. They had set times. So I didn't ask the patient what time they want to take their bath. It was because of the environment, the working environment. I didn't have the chance to ask the patient. (Nurse Samantha)

Health professionals identified that in certain work environments there was no time or encouragement for activities that might influence patients' perceptions of health professionals' manner and focus: by spending time talking about non-treatment related issues in the patients' lives and discussing issues about decisions that were not directly related to professional roles.

Patients were encouraged to be involved in decisions when a connected rapport developed between them and their health care professionals. A connected rapport was more likely to develop when the patients liked the manner of the health professionals and trusted them, and when the culture of the organisation facilitated the health professionals' focus on each patient as individuals. Conversely, patients felt they were excluded from the making of decisions when this type of relationship did not develop.

Often in circumstances where patients did not like or trust health professionals and did not believe the health professionals were interested or focused on them, they also struggled to access information that was critical to their involvement in decisions about their care. In an organisational culture where work practices ensured that health

professionals were not encouraged to develop this type of connection with patients, patients were less likely to develop rapport with any health professional and therefore less likely to gain information that was critical to their involvement in making decisions.

Information Possession

Patients and family members who experienced a lack of involvement in decisions stated that they were unable to access information or explanations about their disease process, their treatment or their response to treatment. In a busy ward where Harry, a patient, already felt excluded from decisions, he was left feeling totally disempowered when he could also not obtain information about decisions health professionals were making, *“No one would make a decision ... and so I was just parked ... I went there for 6 hours and stayed there 8 days, and all the time I was starved of information”* (Patient Harry).

It was suggested that sometimes health care professionals controlled decisions by withholding information. One of the nurses suggested that health professionals achieved this by just *“avoiding”* discussing information that might be pertinent to decisions. She acknowledged this practice in an example where she did not want to answer a man’s questions about his wife’s medications. The patient’s husband was trying to determine the goals in his wife’s care and was concerned about the doses of analgesics being used and, without relevant information remained unable to make decisions about his wife’s care. However, because the nurse was unsure why the man wanted the information and felt professionally threatened by how he might use that information, the nurse used a technique to avoid giving information:

... my technique would be to just answer what the question was, don’t say more, don’t say less ... you sort of stay on the surface of the issue. You don’t really work with the relatives ... You don’t really work with the patient. (Nurse Riki)

Some of the participants talked about the routine practice of avoiding the discussion of information that is considered potentially harmful. This information was said to be difficult to communicate, particularly when patients were being informed of their disease and prognosis. The participants from Japan explained that health care professionals in acute health care institutions believed that patients’ families should take responsibility for decision making. Patients were often given only a sanitised version of

information about their disease and prognosis, in a well-intentioned effort to protect them from the harm of bad news. One of these participants, Betty, was interviewed some months after the death of her husband. She described him as a strongly independent decision maker and yet when he was diagnosed, he was not given information about the extent of his disease. Betty explained that after his diagnostic surgery, the doctor talked to her first and then her husband:

I listened first and then my husband and I listened. But my husband heard about the diagnosis. So he heard about the cancer and the need to have an operation but he didn't hear about the stage, as nearly terminal, but he needed to know all of these things because he is [a] person who will decide by himself ... the doctor didn't come back to tell him the details. (Family Betty)

Being denied some of the information regarding his condition left Betty's husband confused about his failure to get well and created an ongoing conspiracy of misinformation between him, Betty and the health care professionals. Betty and her husband were both powerless to affect this situation. Betty felt burdened with decisions she did not believe she had a right to make and her husband was excluded from decisions by a lack of accurate information. She explained how his inaccurate perception of his situation affected his decision making:

My husband believed he would recover soon after the operation. He didn't think his illness was so severe. So he said to me "don't tell my parents about this". I needed to discuss it with my husband but I wasn't sure about his understanding. (Family Betty)

The uncomfortable alliance between family and health professionals formed to avoid disclosure of particular information to patients served to prevent open discussion between patients, family members and health professionals about personal issues that would have led to a better understanding about the patient's desire for involvement in decision making.

Another patient illustrated, in contrast, how having information facilitated patients' involvement in decision making to ensure that their interests were being looked after. Apart from her original decision to stop chemotherapy, Jenny often commented that though she was not making decisions, she was comfortable with the decisions being made because she had discussed it with the health professional, had determined that they understood her particular needs and she understood all the

information. Giving an example involving a home visit by an occupational therapist, Jenny elaborated:

... she went to the house ... told [husband] where rails should go and ... gave them a few suggestions. And then she came in and saw me, ... gave me some sheets of paper to tell me how much things are ... that they've got to be virtually, or just about set in place by the time I get home ... But there was no decision making on my part either with that one ... because she went out to the house... she knows what she's talking about ... I think that I don't need to be in that decision making. (Patient Jenny)

Patients' sense of involvement in decisions arose from believing that they had been given the critical information relevant to the decisions they made and that they understood that information. There were two types of information critical to patient involvement in making decisions. Firstly, professional opinion, which provided patients with information needed to make decisions about treatment options. Secondly, background information was critical to broader decisions about how patients shaped their remaining life and decisions about care options.

Professional Opinion

For some decisions the information that was critical to patients was based upon professional opinion. The example cited above, of Jenny's confidence in the occupational therapist's advice about home mobility aids, reflected Jenny's reliance on the professional's opinion. When the occupational therapist explained her opinion about physical changes to Jenny's home, Jenny felt sufficiently involved in the decisions about those changes. When health professionals advised patients of treatment options, their opinions were also important to patients. Both Jenny and Wayne talked about situations in which doctors gave their opinions about what they considered to be unsuitable treatment options. Wayne's son John noted that the neurosurgeon advising against surgery to treat his father's spinal chord compression had given his opinion about treatment options, but also explained the background and reasons for his opinion:

... what he actually said was that ... if your Dad progressed to paralysis over the next few days, then we would seriously have to consider that ... but it was a very difficult technical operation, there was no guarantee ... there was bony secondaries in the vertebrae either side ... He was very clear and he brought ... the M.R.I. scans and we had a look ... he was very open and honest and forthright in saying that (Patient Wayne)

In circumstances where trusted health care professionals gave their opinion and the explanation of their opinion about treatment options, even when the discussion had no impact on the course of action taken, patients were often satisfied with not being in control of decision making. Possessing sufficient information regarding the professionals' opinions was also sufficient involvement in making particular decisions. Patients felt they had been involved in decisions because of the conversations they had had with the health care professionals about the professionals' opinions. Sandra explained: *"I have a very good doctor, I am very fond of her, and I am able to discuss ... what are the consequences of doing this or what are the consequences of doing that"* (Family Sandra).

Background Information

The other type of information that was critical to decision making related to professionals giving broader explanation about the background of disease processes, treatment processes, progress reports and resources. This type of information was critical to decisions about the location of patient care, services required and activities of daily living. These decisions naturally required some involvement of patients, because the decisions were made after synthesis of a collection of information, some provided by the patient to the health care professional in the form of their personal circumstances and desires as well as information provided by health professionals in response to the patient's questions. One example came from the counsellor Anna, who explained that giving information about financial and social options helped a patient feel secure in the decisions she was making: *"... I needed to talk with the patient many times until she felt supported in her decision ... She asked me many things and I gave her lots of information so she could decide many things by herself ..."* (Counsellor Anna).

Family meetings were also used as forums for gathering information used in decisions about the way patients would be cared for. In one family meeting, the social worker was able to explain resources, the doctor and nurse identified care requirements, family members identified what had happened in the past and the patient was able to say what she wanted. Multiple decisions about financial and personal resources, the need for special equipment contingency plans were resolved at this meeting in which the patient acknowledged she had been involved positively (Team Observations).

Although information was essential to patients feeling that they were involved in the making of decisions, patients were dependent on the ability and willingness of health professionals to provide information to them. Two types of information have been identified in the data as critical to decisions. Thorough explanation of professional opinion facilitated involvement in decisions about treatment options and background information about aspects of disease and treatment processes and resources facilitated involvement in decisions regarding remaining life and care options. Because decisions about the way that they shaped their remaining time and care options rarely impacted only on patients and health professionals, patient involvement in this latter category of decisions was also influenced by family relationships.

Family Relationships

A further influence on how involved patients were in making decisions about their care was their relationships with members of their family. Power differences between individuals were often long established through entrenched patterns of behaviour within a family. For example, a relative told how he and his wife had always behaved in relation to the patient's approach to making decisions. When asked if he contributed to particular decisions regarding his wife's care, Bob said, "*... it was her choice. I always left it at her choice. I said, well I'm not going to make a decision for you. Because she's very, very independent and bloody minded and single minded ...*" (Family Bob re Patient Jenny).

Likewise, another relative spoke of her enduring frustration at her mother's unwillingness to involve her in making decisions about her health and care options. Linda acknowledged her mother as a "*... private person ...*" (Family Linda re Joan) who would not normally share information with her and that this had not changed during her mother's illness. However, it was observed that Linda's mother, Joan, was not reluctant to share information with other people, particularly Joan's trusted doctors. She also volunteered to participate in this study, which involved sharing very personal information with a stranger. Linda's observation that her mother was a 'private person' was a reflection of how Linda was treated by her mother in their relationship, rather than a reflection on Joan's personality. Joan had a particular way of engaging in decisions about her health that excluded her daughter, and this pattern of behaviour endured throughout her terminal illness.

The structure of Joan's family, particularly her relationship with her daughter Linda, appeared to have a major influence on how Joan made decisions. When Linda bought her house twenty years ago, in the same district as her mother, her plan was that her mother would eventually come to live with her. Linda said it had taken her twenty years to realise that her mother had no intention of moving in to her house. Joan too stated that she was never happier than in her own home. The structure of the family and the relationship between the patient and the daughter influenced how the patient was involved in decision making.

In a different family, Wayne explained how each member had a particular role in making decisions relevant to family members. His son John had always been the one to take control in family emergencies where his father was not available. He contrasted John's role in the family with another son, who was also very concerned and committed to the family, but who did not cope with decision making in these complex situations. In the interview after Wayne's death, John explained that his brother, *"... used to get dad agitated as well, when he tried to do stuff. And you know, he admitted it and he knows he's just not a practical sort of [person] and he just gets in a flap and dad would be worse and it would be a vicious circle ..."* (Family John re Patient Wayne). In this family, as he became more ill, Wayne was observed to gradually hand over decisions to John. Wayne's description of his family indicated that involvement in making decisions was influenced by recognition of individual strengths and traditional roles.

Similarly to Wayne's family Campbell identified his daughter as the family member who assisted him with making decisions. In his interview, he and his daughter identified her role as including *"... ensuring that he has information, understands it and considers all his needs, she keeps the rest of the family informed ..."* (Patient Campbell and Daughter).

Although these examples demonstrate long held family relationships where decision roles are understood by family members and respected, there were two types of situations where issues were created by these roles. The first to be described relates to the effect of cultural expectations of family roles in health care decision making, and the second relates to families where there are relationships that result in conflict.

Family and Culture

It was expected that culture would influence the decision making processes of participants interviewed in Japan. However, whilst there were some differences in palliative care practices, the focus on family and patient involvement in palliative care and the attention given to patient choice appeared similar to palliative care in Australia. In this study, culture refers to the particular ways of living of a group of people (Delbridge, 1986, p.146). One of the cultural traditions related to health care decision making in Japan discussed by participants was the responsibility of the family to assist the doctor with making decisions, particularly in the acute phase of illness. This was highlighted in the explanation given about how patients are referred to the hospice unit, *“The doctor refers the patient to this hospital because he or she can’t control the symptoms, then the family decides whether they will take the patient [to hospital] or not”* (Nurse Cathy). Doctor Sam explained the reason he believed families take responsibility for making decisions around the diagnostic phase of the patients illness in Japan:

It is historical that families make decisions for the patient ... I think it is gradually changing. The doctors think that the family know the patient very well. If the doctor tells the patient first, may be the family might doubt the doctor. They might think why that? Family pressure is very strong. If the doctor and the family are saying the same thing to the patient, they won’t get confused, they are more likely to feel it is ok. [i.e. It adds security for the patient]. (Doctor Sam)

In this explanation, Doctor Sam implies that the health professional and family presenting a united front to patients are in the patients’ best interests. The implied subtle coercion of doctor and family pressure was necessary to ensure patient compliance. However, Nurse Cathy’s explanation of how families are involved in decisions about the physical needs of palliative care patients suggests that health care professionals in palliative care negotiated an agreement between patients and their family members:

If for example the patient can’t eat, he might need to use an IV [Intravenous] drip and the patient says, ‘I don’t want an IV drip’. Next the staff need to explain to the family that he can’t eat and he doesn’t want to use an IV drip. So, we won’t use an IV drip, is that OK? We need to ask the family. The family may agree but also may not agree. If so, we need to explain again or we need to tell the patient again ... what they will do? (Nurse Cathy)

This type of negotiated agreement between patient and family members was also observed outside of Japan. Family meetings identified earlier as a forum for sharing information were also used to negotiate decisions while encouraging involvement of all parties.

However, cultural expectations that family members will be responsible for making health care decisions can make patient involvement in decisions, for those individuals who wish to be more independent, a difficult experience. While in a general hospital in Japan, one patient described her difficulty in getting diagnostic information without inviting her family to the consultation, *“I heard my own diagnosis by myself but at the time the doctor said ‘you shouldn’t do that - you shouldn’t listen to the diagnosis by yourself. You should come with your family’”* (Patient Louise). Though she was able to exercise her preferred decision role of making decisions after listening to her doctor, her perception was that the doctor had tried to exclude her from decisions because he believed her decision making was a family responsibility. In trying to convince her not to make decisions on her own, she felt abandoned by the medical team at the hospital. They further undermined her desire for involvement in decision making by not understanding her preference for making decisions herself.

Family Conflict

Although in some families the established roles of members resulted in patients being confident about their involvement in making decisions, family members who wanted control in decision making sometimes prompted conflict. In other families, these roles, often traditionally resulting in conflict were a source of further family conflict when care decisions were being made. Family conflict contributed to distancing the patient from making decisions.

Arguments between health care professionals and family members were sometimes based on differences in perspectives of best care option for the patient. Some family members clearly described attempts to take control of decisions by arguing with health care professionals and demanding changes in treatment (Patient Morris Observations, Patient Joan Observations).

Family members in conflict with health professionals were sometimes able to recognise that their attempt to take control of decision making was because they

disagreed with the patient's wishes. Linda's mother Joan was fiercely independent and was recognised by staff as needing to be in control of decisions. Despite Linda disagreeing with decisions made about her mother's care, she was able to acknowledge that her mother was in control. Regarding the decision to send her mother home, she explained, "[T]hat is probably the only decision they've made I've disagreed with ... I know my mum ... I think that was Mum's decision and they had to go along with it ... if mum is determined to go home, then they can't keep her there" (Family Linda re Patient Joan). However, other family members attempted to take control of decisions because they knew the patient was unable to and because the health professional's decision making did not appear to consider what the relative knew the patient would want. From this viewpoint, some family members would argue with health care professionals and demand changes to treatment plans.

For example, at the time of patient Wayne's diagnosis, because he was particularly unwell and unable to participate in making decisions, his son John was his acknowledged surrogate in making decisions. Wayne nodded in agreement when John described an episode in hospital where a doctor proposed to send his father home without investigation of his severe and unresolved back pain. This decision was reversed when John argued heavily with medical staff about further tests to ascertain the cause of his father's pain (Patient Wayne). John was successful in ensuring his admission to hospital, but needed to argue again with a consultant for further tests to ensure the reason for his father's pain because, "... he [the consultant] wasn't planning to do anything" (Patient Wayne). Arguing with the consultant did convince the consultant of Wayne's concerns and further investigations were done. After the argument, John described the decision making in more confident terms; "... then things sort of finally swung into action, that consultant was really good. She was a really nice person ... said we do need to do these investigations and [to] find out ..." (Patient Wayne).

Many patients in this study, at some stage during their illness required family members to make compromises in their own lives to ensure patients' wishes were fulfilled. Some families, for example in Wayne and Campbell's families, had established patterns of behaving that enabled successful negotiation of care needs and care provisions. However, in other families the patterns of behaviour resulted in

widespread argument and conflict that further excluded patients from the health care decisions being made.

Morris's family demonstrated the endurance of these relationship and behaviour patterns of conflict in the way his health care decisions were made. Morris identified his wife as determined in the decisions she made regarding herself and Morris, "*She's terrible headstrong, the wife, and she'll, once she makes her mind up, that door's shut, and it's bloody not*" (Patient Morris).

Over the time of their marriage, in situations when Morris was incapacitated his wife's determination ensured he received the care he would have decided for himself. Morris described a situation where he had been most unwell and whilst staff wanted to observe his condition over the following 24 hours, Morris' wife insisted that interventions be undertaken to make him more comfortable. Morris considered it was his wife who, by advocating for him, had saved his life. Although Morris described his wife as acting as his advocate in supporting his decisions when he was unable, he also gave examples of his wife engaging in decision activities that were inconsistent with his wishes. Most of the time, Morris indicated that he kept the peace by acquiescing to her wishes. However, on occasions when he had insisted on having his way, they had argued and the dispute would have negative effects on the relationship for a couple of months.

This pattern of decision making endured throughout Morris' terminal illness when he became physically and emotionally less able to influence decision outcomes despite making his wishes clear. Morris was conscious that his wife had sold their house and he wanted to be there again before the sale was completed. Morris' wife refused to change her lifestyle to accommodate his care needs and kept presenting potential problems associated with him being at home. She did not engage in problem solving with Morris or the staff. Further family tension was obvious as others were involved to try to resolve the situation. Though Morris managed to negotiate a short day at home, he had returned to the palliative care unit where his condition deteriorated as he waited for discharge and he did not return home again before he died.

The lack of family cohesiveness was also identified as influencing the way relationships with staff developed and put constraints on the way information was shared, affecting how staff were able to encourage Morris' involvement in decision

making. Morris had remained unable to control his health care decision making in the face of his wife, determined to limit his involvement. The pattern of this relationship endured throughout his illness and despite attempts by staff to foster his involvement in making decisions, his perception of lack of involvement control endured. In a ward meeting following Morris' death Doctor James noted that normal bereavement follow up would be offered but there was no expectation that it would fix the rest of the family problems (Patient Morris Observations).

As identified previously, families and health professionals in Japan formed an (often uncomfortable) alliance to withhold information from patients according to cultural demands in Japan. In Australia, alliances between families and health professionals also occurred, sometimes in response to longstanding patterns of family behaviour. In the example above when Morris wanted to go home, his potential discharge was discussed with his wife. For reasons of her own, she did not want him to go home and each time health care professionals tried to convince her that he could go home, by offering support systems, Morris' wife would argue against it. She asked to speak to the doctor away from Morris and made an agreement with the doctor outside; “[His wife] *did not want to say in front of [Morris] that she was not willing to take him home (permanently) as she couldn't manage him. ... They then entered the room ...*” (Patient Morris Observations) and presented a united opinion to Morris that he should only go home for day leave.

The observations of team meetings often revealed the concerns of health care professionals over whether the demands of family members were congruent with the patients' wishes. In one situation, the team meeting discussed a man whose family were located in Germany and only aware that he was ill, but not that he was dying. He was unable to verbalise his wishes. However, his wife argued that the relatives should not be informed, as they couldn't, “... *communicate with each other and it will be too difficult for them to come and stay with her ...*” (Team Observations). In another situation the family members were in conflict with each other, some wanting the patient sedated and others preferring the patient awake. In the absence of clear medical answers to whether the patient needed sedation clinically and knowledge of the patient's preference, the staff tried to be advised as to what the patient might have wanted by the family but there was conflict in their opinion (Team Observations). Family conflict resulted in another situation where a previous family meeting decision that active treatment would be

withdrawn, was in question. The observations of the team discussion indicated, “... *Family are now targeting staff about a number of issues, including active treatment ...*” (Team Observations).

In situations of family conflict, the demands of family members influenced the exclusion of the patient from making decisions about their care. One health care professional explained that “... *the person who has the strongest voice, the most sway ...*” (Nurse Sui) in decision making might be a relative, even when the patient is able to be involved in decisions, because the health care professional “... *gets a bit of pressure put on them from family members ...*” (Nurse Sui).

Although the life patterns of family structures, conflict and culture influenced the making of decisions in some circumstances, particularly for family members, other personal characteristics were responsible for the patterns of behaviour that influenced the ability of patients to affect their concerns about being involved in decision making.

Personal Characteristics

A further condition affecting the patients’ involvement in palliative care decisions were certain personal characteristics. The Macquarie Dictionary defines a ‘characteristic’ as a “distinguishing feature or quality” (Delbridge, 1986, p.94). In this study, personal characteristics refer to the unique features of individual patients and their circumstances. Patients’ preferred decision role, past experience, interpersonal style and level of dependence were four personal factors that affected how patients experienced and responded to their involvement in making decisions about their care.

Decision Role Preference

In the design of this study participants were asked about their preferred role in making decisions using the Decision Role Card Sort (Degner & Sloan, 1992) described in Chapter 2. The data about desired roles in the making of decisions demonstrated one of the conditions that affected the way that patients responded to their concern about their involvement in decisions made and about the health care professionals who were involved in their care (Table 4.1). A further breakdown of the decision role preference of patients related to their age appears in Table 4.2.

Table 4.1:
Preferred Decision Role

	A	B	C	D	E	A or B	A or C	B or C	C or D	A,B or C	Any	Total Respon dents
Patient (16)		7	5	3	1							16
Family (8)		2							1			3
Health Professional (24)		4	8			1	1	2		1	2	19
Total	0	13	13	3	1	1	1	2	1	1	2	38

Key: A = Patient's decision (Active), B = Patient's decision with health professional's advice (Active), C = Patient's and health professional's decision (Collaborative), D = Health Professional's decision with patient's advice (Passive), E = Health professional's decision (Passive).

Table 4.2
Patients' Age and Preferred Decision Role

	A	B	C	D	E	Total Patients
20-40 years			1		1	2
41-50 years			2			2
51-60 years		1	1			2
61-70 years		1	1			2
70-80 years		4		2		6
80 + years		1		1		2
Patients (16)	0	7	5	3	1	16

Key: A = Patient's decision (Active), B = Patient's decision with health professional's advice (Active), C = Patient's and health professional's decision (Collaborative), D = Health Professional's decision with patient's advice (Passive), E = Health professional's decision (Passive).

Although the Decision Role Card Sort was not used to measure the systematic variations in decision making roles, it was used as a discussion prompt to clarify variations in decision involvement. The clustering of responses preferring decision roles B, C and D have in common the participation in the decision process by both the patient and health care professionals. No conclusions regarding the trend of particular age groups and preference to decision roles could be drawn and this was not the intent of the cards in this study. However, it was of interest to note that no patients preferred to make decisions independently and only one patient, aged 28 years, preferred health professionals to make decisions for him.

Despite the similarities in decision role preference, even subtle differences between patients and health professionals in their preferred decision role were found to

have affected how each was able to carry out that role. Dissonance between individuals' preferred decision roles made it difficult for one or the other of the parties to act in the role they preferred. For patients, this dissonance influenced the way that they responded to their desire to be involved in the making of decisions. The clearest example of this was the case of Harry, who had a preference for making decisions after listening to the advice of his health professionals (Role Preference B). Harry's health professionals, particularly his doctor (Doctor James) had a preference for making decisions collaboratively with patients (Role Preference C). Doctor James found it difficult to get to know Harry and his needs and therefore to advise him about his needs, because Harry felt no need to tell Doctor James about his personal life. Harry's preference for making his decisions more independently influenced the way he responded to his perception of involvement in making decisions. If he did not feel involved in decisions being made, he withheld information about his personal circumstances, which meant only he could make decisions that affected these circumstances. Although Doctor James had approached Harry in a manner and with some information that had made Harry feel more involved in making decisions, Harry's lack of desire to collaborate in decisions meant that he missed out on further information about the future that may have influenced his decisions.

The problem of dissonance in decision role preferences is compounded when the advice of the health professional is contrary to other opinion, whether this be another health professional, the patients' or a family member's opinion. The situation between Joan and her community nurses demonstrated this dissonance following the decision to remove medication from her home, a decision made independently of Joan, when it was Joan's decision role preference to collaborate (Patient Joan). Later, Joan resisted any attempts to develop a better rapport with the nurses by avoiding answering questions directly when a nurse tried to engage her in conversation during care (Patient Joan).

There were a few instances where patients resisted attempts by health professionals to engage in collaborative decision making roles. However, more often patients and family described their health professionals as expecting that the patient would passively follow their advice without question. This is a role more in line with role preference E. In these circumstances, patients often felt that their preference was irrelevant, so they just followed the health professional's advice, though they remained unhappy with their level of involvement in the decisions made (Family Bob re Patient

Jenny, Family Sonia, Family Betty, Patient Wayne, Family Joe). Most of these circumstances were described in retrospect of their current care, describing events that occurred with previous illnesses or earlier in the diagnosis and treatment. These past experiences with a perception of a lack of involvement in making decisions influenced the way they chose to work with health professionals in their palliative care environment.

Past Experience

A number of patients were also asked about their preferred decision roles prior to their current illness. Four of the eight patients asked this question indicated they had changed from a more independent (Role Preference A) or dependent role (Role Preference E) to a more collaborative role (Role Preference C), since being in palliative care. Two other patients had changed their preferred decision role from a more active one, to a more dependent role. The remaining two patients had not changed their preferred decision making role since entering palliative care, but they both preferred roles where they participated in making decisions.

When patients discussed their past experiences with decision making, they often referred to situations where they had non-life threatening illnesses or when they were first diagnosed and treated for their current illness. Health care professionals often referred to their prior work in acute care environments. They contrasted these experiences with their current situation with palliative care decisions. When goals of care are to cure the patient of a disease and return them to their former health, a focus on the disease, and less so on the person with the disease, was an approach often experienced by patients. These patients sought advice from health professionals, often expert in their disease, which would lead to their cure. Patients had no reason to expect that if the professional had known their personal circumstances, their expert advice would have changed, as there was little attempt by the expert to develop a relationship with patients where that type of information would be exchanged. Having approached the expert for advice, the expert assumed the patient would take their advice and the patient has no reason not to. A preference for patients to be somewhat passive in the decision making process (Role Preference E) in these circumstances seemed on the surface to be logical, and was common in the past experience of health professionals, particularly the doctors. However, the patient Barbara, clearly linked her preference for

a collaborative decision making role (Role Preference C) with her past experiences of health care professional decision making when she was given no options for curative treatment (Patient Barbara).

When patients have a life-threatening illness, the changes to their lives and the lives of their families may be substantial. Every decision they make is in the light of many complex and personal contextual factors. When decisions about limited treatment options occurred in acute care environments, there was evidence that patients were frustrated that they were not involved in decisions that were being made by health professionals without any understanding of their personal context. The reaction to this frustration was often passive refusal to cooperate in decisions or in the outcomes of decisions they did not like. For example, on some occasions, Sandra's husband, who was unable to communicate verbally, would become lethargic and uncooperative when health professionals failed to involve him in decisions. However, when these decisions were contrary to what he wanted, he would be angry in trying to ensure these decisions were reversed (Family Sandra). Another patient, overwhelmed by the number of health professionals telling him what to do pulled the bed-covers over his head and refused to talk to any body (Team Observations). In these examples, there was no evidence that their past poor experiences of lack of involvement in making decisions resulted in changes in the ways that patients approached their involvement in subsequent decisions with other health professionals as these patients maintained their desire to be involved.

With a few participants, illustrated by Harry's case (Patient Harry), his decision making role preference and his decision making behaviour had endured despite the changes in his health professionals and their preferred roles in decision making, once he became involved in palliative care. Although he stated that he had always been independent in making health care decisions, he also said he would listen to a health professional's advice before making a decision (Role Preference B). However, concerns expressed by health professionals in his latter care indicated that he did not seek or agree with advice given. Whether this behaviour was in response to his negative experiences with lack of involvement in decisions being made earlier in his treatment at the same health organisation was not clear.

In the patient Joan's situation, her previous experiences with the community nurses did affect the way Joan managed her involvement in subsequent decisions made

with community nurses. Initially, some of the community nurses did not consult her before they advised her daughter to remove medications from her home and before they advised against her discharge because of a perceived safety risk with her animals. In subsequent decisions with community nurses, Joan was very particular about being in control of decisions even against the nurses' advice (Patient Joan Observations). When the nurses felt she needed multiple visits per week, Joan refused. She explained, "*She wanted to come in 2 or 3 times and I said no thank you. Once a week will be enough*" (Patient Joan).

Many patients were affected by their past experiences with lack of involvement in health decision making in a way that affected their response to their decision making in palliative care. Some patients however, approached each decision making experience with similar preparedness to be involved. Although they experienced frustration if their involvement was not encouraged, they still sought involvement with other health care professionals. However, sometimes patient involvement in the making of health care decisions in palliative care was also affected by their style of interacting with others.

Interpersonal Style

The life patterns of behaviour associated with how people interact with others also influenced the way that participants responded to their issues with making health care decisions. Interpersonal style is defined in this study as the aspects of personality that are related to social interactions. Patients' interpersonal style involves their behaviours towards others involved in making decisions about their care.

It is difficult to determine whether Harry had ever behaved differently toward health professionals and his family. At 43 years old and with a six-year history of treatment for bowel cancer and a complex history of family diagnoses of cancer and bereavement, Harry's assertion that he had always been an independent decision maker was difficult to challenge. With long hair and beard, abrupt manner and his complaints about hospital services, Harry could easily have been perceived as an angry man. Harry was described in the team meeting as an "*independent character*" (Patient Harry) and staff acknowledged that he was difficult to get to know. Joan was also described as having an independent character that made it difficult for staff to understand what would influence her decisions that they needed to inform her about. As a consequence, a

number of staff had made her angry by the way that they had approached decisions and she reacted by ignoring their advice (Patient Joan).

The personal style of some people were indicated to have made them difficult to get to know, difficult to get close to; so not only did their personality influence the way that they responded to the need to make decisions but their interpersonal style influenced the way that others responded to making decisions with them. One patient was described in a team meeting as withdrawn and not complying with treatment. Nevertheless, Doctor Thomas explained that though this patient was difficult to get to know, he was not depressed. Doctor Thomas said that patients like this young man would not get good palliative care, because it was difficult to have full discussions with them and they would be more likely to make decisions that were not in their interests.

Another patient who had a personal style that made him difficult to engage in decision making with was Conrad. To the staff caring for this patient, his physical appearance due to his nasopharyngeal tumour, particularly when he ate was unpleasant. His social habits were also perceived to be strange. Nurse Sui explained these issues from the perspective of many of the staff:

... whenever he ate anything it came back up out through his nose and into his bowl of soup. [Conrad] wasn't terribly well liked by the nursing staff ... he was up and about looking after himself, he washed his dishes in the sink (Nurse Sui).

Personality and personal style sometimes enabled patients to endure the lack of control they had over their lives and their care decisions. Nurse Maoki described a situation where a patient was forgotten, outside in her bed during a thunderstorm but was not angry and laughed with the nursing staff over her predicament:

I was doing an afternoon shift ... We [the nursing staff] sat opened to the tea room because we wanted to see the lightening and how fantastic it was ... She wasn't my patient but ... she's stuck in her bed unable to move herself with only a brass tinkle bell ... She was drenched ringing that bell ... we can't hear [the bell] because of the thunder ... I'm sure she's somewhere laughing with us ... [it] was pretty funny. I just think it was in her personality. She would have laughed anyway (Nurse Maoki)

Although life patterns of interpersonal style and family structures influenced decision making processes in some circumstances, sometimes these long held patterns of behaviour changed for the patient faced with a terminal illness and engaged in

palliative care decision processes. Many participants altered their preference for particular decision roles in response to their level of dependence.

Level of Dependence

The term dependence refers to “a state of relying on another for love, affection, mothering, comfort, security, food, warmth, shelter, protection and the like” (O'Toole, 1992, p.401). In this study level of dependence refers to the effect of illness on patients' physical and mental capacity. The patients' illness and mental state were found to influence their ability to be involved in activities that addressed their involvement in making decisions about their care. A number of health care professionals, patients and family members acknowledged that on some occasions, patients were too sick to make decisions, or be involved in decisions. Jenny had wanted to be at home for Mother's day, but when her pain was exacerbated her hospital stay was prolonged. When asked whether the decision to remain in hospital was a difficult one, she explained she did not think that decision was a hard one because:

... when you are in pain, you don't control decision making. You just go to those who can help and tell them to 'do what you have to do to fix me'. You are not in that state of mind [for making decisions] when you are in that much pain.
(Patient Jenny)

Jenny's husband Bob, described Jenny' state of mind in a medical consultation, where the doctor made decisions with which they just agreed, “*You're pretty crook, you're tired, sleepy ... not with it ... probably not in a position to make a decision*” (Family Bob re Patient Jenny).

Confusion and physical disability made it increasingly difficult for another patient, Morris, to remain actively involved in decisions, to assert his wishes when his wife did not want him to go home. The field observations noted his shaking hand and his slight confusion. He found it difficult to remain focused on the discussion about his return home while his hand was shaking and kept introducing other problems such as his ill fitting denture. Eventually his doctor stated to staff that because of Morris's physical and mental inability to be involved in the debate with his wife about his return home, going home became less possible (Patient Morris Observations).

As a patient's condition deteriorates, he or she also often becomes more easily fatigued. As his father's disease process progressed John said that his father "... *just doesn't have the energy now, to get involved ...*" (Patient Wayne and Family John) in making decisions about his care.

All of the health care professionals who were asked about the influence of the patients' stage of illness on their decision making behaviour, indicated that they thought that patients were more dependent on the health care professionals when they were sicker. Many of the patients also indicated that health care professionals had to make decisions for them when they were sick. One example was clearly articulated by Doug who acknowledged that he collaborated in decision making when he was able but when, "*he is really sick ... then the Doctor has to make the decision ...*" (Patient Doug).

There was substantial evidence to suggest that patients expected that when they became too physically unwell, or mentally unable to be involved in making decisions, that the health care professionals they had got to know, as well as their relatives, would make decisions in a way that the patients would have made them, had they been able. Martha, indicated that, "... *it isn't right that health care professionals made all the decisions and if they were, they should know you really well and be making the decisions as if you were ...*" (Patient Martha). Another patient believed it was important that health care professionals encouraged family discussions in order that family members would understand her wishes:

When I am well, I want to decide myself. I want to discuss my decision with the doctors; I want to share their opinion. As well, I want to share my decision with my family before I become unwell. And they want to discuss how I will die. It becomes my decision [So they know my decision]. Also so the family can understand my decision. (Patient Barbara)

Campbell was an elderly man easily overwhelmed by health care environments. He relied heavily on his daughter to ensure that his care needs were met at home and in hospital. His daughter believed that, "... *trying to understand what her dad would want in particular circumstances*" (Patient Campbell and Daughter) was her particular responsibility.

However, other patients' families did not feel the same burden of this responsibility. In a situation noted earlier, the field notes indicated considerable concern

expressed by health care professionals at a team meeting when an unconscious patient's wife decided not to phone her husband's family in Germany. His wife was of a different ethnic background and believed that if her husband's family wanted to visit him, it would be difficult for her and them to understand each other. It was suggested by one of the doctors that some investigation was required to determine the patient's past expressed wishes in this matter (Team Observations).

In this situation and in others, the health care professionals involved believed they had a responsibility to determine and action patients' wishes when the patients were unable, because of their level of dependence, to express these wishes themselves. Another example in the observations was a situation where a patient had developed a fracture as a result of an injury while in hospital. In planning the patient's treatment, health care professionals were concerned that the situation needed to be discussed with great sensitivity in order that the patient's wishes as well as her daughter's wishes regarding the treatment of the fracture could be determined (Team Observations).

Patients' level of dependence in relation to their pain, debility, confusion and consciousness influenced their ability to be involved in decisions about their care. However, many participants recognised that patients, when they are not able to be involved in making decisions, preferred to have decisions made in a way that reflected their wishes. The preparedness of family and health care professionals to facilitate decisions reflective of patients' wishes ensured that patients were involved at least to the extent that this proxy decision making allowed.

Language and Culture and Communication

A further personal characteristic that influenced patients' abilities to converse with health care professionals about their care decisions was their cultural and language background.

In one example, it was acknowledged that a patient who was very unhappy about a decision, made by health professionals and his family that he should remain in hospital had issues with the female dominated workforce caring for him. Nurse Sui explained that, "*He was Egyptian and had a bit of a downer on women*" (Nurse Sui). In his own home, it is likely he would have been the head of his household and controlled decisions very independently, being accustomed to controlling his environment without

challenge, particularly from the women in his family and having his decisions respected. However, in the inpatient health setting, his environment was controlled by others, many of them women who were not accustomed to his behaviour and by institutional policies, procedures and processes that did not fit with his desired behaviour.

In this situation, the issues in making decisions about his care were also compounded by the difficulty staff had in understanding him and communicating with him. Not only was English not the man's native tongue but he was profoundly deaf and required all communication in writing, an effort not all staff made. As a result, he did not develop a rapport with any of the staff that would have facilitated his decisions:

I wouldn't have said [he developed a rapport] with any of the staff. He was also very deaf which made it very difficult to communicate with him. On the days I was looking after him, I would go in and write to him over the day, screeds and screeds and I would come back a week later and there wouldn't be much else written in it. (Nurse Sui)

In another situation, delays to the implementation of decisions occurred and were not investigated because of language barriers. Maoki, a nurse, described a situation where a decision for a patient to have an enteral feeding device inserted was never implemented,

It was a gentleman, early sixties from non-English speaking background who had head and neck cancer and he was query for a possible PEG [Percutaneous Entero-Gastric tube for enteral feeding] because he was unable to eat at all ... The window of opportunity to provide him with some nutrition was lost [because nothing was done] I don't know even why that happened ... Because he was Spanish and there was a language difficulty with his family ... An interpreter was called in ... that [he did not speak English] was a block to what happened to him [getting the PEG tube] ... A big barrier. Sure we knew when he was in pain, we had minimal words on cards written down and we dealt with that. But in terms of him getting the treatment that he wanted, and his wife wanted, it got lost some where in the ethos. I remember it was clearly discussed that the team meeting at one point ... most of the time he was quite isolated in the room. The fact that we all speak English and not Spanish would have been quite difficult. And getting down to the nitty gritty of him wondering why procedures weren't done. I don't know. Because I couldn't discuss it with him. (Nurse Maoki)

The patient's culture and his or her ability to converse in the language of the health care professionals facilitates the development of relationship with the health care professional and the flow of information that is significant in the way that the patient manages issues they have about making palliative care decisions.

Reflections on Related Literature

This chapter identified four conditions affecting patients' perceptions of their involvement in making health care decisions in palliative care. The literature confirms that relationships with health professionals, information, family relationships and personal characteristics influence the ways that patients make health care decisions.

Relationships with Health Care Professionals

From the perspective of participants in this study, the development of relationships was central to patients being involved in decisions in palliative care, and was recognised as such by all health care disciplines. However, the behaviour of health care professionals, in terms of their manner, focus and trustworthiness and the culture of the organisation was critical to the development of the type of relationship that fostered patient involvement in making decisions.

A study examining patient choices following an invitation to participate in decisions about cardiovascular risk management treatment also found that the approach of the health professional influenced how much control patients perceived they had in decision making and also influenced their choices (Legg England & Evans, 1992). The influence of health professionals, particularly doctors, is a well-established phenomenon that affects the way that patients involve themselves in decision making (Davis, 1982; Opie, 1998; Paterson, 2001).

Opie (1998) used the method of discourse analysis to determine how teams empower patients and family members. She analysed transcriptions of observations of team and family meetings at three different community based services. Her analysis of multidisciplinary teams and their effect on the realignment of power between health professionals and patients, acknowledged that the key to empowerment lay in how health care professionals in these community teams used language to "position users" for decision making (1998, p188). Paterson (2001) affirmed this finding in her grounded theory study of chronically ill adults whose decision making was analysed. Paterson asked 22 participants with long histories of Type 1 diabetes to audiotape their self care decisions by thinking aloud (Paterson, 2001). She then used these tapes as a prompts for in depth interviews with the participants. Paterson found that though they claimed to have the goal of empowering their patients, health care professionals frequently

discounted patients' beliefs about their health and decisions. There was also evidence in this current study that some patients were influenced in their decision making by the behaviour and attitudes of the health professional in health environments. In many cases where patients were dissatisfied with decisions and sought to exclude professionals, the health professionals had approached the patients in ways perceived as being uncaring or ignoring the patients' history or background. In this current study, the type of relationship developed by health professionals with patients was one of the influences on patients' ability to be involved in making decisions about their care.

One of the features of developing good relationships with health care professionals in this study was the friendly manner of the health care professional. Chatting has been viewed as an important component of developing a relationship between health professionals and patients that fosters confidence (Fenwick, Barklay, & Schmeid, 2001; Jarrett & Payne, 2000; Williams, 2003; Williams & Irurita, 2004). A study by Jarrett and Payne (2000) suggests that chatting and friendliness of health professionals is an important feature of creating and maintaining patients' optimism, requiring skills in communication that were traditionally regarded as absent in these conversations. In four cancer treatment centres, they recorded nurse-patient interactions and interviewed fifty nurses, patients and relatives about day-to-day communication. They found that patients and nurses contribute to positive talk that sustains optimism in terms of patients' circumstances and contributes to the hopeful atmosphere of the workplace (Jarrett & Payne, 2000). In contrast, there was a shared understanding between patients and nurses that dwelling on negative attitudes towards patients condition or prognosis were "unhelpful and detrimental to the patients recovery and the general ward atmosphere" (Jarrett & Payne, 2000, p89).

Despite this acknowledgement of the potential significance of chatting, in an extensive study of nurses from six wards of a cancer hospital and a general hospital, Wilkinson (1992) analysed the verbal behaviours of nurses during interviews for patient history. She found that small talk was also used as a conversational tactic to interrupt interactions that focussed on areas the nurse found difficult, such as prognosis and treatment.

Aranda and Street (1999) suggest that the approach of nurses to interactions with patients was dependent on nurses' assessment of the sort of person the client or patient

needed the nurse to be. They described how nurses used a “skilled adoption of different subjective positions through nursing responses to the apparent needs of the patient and family” (1999, p79). Similarly to nurses in this study who acknowledged that they contrived a manner of approach to patients, the nurses in Aranda and Street’s study were concerned that they were deliberately not being authentic or “real” in their interactions (1999, p76). Aranda and Street acknowledge that the taking of a subjective position in response to a patient is not a passive response, but rather reflects the intersubjectivity of nurse-patient relationships where both patients and nurses contribute to the development of the relationship.

The development of relationships between patients and nurses has been described as central to the work of nurses (Liaschenko, 1994, 1997; Williams & Irurita, 1998). Much of the literature regarding the development of relationships between patients and health professionals is related to caring relationships in nursing. However, others have written about the importance of developing of relationships built on trust and caring for radiation technologists (Cunningham, 1998), occupational therapists (Devereaux, 1984), doctors (Gerbert, Love, Caspers, Linkins, & Burack, 1999) and counsellors (Mearns & Thorne, 1988). Nevertheless, it is from nursing that much of the theoretical development of relationships between health professionals and patients is drawn.

In a grounded theory study that described the development of nurse-patient relationships, Morse (1991) interviewed nurses from a range of clinical inpatient and community fields about their relationships with patients. She identified a process of mutual negotiation between some nurses and patients for development of a relationship that may begin as a clinical relationship and could proceed to a more connected relationship or an over involved relationship (Morse, 1991). In this study, the development of mutual relationships that were observed and discussed in interviews was of the therapeutic or connected type of relationships.

The terminology used to describe relationships in this study varied. However, most of the variations in terms are related to those that the researcher used to encourage discussion about various aspects of relationship. Some of these terms; developing a connection, or a good rapport were used specifically to qualify the particular activity undertaken by the participant. In response to the researcher’s questions including these

terms, participants were fairly congruent with the terminology they used, most referring to the term 'relationship'. To qualify the type of relationship participants valued, they used adjectives such as real, good, close and established. In contrast, the nurses in Liaschenko's (1994) study used the term 'connection' to patients rather than relationships. The difference in use of terms may be due to the focus of Liaschenko's study on ethical concerns or the relative experience of the nurses who were all highly educated and experienced, or that this study was broader in its context, drawing participants from patient, family and different health professional groups. The language may also reflect the North American culture and use of the term 'connection' in this context.

Morse also described relationships where one of the parties is unwilling to develop the same type of relationship as the other. She identified this type of relationship as unilateral (Morse, 1991). Unilateral relationships were described by participants in this study as a failure to develop relationships, and occurred rarely in palliative care. However, some situations were observed or discussed where health care professionals were at odds with the type of relationship desired by patients. The patient, Harry was described as someone with whom staff had found they could not develop a satisfactory relationship. Two of the participants identified their relationship with some health professionals involved in their initial diagnosis and treatment, as not satisfactory because these health professionals were unwilling to show their humanity (Patient Barbara and Family Betty).

Health professionals were criticised for creating feelings of being dehumanised in a study of satisfaction with hospital care in the last year of life (Rogers, Karlsen, & Addington-Hall, 2000). Rogers et al. (2000) used a random sample of registered cancer deaths and sent post-bereavement surveys to the relatives who registered those deaths. In situations where dissatisfaction was reported related to inadequate nursing care, often it was with relation to the expected relationship between patients and nurses, breaches of trust and a perception that patients' individual needs had been disregarded.

Trust also features significantly in the literature regarding the development of relationships between health professionals and patients (Morse, 1991; Shortell, Waters, Clarke, & Budetti, 1998; Thorne & Robinson, 1988; Williams & Irurita, 1998; Wilson, Morse, & Penrod, 1998). Williams and Irurita (1998) identified trust, as a significant

outcome of health care professional and patient relationships, that ensures patients will take the advice of health professionals. An analysis of the concept of trust by Johns, (1996), resulted in a process and outcome model that described how the consequences of developing a relationship that featured trust fed back into the process. As a result of this feedback, she described the “level of trust may vary substantially over time, increasing and decreasing” (Johns, 1996). However, the manner of developing trust does not rely solely on the testing of trustworthiness, it also relies on reciprocity (Thorne & Robinson, 1988; Wilson et al., 1998).

The cases of the patients Jenny and Barbara illustrate how reciprocal trust develops in health care relationships. In both cases during their early experiences, their attitude towards decision making and trust was as Thorne and Robinson, (1988), put it “that answers to [their] health care problems would be forthcoming and that the health care providers would be singularly dedicated to providing [them] with those answers” (Thorne & Robinson, 1988). When the answers failed to materialise, both patients became more distrustful. They reconstructed their trust and relationships with health professionals by exercising more control, on a more informed basis and were more guarded to what health care they would agree. This situation only changed for Jenny and Barbara once they felt the approach and manner of health professionals had changed, when others were listening to them and valuing their ideas about their health care decisions. Thorne and Robinson (1988) described being trusted by one’s health professional as an “... affirming and validating phenomenon, one which promoted self esteem and fortified the health care relationship” (p.784-5). As Jenny and Barbara also eventually experienced, the informants in Thorne and Robinson’s study felt that their competence to present their experience accurately, care and make decisions for themselves had been validated and this generated trust in them and in their health care professionals.

One study provides a contrasting explanation for why patients adopt passive roles in making health care decisions (Clover et al., 2004). In their study, Clover et al. (2004) asked palliative care patients to discuss the decisions they had made about their care that involved nurses and the role of their conversations with the nurses in affecting the decision. In their discussion, they suggested that patients reflect the approach used by the health care professional, taking passive roles in response to professionals who make decisions for them and conversely take active roles in decision making if

professionals encourage them to feel empowered. This view is affirmed in an earlier study by Leighl, Gattellari, Butow, Brown and Tattersall (2001), who studied audiotapes of over one hundred patients in initial adjuvant therapy consultations with medical and radiation oncologists. Their findings suggested that doctors making explicit statements about patient choice influenced the active decision making behaviour of patients.

The concept that patient behaviour is a response to health professional behaviour is also discussed by Scott (1999) in an analysis of autonomy, power and control in palliative care. She suggested that the routines and bureaucratic practices of staff force patients to be more passive. She argues that if patients were treated with more regard for their emotional and physical needs as human beings, there would not be a need for strategies to empower patients and their family members.

In addition to the manner, approach and trustworthiness of the health care professional being factors important in developing relationships that fostered patient involvement in making health decisions, patients' personalities and willingness to develop relationships also impacted on that involvement. Patients like Harry, who avoided the attempts of staff to develop a relationship, are often also people who are difficult to like. Liaschenko (1984) differentiated this form of liking from the superficial dislike of, for example, the way a person looks. The form of not liking patients, as described in Liaschenko's study of experienced community and psychiatric nurses, was related to an inability to form and maintain relationships with patients who evoke strong negative emotions for serious reasons including those who reject the care offered by nurses. Liaschenko described this as a moral problem for nurses since the work of nurses in helping patients to live meaningful lives required an understanding of the patient as a person and not just in terms of their medical condition. This understanding of patients was gleaned in the type of open shared communication that occurs when a connection is built between nurse and patient (Liaschenko, 1997).

In a phenomenological study of nurses, Drury (2001) reported that a poor rapport and unlikable patients were factors described as impeding the quality of nursing care. Nurses described their behaviour with these patients as avoiding the patient and their non physical needs, the delaying of care and poor communication (Drury, 2001). In this current study, when staff described developing a rapport with patients as

difficult, staff did not admit to finding patients unlikable and there was no evidence of finding them unlikable in staff behaviour. However, the strategies staff used to cope with their lack of rapport with patients were similar to those explained in Drury's and Lischenko's studies particularly the strategies of discussion with other staff and trying to find something in common with patients.

Information

In this current study, when patients perceived a lack of information about their condition, treatment or circumstances, they were frustrated by their inability to make decisions or to be involved in decisions. Some patients associated their lack of information with staff they thought were too busy to provide information. In other situations, lack of information was associated with cultural traditions that prohibited disclosure of information. The link between information and patient involvement in making health care decisions is strong in the literature related to palliative care and other patients making health care decisions (deHaes & Koedoot, 2003; Fallowfield, 2001; Heyland, Tranmer, & Feldman-Stewart, 2000; Huang et al., 1999; Legg England & Evans, 1992; Peplar & Lynch, 1991; Wilkinson, 1992).

Two further studies reporting from the perspective of caregiver relatives on health care decisions and related concerns about information. In a study mentioned earlier by (Rogers et al., 2000), a satisfaction survey's qualitative explanations were utilised to examine issues regarding dissatisfaction with hospital care. One of the major themes reported in that study was related to being unable to get particular information. The examples given in the report of the satisfaction survey related to concerns of relatives in not being invited to discuss their sick relatives condition, and not being given information relevant to the sick relatives rights. Another study reporting on the caregiver perspective, examined symptom control and communication related to stroke patients in the last year of their lives (Addington-Hall, Lay, Altmann, & McCarthy, 1995). Nearly 40% of the non-official caregivers interviewed reported that they were unable to obtain sufficient information about the patient's medical condition. Though it was not stated how lack of information affected decision making, the majority of these participants had asked for further information and many had perceived the health care professionals to be rushed (Addington-Hall et al., 1995).

In a review of studies on women who had surgery for breast cancer, Fallowfield indicated that:

... information needs to be given systematically, at the right time and via several different routes, to maximise the chances for patients to understand the implications of treatment options and make really informed choices ... underscore the need for clinicians to assess individual patient's needs and elicit their information preferences. (Fallowfield, 1997, p212-13)

Patients in the study on end-of-life decision making by Heyland et al. (2000) were able to specify the sort of information that they thought was important. Heyland and his colleagues used a taxonomy of information needs to ascertain from eighty-seven patients with end stage disease, what information they would rank as most important. Similar to this study, in addition to information about their condition, patients also considered information on the effect of their condition on them and their family in everyday life was also important to making decisions.

The Australian Government guidelines for doctors on providing information to patients (NHMRC, 2004) supports the scope of information required by patients suggested in this study. The guidelines suggest that discussion and sharing information between doctors and patients are essential for making decisions:

An open exchange between doctors and patients is crucial. Each brings to the consultation different information, options and understanding which are important for making decisions and achieving the patient's well-being. Allowing opportunity for discussion may be as important for patients as giving and receiving information. (NHMRC, 2004, p7)

Faden and Beauchamp (1986) suggested that ideal information disclosure is a process of communication that is shared. Their proposal was that three core disclosures form the basis of a dialogue that leads to sharing of understanding between doctors and patients (Faden & Beauchamp, 1986). These core disclosures include information the patient believes is material to their consent or refusal, information the health professional believes is material to consent or refusal and information related to understanding the purpose, nature and implications of consent (Faden & Beauchamp, 1986, p308). At least the first two of the core disclosures described by Faden and Beauchamp are reflected in the requirements of patients in this current study who

believed that their own and health professionals' subjective views of information were relevant to their ability to be involved in making health care decisions in palliative care.

Although not specified by patients in this current study, the way that information was delivered to patients has also been reported as influencing their decisions (deHaes & Koedoot, 2003). De Haes and Koedoot, (2003), examined the patient centred model of decision making and audio taped consultations between medical oncologists and patients where a decision about palliative chemotherapy was being made. During these consultations, extensive attention was paid to information about options for palliative chemotherapy, but the alternative option to provide "watchful waiting or supportive care" was given scant attention and tended to be presented as "no- treatment" (deHaes & Koedoot, 2003, p47). De Haes and Koedoot suggest that patients interpret 'no-treatment' options as being offered no options.

The lack of skill of health care professionals in communication, particularly involving the concepts of death and dying, has been an issue described by Wilkinson (1992) and by Georgaki, Kalaidopoulou, Liarmakopolous, and Mistakidou (2002), in relation to nurses. A number of authors also comment on the varied communication skills of doctors affecting how involved patients are able to be in decision making (Brody, 1980; Gattellari et al., 2001). In this current study, a number of health professionals indicated that the improvement in their communication skills, over time had enabled them to involve patients more in decision making.

Family

In this study and in the literature related to end of life decision making, family members play significant roles in making decisions on behalf of patients and supporting patients' decisions about care (Andershed & Ternestedt, 2000, 2001; Huang et al., 1999; Norton et al., 2003). However, in this study and in others (Aranda & Peerson, 2001), family members do not always feel that their contribution to decision making is acknowledged by health professionals. Aranda and Peerson, (2001), challenged the frequently cited notion of family as the unit of care in palliative care, because none of the family members in their study identified that they had made choices or received information about their role, or the impact of the move of the patient to home care.

In this current study the influence of family on patients' decision making was also related to cultural expectations of family roles, particularly in Japan. Participants acknowledged that attitudes towards disclosure and the responsibility for decisions in Japan are different in palliative care to general health care practices. The cultural tradition of medical and family control over health information and decisions is acknowledged in a number of studies (Gattellari et al., 2001; Huang et al., 1999; Miyata et al., 2004).

A qualitative study by Huang et al. (1999) examined the attitudes and needs of 36 Chinese-Australian cancer patients and 12 relatives in Sydney, Australia, using focus group and individual interviews. Most of the patients involved in their study wanted a small number of family members present for physical and emotional support, when given information about their illness and treatment. Huang et al. (1999) reported diverse views amongst patients and family members about the withholding of information of poor prognosis, although sensitivity and accuracy seemed to be paramount.

A study of decisions regarding withholding treatment from Korean patients with terminal cancer conditions (Oh, Kim, Lee, Lim, Jung, Heo, Bang, & Kim, 2004), administered a questionnaire covering a wide range of interventions such as nutritional supplements, antibiotics, analgesia and resuscitation. The questionnaire was administered to 97 families, their physicians and concordance noted between their responses. The family members who consented were then approached for access to the patients. Only 14 families agreed and of these patients, only nine participated in the study. The authors noted the strong community value that the withdrawal of treatment constituted a form of passive euthanasia. They also noted the cultural difficulty of promoting individual autonomy when discussions about death are avoided. Despite this, noting the discordance between family and doctor responses to different decisions, the authors recommended that, in order to avoid conflict regarding decisions, family members should be more involved in care decision making (Oh et al., 2004). Although only nine patients were involved, the fact that only one patient was of similar opinion to the doctor and family, should have flagged concern about promoting family involvement and dismissing the involvement of patients as too difficult.

In a recent study involving general public views on disclosure of cancer diagnosis and prognosis in Japan, it was reported that doctors are given a wide range of discretionary power regarding disclosure by law (Miyata et al., 2004). In providing background to their study, they also noted that patients' needs for information were often unmet because family members were unlikely to discuss these issues with patients. The results of their questionnaire indicated that of 246 participants (more than half) indicated that they "would like to obtain diagnosis and prognosis information ahead of their family" (Miyata et al., 2004, p5). In their discussion they acknowledge the changing views of patients over the last decade towards preferring disclosure to non disclosure of diagnosis and prognosis. These results are also reflected in this current study where Japanese patients and family members interviewed, used examples demonstrating their preference for making health decisions in an environment of disclosure and collaboration with health professionals.

In this study conflict over health care decisions between family members and health care professionals was less of an influence on patients' involvement in making health care decisions than patients' long standing patterns of conflict with their relatives. There was a paucity of literature exploring this problem in palliative care, however reports in the literature related to family involvement in decision making with health care professionals where conflict was a feature were prominent (Abma, 2004; Andershed & Ternestedt, 2000; Norton et al., 2003). In all of these studies, a lack of communication, or poor communication, was described during changes to the patients' condition or treatment.

Personal Characteristics

In this current study, interpersonal style, decision role preference, level of dependence and past experience were four personal characteristics of patients that affected their perception of involvement in decision making and their response to lack of involvement. In contrast to these findings, a study by Pritchard, Fisher, Teno, Sharp, Reding, Knaus, Wennberg and Lynn (1998), found patient characteristics had little to do with decisions made regarding place of death. They used data from an observational phase of a large national program of study examining the prognosis, preferences for outcomes and risks of treatment known by the acronym, SUPPORT (Pritchard et al., 1998). Patients drawn from the five teaching hospitals enrolled in the SUPPORT

program were compared to data drawn from the national referral regions (Medicare). The findings indicated that although most of the patients indicated a preference to die at home, most died in hospital and that the risk of dying in hospital was increased in regions with higher hospital bed availability. They concluded that “whether people died in hospital or not is powerfully influenced by characteristics of the local health system but not by patient preferences or other patient characteristics” (Pritchard et al., 1998, p1242).

In a grounded theory study of the therapeutic effect of interpersonal interactions on hospitalised patients, Williams (2003) found that feelings of reduced personal control and associated emotional discomfort was influenced by a range of personal characteristics such as the patients, dependence, length of stay in hospital, type of illness, experience as a patient, communication difficulties and lack of interaction with family, friends or other patients. In congruence with this current study, past experience of control over health was also found to influence involvement in decision making in the study by Legg England and Evans (1992).

In this current study, interpersonal style; the patterns of behaviour used by patients in their interactions with others, influenced their perceptions of lack of involvement and the strategies they chose to manage their perceptions. Braman and Gomez (2004) examined the value of personality variables in predicting the relationship preferred by patients in a study involving 120 white, middle class, men and women from a pool of psychology research volunteers. They used a range of personality measuring tools, to assess the variables of health locus of control, assertiveness, self-efficacy and conservatism. Although limited by the type of participants, all being experienced volunteers, well educated and preferring high levels of information, they found that personality, particularly reliance on powerful others, contributed to up to 20% variance in patients’ relationship preferences in respect of decision making and information-seeking preferences. The more assertive patients were, the more likely they were to desire information (Braman & Gomez, 2004).

In an earlier study by Corazzini-Gomez (2002), 350 case managers of elderly patients in home care services were given a series of vignettes to determine the factors that related to care planning. Although the characteristics of physical and psychological functioning and resources best predicted the generosity of the plans made, clients who

denied they needed services, or who refused services were assessed as needing lower service levels than patients who were passive or appreciative (Corazzini-Gomez, 2002). This study indicates support for the finding in the current study that the personality of patients does affect the perception of others of their need and their involvement in decision making.

The decision role preference of seriously ill patients, measured with the role card sort (Degner & Sloan, 1992) described in chapter 2, or a modified version of this has been used in a number of studies (Gattellari et al., 2001; Heyland, Tranmer, O'Callaghan, & Gafni, 2003; Rothenbacher et al., 1997). In all of these studies, in congruence with this current study, more patients preferred active roles in making care decisions, either after taking the doctor's advice or by sharing decisions, than more passive roles such as allowing the doctor to make the decision. It was acknowledged that patients' preference for particular roles changed and was difficult to predict (Heyland et al., 2003). Behaviour, personality and character traits in general, have been argued in the psychology and ethics literature as inconsistent across different situations (Doris, 1998; Ross & Nisbett, 1991). England and Evans (1992) also argued that the desire to control decision making was not related to age, sex or marital status, a finding echoed by Braman and Gomez (2004).

In this current study, patients who preferred more passive roles in making care decisions often still expected to be involved by being kept informed. Sanders and Skevington (2003), undertook a longitudinal qualitative study by interviewing 37 recently diagnosed patients with bowel cancer of which 28 were reinterviewed six months later. As in this current study, Sanders and Skevington found that although many patients preferred their doctor to be responsible for decisions, they did not view themselves as passive in the process.

A number of patients in this study described a more passive decision role in the diagnostic phase of their illness, a view supported by Rothenbacher et al. (1997). They examined a number of studies of patient preference for particular roles and proposed that differences in rates of patients preferring active roles was related to patient prognosis, the length of time to understand their disease and to develop relationships with caregivers:

... patients with a likelihood of cure rely more on their physician's expertise to choose the appropriate treatment and therefore prefer a more passive role in the decision making process. In addition, patients with advanced disease may have had longer time to have a critical look at their disease and the caregivers. (Rothenbacher et al., 1997, p1187)

Rothenbacher et al., (1997), found that patients tend to change towards more active decision roles over time. However, this study found that patients, whose physical and mental dependence increases, were more likely to accept the decisions made by others on their behalf. The study discussed earlier by Bottorff and colleagues (1998) explains this change of decision role not as more passive but as an active choice to conserve energy by letting go of some decisions.

Summary

Four major conditions affecting how patients respond to their problems related to lack of involvement in palliative care decisions, have been identified. The relationship that health professionals developed with patients, governed by their approach and focus on patients' needs and the culture of the environment in which health professionals worked affected how patients felt they could trust health professionals and therefore be involved in decision making. Further, patients' access to two types of information; professional opinion and background information on disease and treatment processes, were also critical to involvement in making care decisions. Patients' relationships with their family members and their personal characteristics related to their preferred roles, past experience, interpersonal style, level of dependence, language and culture were also significant conditions related to how patients experienced and managed their involvement in palliative care decisions. Though some differences exist in the language used to describe relationships, the literature acknowledges that the development of relationships between patients and health care professionals that support patient involvement in making health care decisions is dependent factors related to health care professionals' behaviour and patients' willingness to engage in relationships with them. The literature also reports that patient involvement in care decision making is dependent on the quality of the information they receive and that they receive it in the context of a dialogue with the health professional. Family discord during end of life decision making is discussed in the literature and supports the findings in this current study that family, culture and conflict affect patient involvement in decisions. The personal characteristics of personality and role choice,

identified in this current study as affecting how patients involve themselves in decision making are also affirmed in the literature.

CHAPTER 5

The Basic Social Process: Controlling Involvement to Promote Confidence In Decisions Related To Palliative Care

Introduction

In a grounded theory study, theory building involves identifying how individuals go about resolving their main problem or managing the common phenomenon, “as it exists in context or under a specific set of perceived conditions” (Strauss & Corbin, 1990, p104). The behaviours or actions used by individuals in the management of their main problem are termed strategies. There are four aspects to the examination of strategies in grounded theory studies. Strauss and Corbin (1990) suggested that the first is “processual” (p104) focused on how the strategies or actions and interactions might be sequenced or changed over time. The second aspect relates to the purposeful and goal oriented nature of the strategies. The third focuses on what happens when participants fail to use the strategies. The fourth aspect identifies the effect of intervening conditions on the use of strategies. Examining strategies in this way results in the identification of a Basic Social Process, defined by Glaser as: “fundamental patterned processes in the organization of social behaviours which occur over time and go on irrespective of the conditional variation of place” (Glaser, 1978, p100).

In this study, participants were found to be responding to a core concern, which was identified as a lack of involvement in making palliative care decisions. The context in which they responded was dependent on the type of decision and the importance of that decision to them. The consequence of their strategies also reflected their confidence in the decisions made about their care and the health professionals involved in their care. The Basic Social Process identified in this study was named *Controlling Involvement*. This chapter describes the Basic Social Process of *Controlling Involvement* and the particular actions or behaviours associated with four strategies, the intervening conditions influencing them, and their effect on the issue of a lack of

involvement in decisions made about care and the consequences of controlling involvement.

The Nature of Controlling Involvement

The term “control” may be defined as “to exercise restraint or direction over; dominate; command” or to “hold in check; curb” (Delbridge, 1986, p129). Both these definitions are reflected in the basic social process described as *Controlling Involvement*. Patients responded to their concerns about their involvement or lack of involvement in making palliative care decisions by either controlling their own involvement or attempting to direct others involved in making care decisions, in particular whether the health care professional is involved or excluded (Table 5.1). When patients did not like a health care professional, they perceived that the health professional was excluding them from decisions about their care. In order to improve their confidence in decisions, they attempted to control who was involved in making decisions by excluding the health professional. When patients perceived that they were being involved in decision making by a health professional, to maintain their confidence in decisions being made, they included the health care professional in decisions about their care.

Table 5.1:
Controlling Involvement – the relationship between involvement and strategies used in response to the patient’s perception of lack of involvement in making palliative care decisions.

Controlling Involvement	Responding to perceptions of lack of involvement: Exclusion of Health Professional	Responding to perceptions of involvement: Inclusion of Health Professional
Strategies featuring own involvement	Self-Reliance in making care decisions	Making palliative care decisions with others
Strategies curbing own involvement	Evading care decisions	Reconciling less involvement in care decisions

The other feature of *Controlling Involvement* is that it is not a process characterised by progressive movement between strategies; instead, this process is situational. *Controlling Involvement* was a response to the way that patients interpreted individual decision making moments. They managed their concerns about involvement in decision making by selectively responding to the particular decision making moment they experienced. They used four major strategies to address their concerns about their

involvement in making palliative care decisions. *Self-reliance in making care decisions* was used to respond to lack of involvement in care decisions being made that entailed patients increasing their own involvement and excluded health professionals from decisions about their care. *Evading care decisions* was where patients curbed their own involvement to exclude the health professional from decisions. In contrast, patients who felt more involved in care decisions were more inclined to respond by including health professionals by *sharing the making of care decisions* with them. Under particular conditions, such as when they were more physically ill, patients would also include health professionals by use of the strategy that curbed their own involvement; *reconciling non-involvement in care decisions* (Table 5.1).

The term “process” is defined by the Macquarie dictionary as; “a systematic series of actions directed at some end” or as a “continuous action, operation or series of changes taking place in a definite manner” (Delbridge, 1986, p489). Strauss and Corbin suggest that “process” is an intangible term because a series of actions or changes “doesn’t necessarily stand out as such in data” (Strauss & Corbin, 1990, p143). The basic social process of *controlling involvement* was uncovered by linking the series of patient behaviours in response to involvement in care decisions to the changing conditions they faced and the effect of the consequences of their behaviour on future action. Patients were found to respond to individual *decision making moments* by being selective about the strategies they used to improve their confidence in their palliative care decisions.

Decision Making Moments

The process of *Controlling Involvement* was comprised of various strategies and responses. There was no one simple progression of strategies used to make decisions. Patients seemed to use different strategies in different decision making situations or moments. A decision making moment involved the period of time in which the patient was responding to his or her involvement in a particular decision. A particular moment was different to other moments because the conditions surrounding the decision, as well as the decision itself were different to other decision making moments.

All of the patients described their health care decisions in terms of diverse situations or moments. All patients used discrete strategies to manage their involvement in making decisions about their palliative care. They reacted in different ways to these

different decision making moments. Two cases illustrate that patients selected strategies that correspond to decision making moments because of the conditions influencing the moment. The first case relates to Jenny, a 47 years old woman with lung cancer. Among the many decision making moments disclosed in interviews and observed, three decisions illustrate the different strategies Jenny used. The first relates to the decision to undergo radiotherapy for the treatment of her cancer. The strategy Jenny used to control her involvement in this decision was reconciled non-involvement.

The specialist oncologist who diagnosed Jenny's cancer recommended that she undergo a course of radiotherapy, which she did. Prior to seeing the oncologist, Jenny had little experience with illness or health professionals and health care decisions, other than a history of 12 months of back pain for which she had been seeing local doctors at a medical clinic. When the specialist advised her that she should have radiotherapy, she felt involvement in that decision was unnecessary and reconciled her non-involvement by feeling assured by the expert advice the oncologist had given her. She explained, "... *I'm not sure what options I was given ... I know that when it came to ... I just thought well that's what we have to do ... so I didn't question that ...*" (Patient Jenny). Of this decision, she said:

... it was a big shock when they actually said that I had cancer. I was very, very shocked ... it was the most furthest thing from my mind that I would have cancer ... just that I had this lower, very bad lower backache and it was actually cancer of the bone. So I had radiation, which ... I had a really bad reaction to and ended up in [hospital] for about 10 days, because they radiated the tummy as well of course, and I had a shocking reaction to that, diarrhoea and vomiting ...
.(Patient Jenny)

The second decision that illustrates her use of different strategies to control involvement in decisions about her care occurred subsequent to her experience of radiotherapy. When her oncologist recommended chemotherapy, Jenny was more concerned about her involvement in the decision. Her recent experience of the oncologist's decision that she have radiotherapy, and the effect of that decision on her health, made her less trusting of the oncologists understanding of the aspects of the decision that were important to her as an individual. She said "... *I questioned it more with the chemo ...*" (Patient Jenny). However, although Jenny agreed to trial the chemotherapy, when she became increasingly unwell due to side effects, she used the strategy of self-reliance in this decision and:

... told the Oncologist that I wasn't willing to ... have any more treatments of chemo, so that was my total decision ... I didn't discuss it with him at all ... I was quite sure that I wasn't going to have it any more, it was making me sick and taking away my quality of life, I didn't think that it was doing me any, any benefit at all. And I felt so much better after it had all finished, and come out of my system. (Patient Jenny)

Jenny did not have a close relationship with the oncologist and indicated that they did not work as partners, which was her preferred way of making decisions. She indicated that she had excluded this health care professional from the decision by telling him she would not have further chemotherapy. She said *"I do that [make decisions in a partnership] more with my own doctor ... more so than the Oncologist, ... I told him that I wasn't going to have this treatment"* (Patient Jenny).

The strategies used by Jenny in these situations contrast with those she used in the decision about treatment for her acoustic neuroma. The health care professional involved in this decision was her general practitioner, who she knew well and felt had an understanding of her needs and wishes for her health and future. With this doctor she used the strategy of sharing decisions about her care. Jenny explained that,

... with this palsy on my face, we discussed ... he [general practitioner] came up with a suggestion of ... doing acupuncture on my face, to try and help that. So that was like a joint decision that we made ... I say to him, like with different medications ... that I think that ... should increase the Fentanyl patches or decrease them, or however I think at the time or what does he think about this or that, this medication or that medication ... I just discuss that with him on how I'm feeling (Patient Jenny)

Jenny's involvement in the decision regarding treatment for her acoustic neuroma was influenced by her overall condition at the time and her experience with decisions made about her care in the past. She felt she had to be involved in this decision because the options affected her quality of life.

That's quite a horrible operation ... I really don't want to put myself through that ... if there was nothing else wrong with me, I was definitely going to have it done, but there is something else wrong with me, and it's major (Patient Jenny)

However in this situation, because of this doctor's approach and rapport with her, she included him by sharing the decision making rather than making the decision independently.

Jenny often described her confidence in decisions made about her care when she perceived she was involved and sharing decisions with health professionals. In contrast, another participant, Harry, was often lacking in confidence regarding decisions made by health professionals, because he perceived that they were excluding him from decisions about his care. Harry, described earlier as a patient who staff believed was independent in making decisions, acknowledged that he often liked to make decisions independently of health professionals, though he would listen to their advice. His experience with health care decision making and his personality influenced his use of strategies that excluded health professionals from making decisions about his care. Even though health professionals made efforts to include him in decisions they were making, Harry was reluctant to share decision making with them. Nevertheless, Harry did use different strategies in different decision making moments.

One example where Harry used the strategy of self-reliant involvement in making a decision, involved him responding to staff he felt were ignoring him by threatening to leave the hospital. His response to the staff in this situation was precipitated by his lack of information about the medical plan for his care. Harry explained that he judged his current experiences by measuring them against past experience at a different hospital, where he valued the communication style of the staff caring for him.

... the doctors I saw there were mainly specialists in whatever they did, and they would generally be around every day, without fail, at a certain time, telling you what your status was. Now, as far as I'm concerned that's the way it should be (Patient Harry)

In another decision making moment, the community nurses phoned Harry to suggest that they visit him. His reaction to this suggestion, influenced by his independent personality, was to exclude them from his decision to have the nurses visit. He evaded or resisted their care and their decision to visit him, by moving to his mother's house without telling the nurse. The nurse explained his response to their call, "[Harry] had refused the nurses visiting before the weekend saying " I will tell people when I want them" and hadn't liked the district nurses phoning him to check on his condition ... [Harry] went to his mother's house" (Patient Harry Observations).

However, in a different decision making moment, when Harry had wanted to be at home, he reconciled his non-involvement in the decision to return him to hospital,

because he was ill. When he was very ill, in pain and vomiting, his physical dependence prompted a more pragmatic response to making care decisions and Harry allowed decisions about his care to be made without argument. Although his preference was not to return to the hospital, he agreed because he was realistic that this was an appropriate decision, despite that it was not his decision. After his admission with sepsis secondary to cholangitis, the field notes observed his doctor stating, "... [Harry] *was happy to come back to the inpatient unit when he needed to*" (Patient Harry Observations).

The cases of Jenny and Harry illustrate that patients make decisions differently in particular decision making situations or moments. The strategies they used in making care decisions were a response to how they perceived they were being involved in making decisions. The strategies were influenced by changes in the conditions, such as the approach of the health professionals, family roles, culture, past experiences and patients' level of dependence that affected that perception.

Excluding Health Professionals in Decisions related to Palliative Care

Patients who perceived a lack of involvement in palliative care decision making moments often responded by attempting to stop health care professionals' decision making efforts by excluding them. This occurred more often when the approach of the health care professional was not consistent with the way that the patient expected to be approached (Figure 5.1). The two strategies patients used to exclude health professionals were to be *self reliant* in the way that they made decisions about their care, or to *evade* decisions made about their care by others.

Self-Reliance in Making Care Decisions

When patients felt excluded from decisions regarding their palliative care, particularly when patients felt that health professionals had discouraged involvement by their manner or lack of understanding of patients' perspectives, patients responded by taking control, and making decisions themselves, independent of health professionals. They relied on themselves to make decisions. Reliance is defined by the Macquarie Dictionary as: "... having or showing trust, confidence or dependence ..." (Delbridge, 1986, p.520). In this study, self-reliance in making care decisions refers to patients directing their health care themselves, depending on their own decisions, independently of health care professionals. Most patients who were self-reliant in making care

decisions acknowledged that they would still listen to the advice of health professionals. However, these patients also indicated that they would be prepared to ignore the advice of health professionals if they did not believe that advice was in their best interests. Self-reliance in making care decisions was the strategy used by patients who, having perceived a lack of involvement in decision making, also lacked confidence in those making decisions and in the decisions being made about their care.

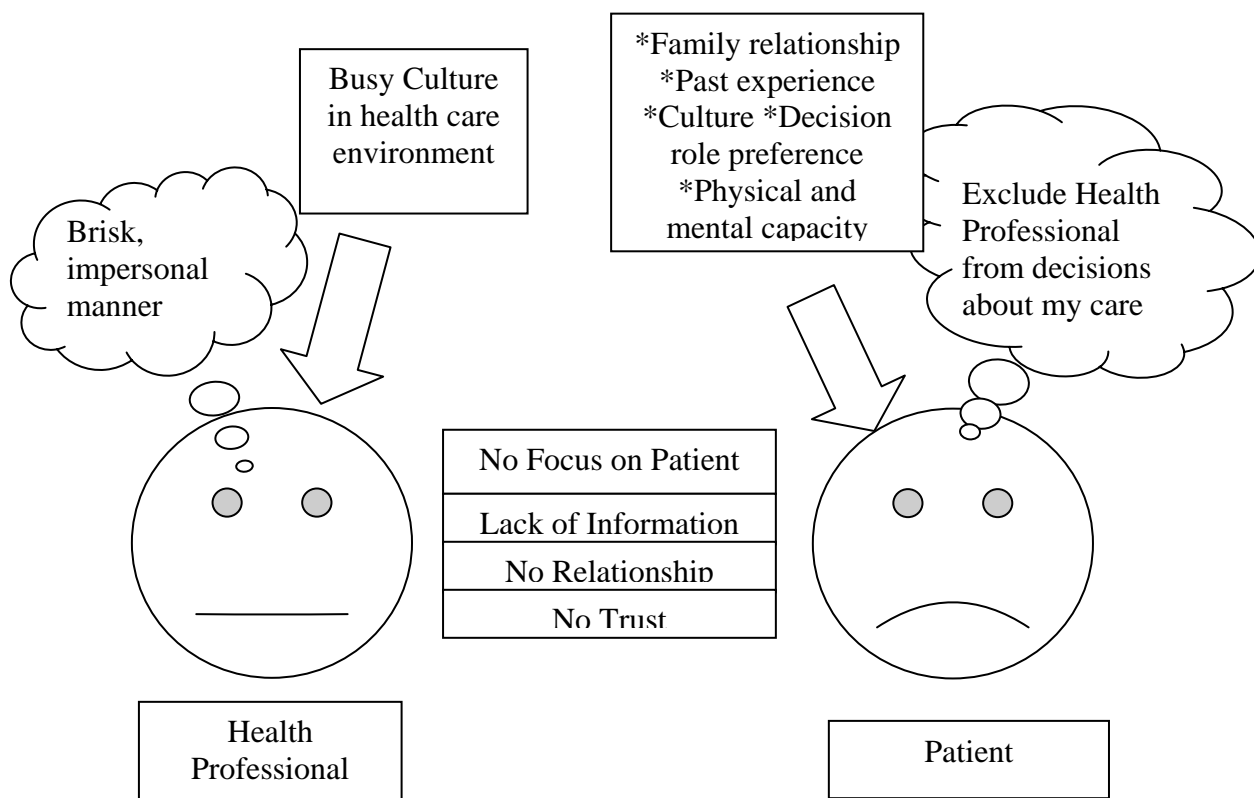


Figure 5.1:
Characteristics of situations where patients excluded health professionals

There was no evidence that patients who stated that they had a preference for making decisions independently also preferred to use the strategy of self-reliance when they were feeling that health professionals included them in decisions about their care. Self-reliance in making care decisions as a strategy was influenced more by the lack of rapport patients perceived they had with health professionals, than the patients' decision role preference. As illustrated in Figure 5.1 above, self-reliance in making care decisions was a response to experiencing a lack of involvement in care decisions and a lack of confidence in the decisions made by health professionals when they did not involve patients.

The self-reliant decision making strategy involved the use of two particular behaviours; *searching for confidence* in treatments and health providers and *being assertive* by arguing with health professionals and demanding decisions be changed.

Searching for Confidence

The act of searching refers to investigating or “seeking to find something” (Delbridge, 1986, p555). Searching behaviour was used as a response to patients’ perceptions of the health care professionals as not caring or not focussing on them and the inadequate advice given by the health care professionals. Patients who were not confident with decisions made because they had not liked the health professional; or felt the health care professional had not listened to them, or had not taken their concerns seriously enough, sometimes took control of making decisions by searching elsewhere to achieve confidence. Searching for confidence involved looking for another health care professional with whom the patient could develop a better rapport or relationship, or who would take further action on their health care needs.

Roma and her husband Joe, in an example mentioned earlier, had been seeing the general practitioner they had decided together was, “*Technically a good doctor*” (Family Joe). As discussed earlier, Joe thought that his wife should continue to see this doctor because of his diagnostic accuracy despite her distress at the way the doctor treated her. Roma felt excluded from decisions, being unable to discuss her care because the doctor’s manner was not gentle or encouraging of such discussion. His “*brutal*” manner (Family Joe) left her distressed following consultations, “... *she came home, she’d be furious ... I can’t remember any of the details. I thought they were minor things, but she’d be trembling furious*” (Family Joe). She had tried to put up with his manner and had talked with her husband Joe, about how she could endure the doctor’s behaviour. Joe’s wife looked for ways of coping with her doctor’s exclusion of her from decisions he was making and then searched around for a doctor by talking to her friends about what their doctors were like. Despite the agreement with her husband to continue to see this doctor, eventually Roma decided to exclude the doctor from further involvement in her care by searching for another doctor with whose manner she was more comfortable and therefore in whom she might have more confidence. Roma’s response to the new doctor she had selected was that he was “*such a nice man*” (Family

Joe). Her doctor being a ‘nice man’ meant that Roma would come home from consultations and be relaxed, and feel more confident about his advice.

Searching behaviour was also used when patients did not feel that their health care professionals were focussed on their issues or taking those issues seriously. Jenny, a patient, explained that she had to seek other opinions to get some acknowledgement of the ear problems she was having; “... *I had a very bad earache ... They kept telling that they didn’t know, there was nothing really wrong with my ear, and I kept going back and seeing different doctors at the surgery ...*” (Patient Jenny). Eventually an acoustic neuroma was diagnosed as responsible for her pain when she was referred to a neurologist by one of the doctors in the clinic. When she continued having problems, she doubted the accuracy of the information she was receiving and this influenced her to seek advice from other doctors.

Another patient, Wayne, also went searching for answers to his ongoing back pain when the information he received from doctors suggested that he had a minor back injury, but it did not respond to the treatment they suggested. Wayne had been playing golf when he developed pain in his back. His local doctor and a radiologist diagnosed a crush fracture of the vertebra; however, the pain did not respond to the recommended treatment of rest. He was still in pain when a bone scan was ordered but that test too, failed to reveal a different diagnosis. Wayne consulted different doctors at his local clinic and other health professionals, but his pain continued.

His wife explained:

... [we] were sick of going to chiropractors, acupuncture. He did have some acupuncture, because at that time we ... didn’t know it was not back trouble, somebody... told us a good ... Chiropractor to go to ... we did that. [We were searching for] the answers (Patient Wayne, wife and son)

In pursuit of confidence in decisions being made about his treatment, Wayne sought answers to his pain by talking to friends and family about his pain and following their suggestions. He tried the multiple treatment options they suggested, but in the face of not knowing what was causing his pain, and not obtaining any relief, his confidence in the decisions being made by various health professionals did not improve.

Another patient had family members who were involved in the medical field who offered options they had researched for his care. David was an eighty-five year old gentleman who had a long-standing relationship with his local doctor. David said that:

... With Doctor [General Practitioner], I'd think ... yes I think she's right. Or if not, I'd tell her straight out I think she's wrong ... She'd take it very reasonably. There wouldn't be any arguments ... I've known [General Practitioner] for a number of years. I've known her, I know her family and everything about her.
(Patient David)

David trusted his doctor enough to be confident in her advice and also confident to discuss any assumptions she had about David's problems that he thought were incorrect. He also trusted the palliative care doctor enough to think his advice was probably reliable, though his confidence was not as high as was the case with his general practitioner. *"I think [I could correct his misconceptions of my needs] ... I've never had the occasion ... Generally [I think he is right], because I've only known him a short time"* (Patient David). David discussed his health care problems with his medically trained relatives, who offered their advice. However, David was not searching for advice, because he relied more on the advice of the health professionals in whom he had developed confidence. David acknowledged that if the opinions offered by his family members were different to those of the doctors in whom he had confidence, he would not take the family members' advice, because he trusted his doctors. David explained, *"... [my son] feeds the information to me. If it's contradictory to my [General Practitioner] or to [the Palliative Care doctor] then I ignore it"* (Patient David).

When some patients whose own efforts at searching for better treatment options or health professionals who would involve them more in decision making, failed to obtain the results they expected, they resorted to arguing with health professionals or demanding alterations in their treatment plans.

Being Assertive

When patients felt that health professionals dismissed their concerns, leaving them feeling that they were excluded from decisions being made about their care, they also attempted to be more self-reliant in making their own care decisions by being assertive. The term "assert" is referred to in the Macquarie Dictionary as "to maintain or defend (claims, rights, etc.)" or "to put (oneself) forward boldly and insistently"

(Delbridge, 1986, p29). Patients and family members who were distressed by a lack of acknowledgement of patients' needs and a lack of sensitivity to their need to be involved in decision making, were assertive. They argued about decisions that had been made or demanded changes to those decisions.

Patients and their family members were indignant and angry about needing to argue or demand. They felt that it should not have been necessary to be demanding if the health care professionals had approached decision making in a way that made them feel involved in the decisions. Their demanding behaviour and arguments with health professionals ultimately distanced the health care professionals from patients and from decision making.

Harry's threat to discharge himself was an indication of his attempt to exclude others from making decisions and to rely on his own decisions. Harry explained how demanding attention was a result of being ignored:

... from the patient's point of view, you must be told what your situation is, what your options are, what's going on, and what they think they can do for you, and if none of that happens, you just start ... getting quite annoyed (Patient Harry)

For Harry, his threat to discharge himself failed to achieve more involvement in decisions or make him more confident about the care he was receiving at this hospital, however, it did mean those health professionals were excluded from his discharge decision:

... all that [threatening to discharge myself] did was get some of them visibly annoyed. 'How dare you'. And other people a bit frantic because of course I had the power to discharge myself, I could just get out and walk whenever I wanted (Patient Harry)

Demanding a particular action from health professionals was not a behaviour in which participants routinely engaged. These patients described demanding changes to decisions about their care after enduring a period of not being involved in decisions about their care. Like Harry, who had a period of days in hospital without health professionals keeping him informed, the patient Jenny had endured twelve months of continued deterioration in her health and increasing pain before she eventually demanded alternative options. Jenny's example of searching for answers to her ear and

back pain was described earlier. In relation to her back pain, she had eventually had to take control of decision making by demanding a referral to a specialist. Her husband explained, “... *because she was getting into so much strife, she demanded to be referred to ... a rheumatologist*” (Family Bob re Patient Jenny). Jenny’s demand achieved what she hoped it would. The doctor listened to her and referred her to a rheumatologist. An X-ray and then scan revealed multiple bone metastases and Jenny was rapidly admitted to hospital for further investigations.

Patients who had difficulty voicing their concerns about lack of involvement in care decisions because of physical incapacity used non-verbal behaviour demanding changes to their care. For example, Sandra’s husband was unable to articulate his needs clearly. When staff made little effort to involve him in decisions, particularly when their decisions were contrary to what he wanted, he demanded their attention and change in the decisions by making distressing noises and sometimes throwing things. Sandra described one situation where nursing staff had indicated to her that her husband had been naughty because, “... *he’d thrown his radio at someone. It really amazed me because he was not a violent man at all. But you see, they had put his brown shoes on with his navy blue trousers. And he was furious about it*” (Family Sandra).

In situations where Sandra was present when health professionals excluded her husband from decision making, she demanded they involve him by drawing their attention to his presence and interest in being involved in decisions. She described a consultation with their dentist who, “... *would think he [my husband] was deaf. He used to say to me ‘now I am going to do this to Mr X’s denture’ and I would say ‘oh I think [my husband] would like to know that’*” (Family Sandra). In her description of Ted’s care it is possible to conclude that he was often excluded from decision making because of his disability. Sandra’s and Ted’s attempts to change the way that health professionals approached decisions about Ted’s care, had little effect. Sandra described her efforts to ensure her husband’s dentist involved him in decisions about his dental health:

I used to try very hard to keep him [Ted] involved in conversations, because it was him that we were talking about ... Peoples attitudes when you are in a wheel chair can be quite extraordinary. [Ted’s] dentist was impossible ... He couldn’t make eye contact. And he was a professional man. He would raise his voice as though [Ted] was an imbecile. (Family Sandra)

Ted's efforts to achieve more involvement in care decisions were also futile. Following the incident with the radio, staff made no effort to understand his demand, but described his behaviour in terms normally reserved for the description of children's behaviour, "*The staff in the nursing home would tell me he'd been naughty. I mean come on, he is not a child*" (Family Sandra). The staff left Sandra to discover what had caused Ted to demand attention and address the problem with him.

Self-reliance in Making Care Decisions was a frequently used strategy patients employed to manage the problem of being excluded from care decisions. Patients behaved independently of the advice of their health professionals, searching for better treatment options and health professionals who would be more likely to include them in care decisions. Some patients were prepared to be assertive, arguing for or demanding particular decisions that they believed were in their interests. Self-reliant behaviour tended to improve the patients' involvement in decisions about their care, but at the same time excluded the health professionals from the decisions. However, because of the severity of their illness or their personality, some patients were physically or emotionally unable to engage in searching behaviour or be assertive to control involvement in making palliative care decisions.

Evading Care Decisions

Some patients, because of the conditions imposed by their physical debility or personality preference for avoiding confrontation, did not use the strategy of self-reliance to gain control of care decisions. These patients controlled their lack of involvement in decisions by sabotaging decisions made by others. They achieved this by evading the questions asked by health professionals and the efforts that health professionals made to care for these patients. The Macquarie Dictionary defines the behaviour "evading" as, "... to avoid doing or fulfilling ... to avoid answering directly ..." (Delbridge, 1986, p206). Some patients responded by avoiding health care professionals and their decisions. Through their evasion of health professionals, patients often curbed their own involvement in decision by delaying decisions. Patients' evading behaviour was effective in controlling involvement in the decisions being made about care and the decisions themselves. Patients in this study, who evaded decisions, did so by withdrawing from care decisions or by rejecting or resisting the approach of health professionals.

Withdrawal

The example cited previously of Campbell; the patient who drew the covers over his head, indicated to staff that he did not want to engage with them in making decisions. Campbell was an elderly man who had lived alone until he was admitted to hospital. He relied heavily on his daughter who lived a short distance from his house to help him. The field notes recorded that:

[His] ... daughter has been heavily involved in her father's care though he lived on his own. She helps with the decision making by ensuring that he has information, understands it and considers all his needs, she keeps the rest of the family informed and provides some direct care. (Patient Campbell)

The interviewer noted that Campbell was “... *pleasantly confused* ...” (Patient Campbell), although he was able to understand the consenting procedure and role card sort with a slower than normal explanation and his daughter's reassurance. However, his daughter did not stay in the palliative care unit and without her there, Campbell found it increasingly difficult to maintain his sense of involvement in decision making because of the conditions of his emotional dependence on his daughter and lack of relationship with the staff who did not seem to listen to him. Among the instructions for care the nurses had been giving to Campbell, was encouragement to ambulate. Campbell was reluctant to use the frame to ambulate, but was unable to make himself heard. The staff reported that they thought he had been “*over nursed*” (Team Observations). However, the nurses had been trying to encourage him to use a walking frame and had not heard his refusal. In pulling the covers over his head and asking “*to be left alone*”(Team Observations), Campbell isolated himself and the nurses from decisions by evading them and the decisions they made without including him. He had effectively delayed the decision that he should ambulate, as the nurses acknowledged that they had been forced to withdraw from their attempts to get Campbell out of bed; “... *so we backed off and will try to get him to use the frame [another day]...*”(Team Observations).

In another case, described by Nurse Riki, the patient's evasions of her attentions by withdrawing were obvious. The patient had been admitted with pain and an error had occurred with her medication dose and she had an unpleasant experience related to overdose. Although she recovered physically from this experience, the development of relationships with staff was damaged. Nurse Riki explained that the patient “*didn't trust*” the staff (Nurse Riki). Nurse Riki knew the patient did not want to engage with

her in decision making even though the patient did not say anything in particular that lead her to that conclusion;

... I nursed that patient that evening and I really just sat around ... I was around her ... but ... I really didn't know whether she was afraid ... [she] was so locked in this little capsule that it was even hard to get to know [her] name ... She would answer questions in one or two words. She would not keep eye contact. She wasn't unfriendly, she wasn't friendly. (Nurse Riki)

The lack of information provided in the patient's answers led Nurse Riki to limit her decisions. Another nurse also described how she read the body language of patients who wanted to evade her attempts to involve them in decision making as closed; “ ... *they might lie on the bed with their eyes closed. Non-moving ... They're closed. Their eyes are closed. They're body is a bit sort tense and closed*” (Nurse Maoki).

Rejecting or Resisting

In another example of evasion the patient resisted care by refusing to go along with the care of health professionals. Sandra described how her husband, Ted, could behave if he felt ignored by health professionals by not cooperating with them. As discussed earlier, Ted would demand change if he did not like the decisions made by health professionals who excluded him. However if he were indifferent to the decision but felt ignored, he would evade care by being uncooperative. Ted was unable to communicate verbally and had diminished fine motor co-ordination, which limited his ability to respond to those who tried to involve or those who excluded him from making decisions. Sandra explained that, because of Ted's incapacity “... *he couldn't co-operate ...*” (Family Sandra of Patient Ted) with the health professionals who he liked and who involved him in decisions being made. However, she explained that “... *you got the feeling that he was [not co-operating] ...*” with health professionals whose manner and approach Ted did not like and who did not involve him in decisions. She said, “... *he looked lethargic, dull ... he just didn't smile ...*” (Family Sandra of Patient Ted).

When patients judged the approach of the health professionals as excluding, they were more likely to resist the questions of health professionals in order to evade their decisions. Sandra's husband achieved this resistance passively, by making his own manner dull and lethargic and therefore less inviting of conversation. In another

example of evasion, Joan was more forthright in rejecting the approach of a doctor by avoiding the doctor's questions. As a result of her evasions, a decision about the care to address her complaint was not made. Joan had suffered a distressing night of diarrhoea and a visiting medical officer was consulted to advise on her care. The dialogue between Joan and the doctor was recorded from the beginning of the consultation, as follows:

Doctor - Tell me what is bothering you today.

Joan - Pain in the groin.

Doctor - Not diarrhoea?

Joan - I don't know [appeared confused].

Doctor - Did the nurses have to help you with a pan or did you have to get up in the night?

Joan - I'm not sure.

Doctor - How is your memory?

Joan - There's nothing wrong with my memory [appeared annoyed]. Doctor - What month is it?

Joan - March [correct]. ...

Doctor - I am not sure whether it [diarrhoea] is being caused by constipation or whether you've got a bug.

Joan - My brother was in yesterday and he had gastro.

Doctor - How could he have given it to you?

Joan - He kissed me.

Doctor - You can't get it like that. It is from contaminated food or water
(Patient Joan Observations)

The doctor made no attempt to get to know Joan or explain why he had been asked to see her. When he launched into a barrage of questions and dismissed her answers and her symptoms, she became evasive by avoiding answering the doctor's particular questions, or answering the questions with a statement. She was indignant when he suspected she might be confused and asked her how her memory was. She rejected his approach stating, "*There's nothing wrong with my memory ...*" (Patient Joan Observations). In this example, Joan's evasion during the consultation by resisting the doctor's attempts to gather information about her condition resulted in no decisions being made to alter her care or address the problem for which the consultation had been made. The notes recorded by the doctor in her medical record stated she was "*a poor historian as she was unsure that she had had diarrhoea*" (Patient Joan Observations) and suggested no interventions to manage her diarrhoea. The doctor in whom Joan had most confidence in decision making, Doctor James, was aware of how Joan used evasion as a strategy to maintain control over who was involved in decisions about her care. He explained that Joan was, "... *relatively selective about what she says to different people ... Because she still wants to keep a degree of control*" (Doctor James).

Although some examples of evasion enabled patients to stall decisions about their care, in another example the patient's avoidance of health professionals enabled him to make decisions independently of the health care system. Harry was adept at evading the attention of health professionals by rejecting their attempts to care for him, and his friends who wanted to help him with various aspects of care. The community nurse explained what happened:

... on the Wednesday, I put my head in the door basically to introduce myself, to say who I was from Palliative Care ... and he then said he ... already had the district nursing involved ... he agreed to see us then on Tuesday. He really wanted minimal input but he agreed that we could come in on the Tuesday, now he went home on the Thursday. I tried to ring him on Friday morning to see how he was before the weekend to make sure he got home all right and ... couldn't get him. Rang his friend ... [they'd] obviously had a long-term friendship and she was very distressed about him, he hadn't answered the phone for her, or hadn't answered the door. (Nurse Kim)

He was cross when the community nurse tried to phone him to check how he was managing. They left a message and “[H]e rang [back] ... and wasn't very happy that I had actually rung and left him a message” (Nurse Kim). He told them that he would call them when he needed them and had not agreed to them calling him. Harry had moved to his mother's house in another district and had not told the community nurses or his friend. Finally the community nurse acknowledged that, “... I don't think he wanted much input. He wanted to get home to finish things that he felt he had to do” (Nurse Kim).

For these patients, their evasiveness with health professionals was accompanied by irritation at the health professionals' attempts to involve them in particular decisions. However, another patient was more significantly distressed by his inability to affect the decision he wanted. Conrad's nurse described how he had wanted to go home, but his family had convinced staff that he should stay in hospital:

... [Conrad] wanted to go home and his family didn't want him home ... He wanted to go home and he couldn't get home and there was no reason why, with supports he couldn't get home. But there was very much this protection of the family. Rather than respecting his wishes and doing the best by him ... [Conrad] was up and about looking after himself and he lived in a unit out the back of his family's house. With supports, he would have managed ... Even for a week, he would have got home for a little while ... [Conrad] wasn't really allowed to be a part of that decision making ... it distressed him to the point where he took to his

bed and became increasingly emotionally distressed where he actually said he wanted to die and he wanted someone to kill him. (Nurse Sui)

The nurse described how Conrad consequently avoided engaging in care activities proposed by the staff. For this patient, he avoided the decisions made that he did not like, such as rehabilitation goals of maximising his physical ability by setting himself in violent opposition to them. Conrad refused to practice walking and would not leave his bed. When a meal was brought to him, rather than eating, he took his dinner knife and tried to harm himself with it. His ultimate expression of distress at not being included in the decision about going home was to reject all the care proposed for him by dying before his disease claimed his life. The nurse explained how Conrad was excluded even from this decision by a closed answer to his request for euthanasia; *“He did write a letter to the doctor saying he wanted euthanasia. And he got a letter back saying ‘no I can’t do that’”* (Nurse Sui).

In addition to the complex family dynamics that influenced Conrad’s participation in decisions made about his care, this patient’s personal characteristics also influenced his ability to respond to his exclusion from the decision to go home. Although Conrad was apparently physically capable and mentally competent, his ability to engage in conversation relevant to making decisions was limited by his extensive oropharyngeal cancer and profound deafness. Conrad communicated via a notepad and pen, but Nurse Sui observed that she doubted the patient had in-depth conversations with other staff. As explained earlier, Conrad was extremely deaf, which made it difficult to communicate with him.

Conrad’s personal style also influenced his experience and response to his lack of involvement in care decisions. He was physically independent but, as identified previously, he conducted himself in ways that were different to the preferences of the staff. Whether or not Conrad was aware that staff found his manner difficult was not apparent in the data, but his attitude towards controlling his activities of daily living and view of women, would have made it more difficult for him to engage in decision making with the predominantly female health professionals in that environment.

One of the strategies patients used to control the involvement of health professionals in making their care decisions was to evade the attentions of health professionals who had irritated them by excluding them from decisions. Although often

avoidance behaviour by withdrawal, rejecting or resisting was a response to mere irritation, more extreme examples of evasion as a response to great distress was evident in the data. Some evasive responses were overt actions and verbalisations; other evasions were subtler expressions interpreted from the patients' body language and verbal tones. Evasion was an effective strategy that interrupted decisions made by excluding health professionals. However, in stalling decision making, the patients' own involvement in care decisions was affected. Self reliance in making care decisions and evading care decisions were strategies used to respond to decisions of which patients were most critical; where patients felt they were not involved. These two behaviours were used to exclude the health professionals who left them feeling isolated from the decisions being made.

Including Health Professionals

When patients felt confident in decision making because they felt they had been invited by a health care professional they liked and trusted to be involved in decision making, the behaviours they used included the health care professional in decision making. (Figure 5.2). Two strategies were used to achieve the inclusion of health professionals; *Sharing the Making of Care Decisions With Others* and *Reconciling Non-involvement in Care Decisions*.

Making Palliative Care Decisions With Others

Patients whose relationships with family and health professionals encouraged involvement and whose personal characteristics related to valuing involvement, whose physical and emotional dependence was low, tended to share the making of palliative care decisions with others. Collaborating or working with health professionals on decisions about their care was likely to result in patients having more confidence in the health professional and the decision. They would respond to health professionals' interest in them by engaging with health professionals in activities leading to decisions about their care, and in this connection would encourage the health professionals' involvement in their care. Patients and health professionals described decisions made when sharing as decisions "... *mutually agreed* ..." (Patient Wayne and Family John), or that were "... *joint decision[s]* ..." (Patient Jenny). Three activities were noted in the

data relating to the strategy of sharing decision making; *Developing Rapport*, *Exchanging Information* and *Compromising*.

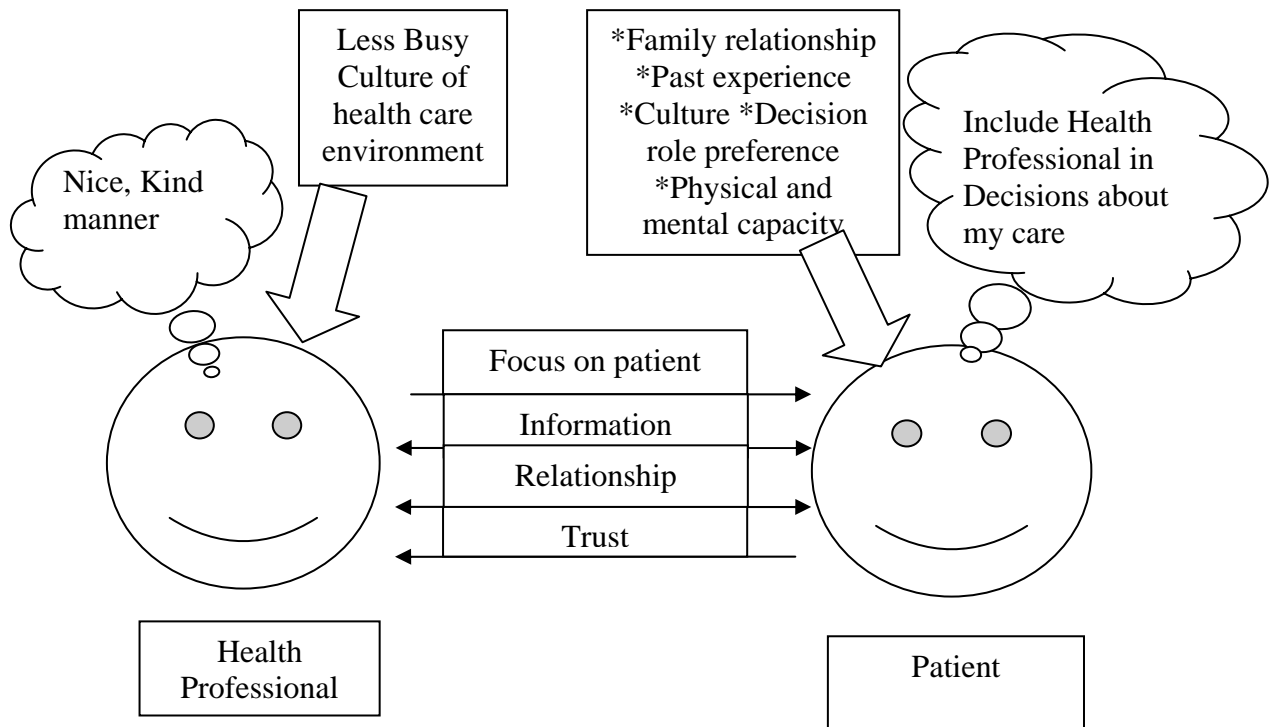


Figure 5.2:
Characteristics of situations where patients included health professionals

Developing Rapport

At the commencement of a decision making moment where the sharing of decisions might occur, patients' initial behaviours in response to health professionals whose manner they liked, was to chat and use humour. Despite the fact that health professionals generally initiated chatting, when patients were prepared to enter into the sharing strategy in making decisions, they responded to the health care professionals' approaches by continuing these light conversations. One health care professional suggested that chatting or asking general questions such as "... [H]ow are you? What is happening for you?" in an initial meeting with patients served to "... find out if there are any issues that they need addressed ..." (Nurse Sui). One of the patients interviewed acknowledged that chatting was part of initiating the business of making decisions.

David valued the relationship he had with his general practitioner and had a preference for being actively involved in decision making. He was an articulate man

who, until his hospitalisation, had cared for himself at home. Although David's family was supportive, they did not take active roles in making his health care decisions. David believed his decision making with his general practitioner always worked well because "... *I've got a tremendous rapport with [my general practitioner]*" (Patient David). He said that at the beginning of a consultation with his general practitioner, "... *it's a real friendly welcome with her and before we get down to medical treatment, we have a nicely little homely chat and then we get down to business ...*" (Patient David). They chat mostly about David's life at home such as, "*What I'm doing at home or how I'm getting on at home ...*" (Patient David).

Health professionals were observed engaging patients in general conversations that required the patient to identify issues about his or her everyday living circumstances. For example, a discussion with one patient about her enjoyment of making scones led to her talking about how well she was eating and discussion about the game bingo led to her identifying activities to which she wanted to return (Team observations).

Another aspect of developing rapport in readiness for sharing decision making was the use of humour. Patients who made palliative care decisions with health professionals also shared a sense of the ridiculousness of their situation. Patients and health professionals shared amusement as a part of developing a rapport early in a decision making moment. However, patients and health professionals also used humour as a response to the sometimes-brutal honesty of the discussion and information shared when making care decisions.

For example, Louise enjoyed sharing care decisions with her health professionals in palliative care because of the individual rapport the health professionals developed with her. She found conversation and humour an essential ingredient of her confidence in being involved in palliative care decision making, "*We have good conversations and sometimes some humour ... Before the health professionals just denied what I said, but here the health professionals accept what I want*" (Patient Louise).

Humour and an acceptance of her individuality allowed her to feel she could indulge freely in fantasies about travel and distant countries, which she had previously been discouraged in doing. She explained, "... *my heart is free ...*" (Patient Louise).

Her previous experience involved health professionals who she said discouraged sharing care decisions and insisted that she face reality and whom she also accused of not showing their "... *humanity ...*" (Patient Louise). The lack of humour in these interactions left Louise conscious of the power difference between them and her subsequent feeling of isolation about the care decisions made.

A number of health professionals and patients were observed sharing humour in their discussions that enabled patients to acknowledge that a decision they had been unwilling to accept, was an appropriate decision. Joan laughed as she suggested that when her doctor said, "... *I can't go home today. He said 'he is the boss' – [I replied] when he is right ...*" (Patient Joan 1 Observations). The humour allowed Joan, whose decision making strategies fluctuated depending on her relationships with health professionals and her level of dependence, and her doctor to acknowledge each other's part in reaching a decision. Joan also used humour to convey to health professionals how she was feeling about their approach to decision making; to remind them of her intention to be involved in making her care decisions. She did not like to be told not to do things and when a nurse visited her at home Joan explained that, "... *when she came in, she started on me because I'd had a cigarette, and I said don't, oh alright, she said what are you doing, I said I'm trying very hard to do everything everybody told me not to do. So, we got on rather well after that*" (Patient Joan). Joan's humour was a prompt to the nurse that she preferred to be asked rather than told what to do. Being asked would allow Joan to be involved in the decision and to enable her to invite the health professional to share in the decision making.

At other times humour was initiated by the health care professional to set a tone of behaviour where sharing control could be feasible and accepted. One nurse explained why her initial approach to patients included humour: "... *have it light and airy and a bit of a joke, if they're up to it ... defuses the situation and starts on a level playing field so they think, oh this nurse won't be too bad. She won't be intimidating or frightening*" (Maoki Nurse). When the rapport was established through chatting and using humour, discussion could take on more serious tones that led to the exchange of information about the decisions to be made.

Exchanging Information

Conversations between health professionals and patients were important behaviours identified by patients and observed during the study, related to the strategy of sharing care decisions. These conversations featured the exchange of information in a discussion. The dictionary describes the activity “to discuss” as “... to examine by argument; sift the considerations for and against; debate; talk over ...” (Delbridge, 1986, p171), and is therefore an activity where each party shares information and comments about that information. Exchanging information as a behaviour related to sharing decisions was described by one doctor as going beyond just giving patients information:

I think if the doctor just gives the information to the patient and says now you decide to the patient, it is too much for the patient. But if I can share ... the information, it helps the patient and becomes good medicine for the patient ... I will give the patient information, give them time to think about it and then the patient will tell me about their perspective. That's ideal (Doctor Sam)

In this study discussion was often, initiated by health professionals. When patients believed they had developed a rapport with the health professional, the discussion initiated by the health professional, could then be steered by the patient into areas they may have felt inhibited in discussing with other health professionals. In such discussions, patients were able to more fully describe their issues and feelings to health professionals. Nurse Sui described a good decision process where by a patient gained the support of his health professional by discussion of a decision that other health professionals, who had not had similar discussions, were less supportive of:

... [George] was an elderly gentleman who had a bladder tumour and over several years had had lots of treatments and catheterisations and cystoscopies. In the final stages [he had] ... incontinence and no discomfort physically but he was being pushed by the nursing staff to have a catheter put in and he really didn't want it. The doctor went in and had a chat with [George] and talked to him about the comfort of having a catheter and [asked] what did [George] want and talked about the fors and againsts and basically [George] still decided that he would rather be incontinent and not have a catheter. That was the way he wanted to be managed. And that decision was left at that – [George] was encouraged by the doctor that ... “that is your decision and that is fine”... it wasn't a case of ... “you aren't going to be dry, if you have a catheter in, you won't have as many frequent changes of position”... [George] was given the opportunity to decide ... they discussed the options of condom drainage and that which the man also declined. He didn't want to go there and was happy to be changed regularly despite the fact that the movement might get uncomfortable

... That was his decision, that was how he wanted it to be managed ... The decision was supported ... the nurses weren't that happy because it was increased workload for them but...I don't think there was a realisation that [George] has had such a lot of these procedures before and it was uncomfortable for him, he didn't like it and he didn't want to go back there again. (Nurse Sui)

George's response to the doctor was quite different to the strategy he used with the nursing staff. Because they were critical of his desire not to have a catheter to manage his incontinence and failed to acknowledge his experience with catheters, he was "... closed off to them a bit because he would lie in his bed with his eyes shut. He pulled back a bit" (Nurse Sui). The doctor's approach to George was different to that of the nurses', in his preparedness to listen to George and develop an understanding of George's perspective. George was prepared to include the doctor in the decisions he made because the doctor's approach was to involve George in making decisions about his care. The discussion between George and his doctor resulted in an understanding between them of the decision. The burden of the decision was shared because they presented a strong and united front to the nurses who were less supportive of the decision. As a consequence, George "... appeared more relaxed because he wasn't under pressure to have the catheter put in" (Nurse Sui).

George's case also illustrates elements of the exchange of information that occurred between patients and health professionals when they make care decisions together. These elements were commenting and asking, and listening and understanding.

Exchanging information as an activity of sharing care decisions is dependent on the preparedness of patients to ask questions and tell health professionals about their concerns. Jenny had an unplanned readmission to the palliative care unit with an exacerbation of hip and back pain. During the initial consultation, Jenny explained to the doctor that she had not undertaken any activity that would have exacerbated her pain,

Jenny - I don't know what happened, I haven't been doing anything ...

Doctor James - ... very tender over old fracture site, which may indicate it has given way again ... will need a few days rest and more morphine

Jenny - What about stronger drugs ... ?

Doctor James - ... if you are in pain, take morphine [every hour] till the pain is relieved. If needed, we can then increase the Fentanyl ... it is possible to give

the pain relief into the spine ... if it isn't possible to get good control with oral medications. (Patient Jenny Observations)

In this study, talking to health care professionals did not always result in a clear understanding of patients' issues. Understanding required health professionals to identify cues and lead conversations in ways that identified problems and clearly articulated decisions. If either party was not clear about their intentions in a conversation, confusion ensued. In a situation where a patient requested a consultation with a doctor, the patient indicated she wanted to discuss the past management of her arthritis. During the consultation the doctor allowed the patient to talk and concluded from the conversation, "*she just wanted to talk ... I think she is quite sad ...*" (Patient Joan Observations). The patient's description of the conversation was that, "... *she had just spoken to the doctor and he was looking for another way of managing her arthritis*" (Patient Joan Observations). Despite the patient's conclusion that a decision had been made about the doctor investigating her arthritis management, the doctor's conclusion was a decision to refer the Joan for pastoral care. This patient expressed her confidence in the way she shared decision making with this doctor; however, it appeared that the decision made was not shared.

Joan's lack of directness in telling the doctor of her specific concern may have led to a misunderstanding about the nature of the decision to be made. Other patients were aware that being straightforward in exchanging information was an important component of decision making. June was a patient who also had a preference for active involvement in decisions made about her care. She went to her doctor regularly in order to, "... *keep in touch with him to let him know what's going on*" (Patient June). She explained that, "... [M]y attitude is unless you tell the doctors what's wrong with you how the hell does he know what's wrong with you ? ... you're up front with everything. You can tell them anything ... You can ask them anything ..." (Patient June).

Another element of exchanging information, related to sharing care decisions, was listening. When health professionals gave explanations or information in relation to the questions patients had asked or the problems under discussion, listening to those explanations provided them with the basis on which to continue the discussion and understand the decisions they were making. The decision to go into hospital was often one that patients made after listening to the health professionals explain the reasons why an admission was preferable for their care. Joan was readmitted after a tiring time at

home where a number of problems had occurred, including confusion over her medications. She explained that although she had been determined to stay at home the decision to be readmitted was, “everyone’s ... *I listened to everyone and then agreed to come in*” (Patient Joan Observations).

Listening to and understanding these explanations enabled patients to feel more involved in decision making, even when they did not feel that they had made the decision themselves. Their sense of sharing the decision was derived from their understanding and agreement with the decision rather than decision control. The patient, Jenny, often described her medical decision making in this way. One example occurred when she asked about further infusions of a drug, which she believed might help her. The doctor had explained that though she had appeared to improve after a previous infusion of this drug, he believed the improvement was coincidental. She had listened to the detailed explanation of his conclusion and agreed that it was the right decision not to have the drug. Although she did not believe she had made the decision, the doctor had been making the decisions, listening to the explanation gave her a sense of confidence and involvement in the process of making the decision.

... I asked him this morning about having another infusion ... yesterday he told me that there’d be no more infusions ... that he didn’t feel as though they were working ... I’m having an X-ray tomorrow done, to make sure that it is broken, fractured, like he thought it was. And so yes, Doctor [James’]s been doing the decision making for the last few days, he’s been telling me what we’re actually going to be doing ... that’s the second time we’ve spoken about them and he seems to be quite adamant that ... we’re on the right track and I don’t need them, they’re not doing me any good ... I’ve improved now ... with the infusions, it should have taken a much shorter time. So if the infusion was going to work, it would have been a couple of days ago, that’s why he doesn’t think it’s worked, that’s why he doesn’t want to give me any more, because he doesn’t think they’re working. So ... I think it’s not coincidence, I think the Morphine and other drugs ... the other patch that he’s increased has really helped ... quite happy [with the way that those decisions are being made] ... it’s been explained. I do [understand] (Patient Jenny)

Later in her admission, Jenny decided to ask more questions about the option to have pain relief in her spine. In preparing for making the decision with her doctor, Jenny first asked the nurses if they thought that the morphine was working to relieve her pain. After listening to the nurses’ explanations, she was ready to share the possibility of further options to treat her pain, with the doctor:

The nurses and I have decided that the morphine isn't working, as I go to sleep on it, but wake up in pain. So I asked to speak to Doctor [James] about other options. I think I am ready to talk to an anaesthetist now, but I don't want to be numb, not able to get out of bed, with heavy legs and that (Patient Jenny Observations)

For patients who were physically or mentally limited in their capacity to participate in exchanging information, sharing care decisions was compromised as a strategy for managing a lack of involvement, by patients' inability to have discussions. Sandra described how she would try to encourage her husband's involvement in making care decisions by ensuring that he was at least given information and asked his opinion. However, he was rarely able to do more than indicate his assent or dissent in decisions. She explained that she felt she had to take responsibility for difficult decisions such as those about resuscitation because, "... *the finer points of being fearful and wanting to talk through that, he didn't have that ability ... to not be able to talk about that would have been sheer hell*" (Family Sandra).

The exchange of information between patients and health professionals by chatting, talking, asking and listening therefore led to better understanding between the parties, sharing the decisions and the opportunities for them to balance options and compromise.

Compromising

The term "to compromise" is defined as "... a settlement of differences by mutual concessions ..." (Delbridge, 1986, p120). In this study, sharing the making of care decisions involved patients weighing up their options based on their discussion with health professionals. Compromising involved finding a balance between the potential harmful effects of their options against the potential benefits of other options. The patient, Jenny, was conscious of compromising on many aspects of her activity as her condition changed. A committed smoker, she often wanted go outside for a cigarette, but had been advised to rest in bed to allow some healing of fractures in her pelvis and minimise her pain. The implications of not resting had been explained to her and she attempted to limit her periods out of bed as a compromise. When questioned about how she negotiated with the nursing staff, she explained:

... They ... don't really order, they're very compromising ... I can suggest ... "can I just ... go outside once more before you lock the door" ... they always say, "oh yes, alright then, go on and then straight back to bed" ... but ... in a very lovely way. (Patient Jenny)

With an occupational therapist that was making recommendations to Jenny about modifications to her home in preparation for her discharge, Jenny negotiated about how much change was required. She said, *"I don't really want bars hanging around the house too much ... but I think the shower's very important"* (Patient Jenny). Despite this negotiation and her agreement with the decision, Jenny said *"But there was no decision making on my part either with that ... because she went out to the house ... and told [husband]"* (Patient Jenny).

David compared the process of making decisions with different doctors. With his general practitioner, David described sharing decisions by negotiating compromises sometimes challenging his doctor. He acknowledged that if this doctor suggested an option with which he did not agree, then he would tell her and they would negotiate options until they agreed on a decision. David explained that, *"... [W]ith Doctor [General Practitioner] ... I'd say yes I think she's right. Or if not, I'd tell her straight out, I think she's wrong ... She'd take it very reasonably. There wouldn't be any arguments ..."* (Patient David).

Although compromise in sharing care decisions enabled David to feel that he was able to correct what he thought were his doctor's inaccurate perceptions about him, sometimes compromise meant that patients accepted decisions that they had originally opposed. Nurse Rikki described a situation that she believed was an example of a good decision, where the patient was involved in the decision and was content with the decision made and yet the decision was not what the patient wanted initially:

The issue at the end was this woman's request to die at home and the family was supportive of that ... deterioration was rapid ... but with the support available the family agreed that they would try their best ... I supported the fact that it would be difficult ... So the ex husband had a meeting with the rest of the family who were suppose to be going to care for this woman and they decided that no, we are not going to bring her home. Because we cannot do what the nurses are doing to make her comfortable ... But it was also that the patient, although she was really drowsy, she was able to participate with the decision making ... the ex husband spoke to her ... and was very compassionately expressed ... And she admitted that she understood how difficult it was going to be ... The following

morning the two doctors came ... And the patient was asked about the decision and she did agree that she would stay in the unit. (Nurse Riki)

Sharing control of decision making with health professionals involved patients discussing their situations and options, compromising their desires based on that discussion and using humour to acknowledge their shared humanity and desire to be involved in care decisions. Sharing decision making was dependent on the approach of the health professional who was prepared to listen and understand the patient, and the patient whose physical and mental abilities allowed them to be involved and to involve others.

Reconciling Less Involvement in Care Decisions

There were a number of examples in this study where patients appeared to be following the directions of their health professionals, neither making decisions themselves nor sharing the making of decisions as explained above. However, in many of these situations, though patients denied being involved in decision making, they did not feel isolated or excluded from decision making, nor were they discontent with decision making. They were reconciled to decisions that needed to be made, even without their involvement. The term reconcile is defined as “to bring into agreement or harmony; make compatible or consistent ...” (Delbridge, 1986, p515). In this study reconciling less involvement referred to the strategy patients used to allow family and health professionals to make decisions when independent control and sharing involvement did not seem possible to them. The two elements of reconciling control identified were *being pragmatic* and *recognising expertise*.

Being Pragmatic

June was asked about what she would do if someone told her she would not be well enough to go to a family wedding she wanted to attend. She initially said that she would, “... *go anyway ... go even if I’ve gotta go in a wheelchair ...*” however, she qualified this by acknowledging that she would need to “... *be practical ...*” (Patient June). Patients acknowledged that sometimes the decisions that they made would need to be changed when it became impractical given the patients’ circumstances at the time. In those circumstances, patients needed to reconcile or come to terms with their lack of involvement in decisions. For example, by saying that she would not be swayed from

her decision to go to the wedding, June did not mean that she would expect to go even if her condition made it impossible for her to even sit in a wheel chair. She expected that every effort would be made to facilitate her decision, but she was still aware that the decision had to be feasible and practical. If the reality of her circumstances at the time of the wedding meant that her attendance was not feasible, then she would be pragmatic and allow her decision to be changed.

The term “pragmatic” is defined as “... treating historical phenomena with reference to their causes, antecedent conditions and results ...” (Delbridge, 1986,p 480). Being pragmatic in this study involved patients weighing their desired decisions against their abilities and those of others, to effect those decisions. Patients found that they needed to be pragmatic when their symptoms were out of control or when their physical condition deteriorated. Being pragmatic meant allowing others to make decisions because of changed circumstances. Although patients acknowledged that they agreed that these decisions were appropriate, they stated that it was others, rather than they, who made the decisions. The patient Jenny explained,

... when you are in pain, you don't control decision making. You just go to those who can help and tell them to 'do what you have to do to fix me'. You are not in that state of mind [for making decisions] when you are in that much pain
(Patient Jenny)

Even Harry, who on a number of occasions exercised his preference for independent control of decisions about his care, was pragmatic when it came to the decision to transfer him from hospital to the palliative care unit. He knew he was not well enough at that point to go home, though that was what he wanted to do. He accepted the decision to transfer because the facilities at the palliative care unit were described as more comfortable than the facilities in the acute hospital. Harry had been anxious about why he was being referred to palliative care:

... I was going shit ... I'm not one for the box yet ... But ... he [Doctor James] gradually got it through to me that that's not really what it's all about ... it can be a lot of rehab ... getting you back upon your feet, even if it's ... not [a] permanent aspect to the work [not likely to improve his condition permanently].
(Patient Harry)

He was given the information relevant to the decision and agreed. He said Doctor James, “... basically described the facilities here, it was a bit like saying, where

would you rather go, to Flinders Street Station, or Tahiti?... the answer was bloody obvious” (Patient Harry).

Like Harry, other patients felt that when they had no options, they had to be pragmatic in decisions. Despite normally using the strategy of sharing involvement in decision making, there were times, particularly when she faced treatment for her cancer, that Jenny was pragmatic. When Jenny talked about her decision regarding the treatment options for her cancer, shocked at the diagnosis and in pain, she did not question whether she should have the only treatment offered, “... I had this lower, very bad lower backache and it was actually cancer of the bone. So I had radiation ...when they said I’d have radiation, I didn’t really question it ... I just thought well that’s what we have to do ...” (Patient Jenny).

As the physical condition of patients deteriorated and their impending death became more obvious to staff, patients were observed focusing on particular decisions and reconciling their lack of involvement in other decisions. For some patients, they seemed aware of a significant change in the way that they were approaching care decisions. When phoned to confirm an interview date, Joan who had been fiercely independent, going to great lengths to be at home and active, stated that she was tired and emphasised that she wanted to go to bed permanently. The next day she agreed to admission to the palliative care unit and refused further interviews and other visitors. She died nine days later. The field observations recorded this change in Joan’s decision strategies over a five-day period towards the end of her life:

26/4 [Joan] only wants nurse’s visits once or twice per week and these will be negotiated visit by visit ... 30/4 [Joan] told me she is tired and wanted to go to bed - permanently. She asked if I knew what she meant 1/5 ... she is tired and unwell. She has been admitted for assessment (Patient Joan Observations)

Joan often described how she was not so “*proud*” (Patient Joan) that she would allow herself to suffer rather than change a decision. In this situation, she appeared to frame her agreement to go into hospital as merely the logical thing to do.

However, other patients struggled to reconcile being pragmatic with long desired outcomes for greater independence. In the month before she died, Jenny remained in the palliative care unit despite wanting to go home. Although the medical record noted that

she maintained control over her pain medications, it also stated that Jenny had said, “*I wonder whether the pain will ever improve*” (Patient Jenny Observations). Over subsequent days the records noted Jenny’s struggle, reported by her health professionals to reconcile the decision to go home with her deteriorating condition and impending death:

26/6 ... the past few days indicate [Jenny] is starting to become more aware of deteriorating and terminal condition. She is starting to make decisions about her funeral etc. and where she wants to die. She is quite distressed and preoccupied ... she is doing remarkably well and should get home ... she is mentally talking about dying and physical deterioration ... if she does go home, she should do what the Occupational Therapist suggests ... 11/7 ... she couldn't go home without a lot of support. (Patient Jenny Observations)

Jenny’s condition continued to deteriorate over the ensuing weeks and she did not go home again before she died. For Jenny, with her limited physical and emotional energy, once she started focussing on decisions about her funeral and the fact that she was dying, getting home became less of an imperative. However, as her condition deteriorated over time, the staff expressed more concern about the feasibility of her going home and no record of her opinion about going home was recorded. Although there was no evidence of any coercion in the data, it suggests that she might have submitted to the pressure; however subtle, to not go home.

Other patients also appeared to be submissive or complacent about care decisions. Concern about patients being submissive was reported by two family members who felt that the patients’ behaviours were out of character with their usual approaches to making decisions about their care. In one example, the field notes record John’s surprise that his father, Wayne, left decisions to his local doctor when he was normally distrusting of doctors:

[John] was surprised because his father had always seemed so untrusting of the medical profession. Yet he trusted the General Practitioner, who was so indecisive. [John] hadn't known this until he met the General Practitioner and found he wasn't as he expected him to be. He did appropriate diagnostic investigations, but didn't follow through, and wasn't questioned by [Wayne]. All along, [Wayne] was defensive of the General Practitioner, concerned if he complained the General Practitioner's nose would be put out of joint. That was unusual for [Wayne], he would normally argue if something wasn't right. (Family John re Patient Wayne)

Wayne's doctor also stated that Wayne was passive in decision making, "[H]e is an extremely difficult gentleman to get to know ... he is introspective, he is relatively passive, very passive and doesn't volunteer much" (Doctor James). However, when Wayne talked about why he was happy for others such as his son and local doctor to control decisions about his care, he did not believe he was being submissive or complacent by not being involved in the decisions. When his son, John explained there was, "... much he [the General Practitioner] ... has been doing, but ... we discussed that with him ... he [the General Practitioner] was more than agreeable and was happy to leave it to ... us and district nurses and Doctor [James]" (Patient Wayne and Family John). Wayne added:

Oh yeah ... it's all worked out very well ... they all know better than me, so why not let them go ... I've got the greatest confidence in what they're doing so, I see no shovelling that over at all, I think it's just ... logical thinking to go their way.
(Patient Wayne and Family John)

Being pragmatic was described as being practical or logical about not being involved in particular decisions. Wayne's example above demonstrated that, in being pragmatic, patients would also reconcile their need to be involved in decision making by acknowledging the particular expertise of a health care professional in the field relating to a decision.

Recognising Expertise

A person who is an expert may be defined as having "... particular skill or knowledge in some particular field ..." (Delbridge, 1986, p211). In the situation discussed earlier where Wayne described his pragmatic approach to not being involved in decision making with his son and local doctor, he also commented that they "... *know better than me ...*" (Patient Wayne and Family John). A number of patients acknowledged that there were decisions, particularly those related to medications and other specialist medical knowledge, where the health care professional was more likely to know the best decision for them. In these situations, patients recognised the health professionals' expertise and were confident about the health care professionals controlling those decisions without involving them.

Jenny discussed the structural changes recommended by an occupational therapist who visited her home and explained that she was confident in the decisions that the occupational therapist was making:

... she's really good ... she was a really good help. But there was no decision making on my part either with that one ... it's not so much for compromise ... we shouldn't have to compromise in situations like that, because that's a safety thing, and she knows what she's talking about (Patient Jenny)

In another example, Joe identified that the expertise of staff caring for his wife, Roma, while she was undergoing radiotherapy, ensured he and his wife had no decisions to make. He said, *"The radiation people ... were absolutely first rate and there were no decisions to be made"* (Family Joe). The patient Harry also acknowledged that he would hand over control of decision making to one particular doctor whose skill he trusted emphatically. Of this particular surgeon, Harry said, *" ... I will accept without question what he says, because he is an absolute expert ..."* (Patient Harry). In these three situations, the patients did not indicate that the health professionals they were talking about were also health professionals with whom they would normally share control of decisions.

However, patients recognised expertise in health professionals who demonstrated their knowledge and skill and with whom patients had developed a trusting relationship. Some degree of reconciling involvement also occurred in these relationships where patients would normally describe the making of their care decisions as shared. Joan provided insight into this behaviour when she explained that she would allow the doctors that she liked and respected to make the decisions. The field notes recorded her explanation off tape as:

... if she feels concerned about it at all then she can ask questions. Providing she can see a benefit to her, she'll go along with their decision. It wasn't that she was a partner in the decision making, just that she expected them to do their job (Patient Joan)

Reconciling control was a strategy involving being pragmatic and recognising expertise, that patients used in response to increasing symptoms, where there were minimal options or when patients believed that the health care professionals' expertise was clearly paramount in these decisions.

Reflections on Related Literature

In this study, four strategies were used by patients to control their involvement in decision making, by either the inclusion or exclusion of health professionals. Scant attention is paid in the literature to how patients involve other participants in decisions about their care in this way. However, the terms “control”, “involvement” and “participation” are discussed in relation to patients and the determination of health care decisions (Cahill, 1996; Peplar & Lynch, 1991).

The Nature of Control and Involvement in Care Decisions

In this study, the process used by patients in response to their perception of a lack of involvement in making health care decisions involved them attempting to control the involvement of others. A number of studies discuss the issue of control of decision making (England & Evans, 1992; Peplar & Lynch, 1991). England and Evans (1992) identified a large body of literature produced in the 1980s that emphasises the importance of locus of control in improving health outcomes. However, participants in this study described strategies they used in response to their lack of involvement in, rather than their lack of control of, health care decisions.

The study by Peplar and Lynch (1991) recorded interactions between nurses and terminally ill patients to discover the relationships between invitations to take control of decisions and the outcome of that invitation. This study revealed the distinction terminally ill patients make about control and involvement. They discussed the difference between being able to control small things and being unable to control big things, such as not being able to control death. However, even though they could not control these larger problems, patients still benefited from the feeling that they were managing their situation (Peplar & Lynch, 1991). This was more likely to occur when patients were involved and involving others in their health care decisions.

The examination of interactions in the study by Peplar and Lynch (1991) emphasised the individuality of decisions undertaken by different individuals, involving different decisions and under different conditions. The individuality of decisions was described in this study as decision making moments. Another study that examined the approaches eleven palliative care patients used with regard to the conversations they had about decision making with nurses also concluded that patients used different

approaches for different decisions (Clover et al., 2004). In addition, a study where thirty-seven relatives of dying patients were interviewed about their own and patient decision making behaviours, found decision making behaviour was highly contextual (Sahlberg-Blom, Ternestedt, & Johansson, 2000). Although their study was limited by reports of patient behaviour by a relative some months after the decision making occurred, Sahlberg-Blom et al. (2000) found that decision making behaviour changed over the course of the terminal illness.

Self Reliance and Evading Decision Making

Sahlberg-Blom et al. (2000) identified four variations in decision making behaviour that included self-determination, co-determination, delegation and non-participation. The self-determination category included patients making decisions independently by putting their own needs ahead of their relatives and others, having difficulty accepting their situation, being determined, exacting and demanding, strong-willed and purposeful, wanting to be in control and sometimes lacking in trust of those around them (Sahlberg-Blom et al., 2000, p302). The authors concluded that those patients categorised as self-determining and non-participating caused relatives more stress and both groups “were characterised by insufficient dialogue between patients and relatives” (Sahlberg-Blom et al., 2000, p309). This category and the category of being adamant, identified by Clover et al. (2000) bear resemblance to the strategy of self-reliance in making care decisions identified in this study, where patients lacked trust in their health professionals and were assertive in communicating their needs.

“Non participation” was a category identified by Sahlberg-Blom, et al. (2000) that included patients who were passive in their behaviour, did not accept their situation, were apathetic or resigned, disappointed, angry, irritated and also distrusting of those around them (Sahlberg-Blom et al., 2000, p303). This category bears similarities to the strategy of evading care decisions in this study, where patients were often dissatisfied with the behaviour of health professionals, and appeared to resist care decisions by avoiding the health professionals’ attempts to engage them in decision making activities.

Clover et al. (2004) found that patients were tolerant of the bossiness of health professionals, excusing the overbearing behaviour of their nurses and reflecting the power health professionals exerted over vulnerable patients. In this study, however,

patients would only tolerate bossiness in health professionals with whom they had developed a rapport. Behaviour that might be perceived as bossy by those outside the relationship, was perceived by those involved as part of the communication style of the relationship. When bossiness was not a part of a developed rapport, patients in this study excluded the bossy health professional by being self-reliant or by evading care decisions. Clover, et al. (2000) acknowledged that patients were willing to manipulate health professionals by withholding information material to particular decisions if they thought their preferences would be ignored.

The attempts of patients in this current study to exclude health professionals that they did not want involved in their care decisions resembles a strategy described by Irurita and Williams (2001) used by nurses to avoid patients. Nurses in that study, faced with threats to their integrity from competing needs of patients and stress, attempted to avoid the attention seeking attempts of patients in order that the nurse could balance the needs of all the patients under their care. Patients in this study also attempted to protect their decisions by evading the attentions and attempts of health professionals to make health care decisions.

Sharing Decision Making

In this study, the decision making role most valued by patients and health professionals was sharing or collaborating on health care decisions. The strategy used to achieve this was identified as making palliative care decisions with others by developing rapport, exchanging information and compromising. The study of palliative care patient participation in decision making discussed earlier by Sahlberg-Blom et al. (2000) identified the category of co-determination where patients, relatives and caregivers were supportive of each other, considerate and cooperative. Patients who were identified in the codetermination category also had insight into their situation and expressed their needs and wishes (Sahlberg-Blom et al., 2000, p302).

The concepts of negotiating and compromising appear as features of palliative care patient and nurse decision making in other studies (Bottorff et al., 1998; Clover et al., 2004; Irurita & Williams, 2001). Although Clover et al. noted that “examples of true negotiation were not widely described” in their study, they did find situations where patients negotiated and compromised on their choices with nursing staff (Clover et al., 2004, p338). Negotiating with others enabled the patients in a study by Bottorff et al.

(1998) to balance their competing needs and the reality of their situation. In a secondary analysis of the data from that study to examine how nurses supported or restricted patient participation in decision making, Bottorff et al. found that nurses also used negotiation to facilitate patient involvement in making palliative care decisions (Bottorff, Steele, Davies, Porterfield, Garossino, & Shaw, 2000).

Irurita and Williams (2001) noted that compromising was a major feature of decision behaviour in the theory developed from two studies of patients and nurses. Patients and nurses were found to use a process of balancing and compromising when threats to their integrity were posed by the vulnerability of patients and the inability of nurses to provide high quality care to all patients (Irurita & Williams, 2001, 581). Balancing and compromising were found to be a reciprocal process, where both nurses and patients negotiated to balance the weight of competing needs and desires. Although this study focused on patients' strategies for managing their involvement in care decisions, the nature of compromising involved mutual concessions between patients and their health professionals and is by necessity, reciprocal.

Reconciling Less Involvement in Care Decisions

In this study, when patients were physically or emotionally unable to be involved in decision making, they often became reconciled to less involvement in care decisions. They allowed others to make their health care decisions by being pragmatic and acknowledging the expertise of their health professionals. Reaby (1998) concluded from her study of women making breast restoration decisions that a lack of insight into their own information-seeking behaviour in decision making resulted in their preference to leave the decision making to others (Reaby, 1999). However, Clover et al. (2004) acknowledged that patients take passive roles in health care decision making for various reasons including fluctuating health, recognition of expertise, fear of health professionals and poor communication skills of nurses that failed to create opportunities for patients to participate in decision making. They described two categories of patient acceptance of health care decision making by others; one where the patient was passive in their acceptance and the other where the patient was more active. Quiet acceptance of health professionals' advice occurred where patients did not seek to understand the decision, but accepted the advice of people they considered experts. The active acceptance of a health care professional's advice involved the patient understanding the

advice of the nurse and agreeing with the advised decision (Clover et al., 2004). However, the strategy of reconciling less involvement in care decisions in this study involved patients more actively deciding that they would be less involved in their health care decisions. Although they often preferred to understand the decision, patients would also accept a decision without necessarily seeking understanding from a trusted health care professional.

A study of 34 cancer patients' decisions about cancer treatment in Finland confirmed that of the patients interviewed, 18 patients passively accepted the recommendations of treatment by not refusing the treatment and were satisfied with decisions because their physicians were expert. However, despite being described as passive in their decision making, many still believed access to information was important for alleviating anxiety and some were active in gathering information (Saino et al., 2001).

The description of delegation by Sahlberg-Blom et al. (2000) in their study of the decision making behaviour observed by gravely ill patients' relatives, supports the notion that patients can be active in the delegation of decisions about their care. They make a contrast between being passive and being apathetic (Sahlberg-Blom et al., 2000, p305). They explained that though patients in this category allowed others to make their care decisions, they were active in trusting their family and health professionals, accepting of their situation, content in the decisions made and wanted others to decide (Sahlberg-Blom et al., 2000, p303).

Summary

This chapter described the Basic Social Process of Controlling Involvement, used by patients in response to their basic problem of a lack of involvement in decision making. Four strategies were described that patients used to control their lack of involvement in making decisions about their care. Some patients responded to a lack of involvement by excluding health professionals by being self-reliant when making their own decisions. Searching for confidence and being assertive were identified as behaviours that achieved self-reliance. Patients also excluded health professionals by evading decisions and the attentions of health professionals who they did not want to be involved with in decisions. Patients who felt health professionals invited them to be involved in making decisions used strategies that involved the health care professional

further in their care decisions. In examples of positive decision making, patients shared decisions with responsive health professionals. Patients were able to share decisions with health professionals by developing a rapport, exchanging information and making compromises. A fourth strategy used in situations where patients realised that they needed to allow others to make decisions on their behalf, involved reconciling their non-involvement by being pragmatic and recognising the expertise of particular health professionals. Although limited literature was found to support the strategies identified as self-reliance and evading decisions (Clover et al., 2004; Sahlberg-Blom et al., 2000), some authors have identified the concept of sharing decision making (Bottorff et al., 1998; Bottorff et al., 2000; Irurita & Williams, 2001) and others have related the strategy of reconciling less involvement to active passivity in decision making (Clover et al., 2004; Saino et al., 2001).

CHAPTER 6

Discussion

Introduction

The theory revealed in this study has been described from the patient's perspective as Controlling Involvement to Promote Confidence in Decisions. This chapter presents an overview of the substantive theory identified in this research. Other theories, identified in the literature and specific to the ethical principle of autonomy, caring and patient decision making are compared to the theory described in this study. Clinical implications of the theory, Controlling Involvement, are explored in relation to health care professionals' behaviour and involvement of families in health care decisions.

Overview of the Substantive Theory

Controlling Involvement to Promote Confidence in Decisions: Decision Making in

Palliative Care from the Patient's Perspective

The substantive theory of Controlling Involvement was developed from this grounded theory study of patients from three palliative care environments. Patients responded to their experiences and concerns about a lack of involvement in care decisions by using strategies that increased their own involvement or excluded the involvement of others to promote their confidence in the decisions made. The experiences of patients' lack of involvement in care decisions and the strategies used to control involvement were influenced by patients' relationships with health professionals, the information they possess, their family relationships and personal characteristics (Figure 6.1).

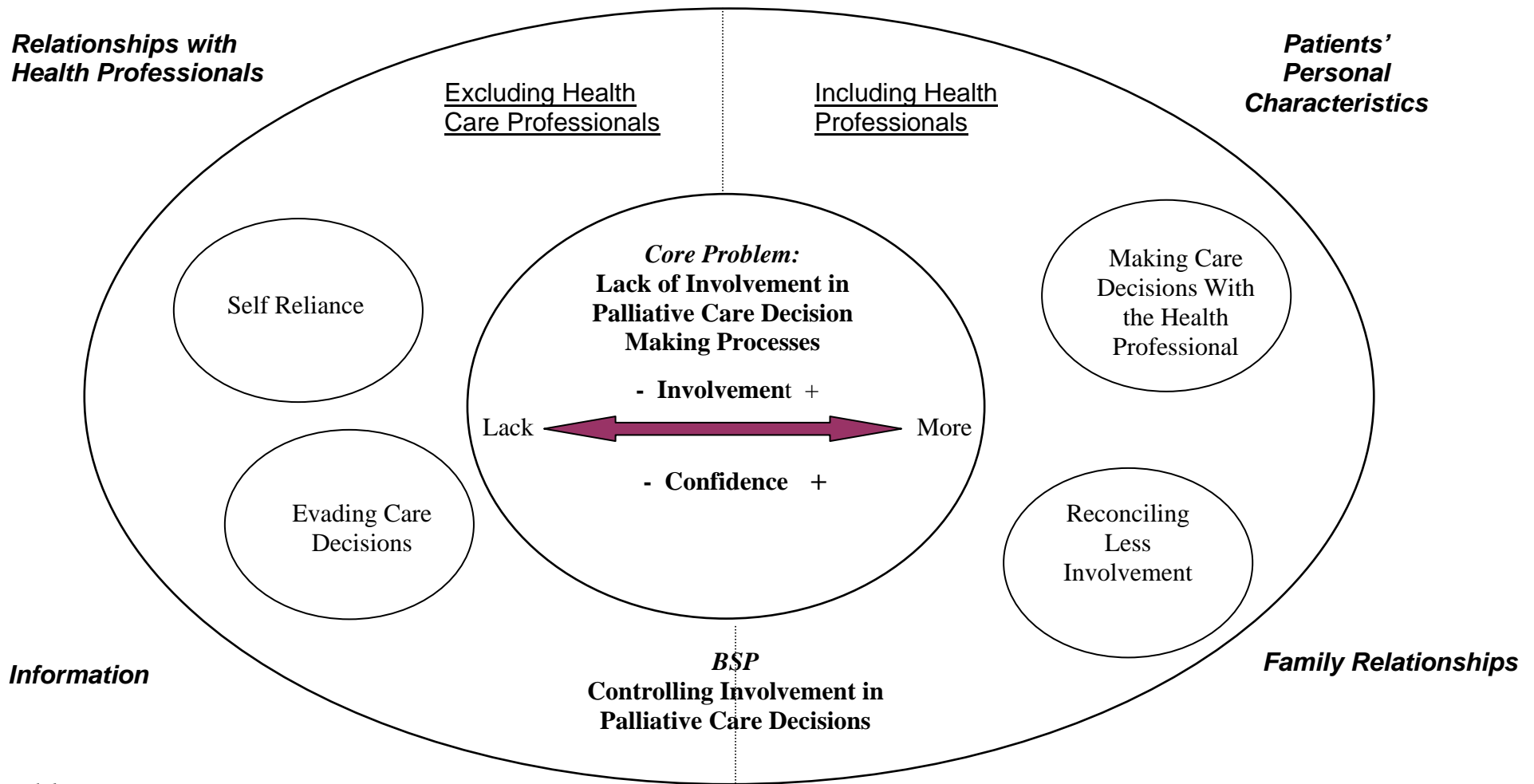


Figure 6.1:
Controlling Involvement: A Substantive Theory of Decision making in Palliative Care from the Patients' Perspective,
 represented as: The Basic Social Process (BSP) of Controlling Involvement in Palliative Care Decisions as influenced by - The Core Problem
 (a continuum of Involvement and Confidence), and the Conditions of Family Relationships, Information, Patients' Personal Characteristics
 and Relationships with Health Professionals.

***Core Problem: Patients' Lack of Involvement in Palliative Care Decision Making
Processes***

In this study, the main concern of patients was their lack of involvement in making palliative care decisions. When patients perceived some involvement in the palliative care decision that was made, they were more satisfied with that decision. These decisions were characterised by a flow of information and understanding between patients and health professionals participating in making the decisions. The patients believed that the health professionals participating in these decisions were focused on their needs and they were confident in the decisions being made by those health professionals. However, when patients felt that they were not involved in the decisions that were made, they were less satisfied.

When patients thought that they lacked involvement in decisions in which they should have been involved, they felt powerless and were not confident about the decisions made. They also lacked confidence and trust in the health professionals making those decisions. Patients who believed that particular health professionals had not involved them in decisions failed to develop relationships with those professionals that would have enabled information to be shared. In those situations, patients were less trusting of the health professionals and the decisions made.

Decision processes described in this study as good decisions, involved patients and their health professionals making decisions in partnership. In these processes, patients and health care professionals described how they arrived at a decision together and although the patients rarely described themselves as being in control of the decision, they were confident that the right decision had been made. When patients felt involved in these decisions, they described the health professional as someone they could trust, someone who focused on them as an individual and someone who shared information that helped them both to arrive at decisions.

Conditions Affecting Involvement in Palliative Care Decision Making

There were four major influences on patients' experiences of lack of involvement in care decisions and their responses to lack of involvement. These included; relationships with health professionals, information, family relationships and patients' personal characteristics.

Relationships with Health Professionals

Patients who felt more involved in making decisions about their care described the health professionals participating in their decisions as having a kind manner and being focused on the patient as an individual. These health professionals developed a rapport with patients, used humour appropriately and based upon these relationship factors; patients developed a sense of trust in them. Trust was not solely a consequence of the health professional's expertise, but also arose from the patient's appreciation of the attention of health professionals who invited patients to be involved in making care decisions. The development of these health care relationships was constrained in care environments that were busy, particularly in acute hospitals, where patients believed there was no time for their involvement in decisions because of insufficient staff.

Information

Patients also perceived a lack of involvement in care decisions when they were unable to access information that they believed was critical to the decisions they were making. Professional opinion was an essential component in decisions about treatment. Background information about aspects of disease and treatment processes and resources were also perceived as information needed by patients to be involved in decisions that shaped their remaining life and care decisions.

Family Relationships

Relationships with family members also influenced patients' experiences of involvement in making care decisions. Long established patterns of behaviour and power differences and conflict amongst family members sometimes made it difficult for patients to be involved in making care decisions, despite the intentions of health professionals to involve them. Sometimes the decision making behaviour of patients and their family members, particularly when family members took responsibility for making decisions, reflected their cultural background. However, in a number of situations when health professionals assumed that a patient's cultural background would govern how decisions were made (e.g. encouraging family decisions) this was rarely a reflection of the wishes of the patient.

Patients' Personal Characteristics

A range of personal characteristics also influenced patients' experiences and expectations of involvement in care decisions. For example, most patients expected to make decisions in collaboration with their health professionals, although some preferred to be more independent and others to be more dependent on health professionals to make care decisions for them. The past experiences of patients with health care decisions also influenced their expectations and their behaviours in making care decisions. In addition, patients' physical and mental condition and their language skills influenced their abilities to be involved in care decisions.

Basic Social Process

Controlling Involvement in Decisions Related to Palliative Care

Because patients in this study experienced, and responded to, each decision differently, the Basic Social Process of "Controlling Involvement" has been described as a non-processual, or non-sequential theory used to manage individual decision making moments. A range of four strategies; Evading Care Decisions, Self Reliance, Reconciling Less Involvement and Making Decisions With Others, were used by patients to improve their confidence in the care decisions made, by controlling the involvement of others in making decisions.

Excluding Health Professionals by Evading Care Decisions and being Self Reliant

When patients in this study experienced a lack of involvement when health professionals whose manner and approach they did not like failed to give them the information they required. When they experienced a lack of involvement, patients attempted to prevent the health care professional from being involved further, in their care decisions. If the patient, experiencing a lack of involvement was particularly unwell or had a personal style that influenced this response, he or she excluded the health professional by evading care decisions. Some patients successfully prevented decisions from being made by resisting or rejecting the approach of health professionals who were trying to make a decision and others withdrew from decisions. However, if patients were physically or mentally able to and had a more assertive personal style, they would exclude health professionals by becoming self-reliant in making care decisions, searching for confidence in decision making in other ways. Strategies that

patients used to exclude health professionals often left patients feeling dissatisfied with the process of decision making and lacking in confidence in their decisions.

Including Health Professionals by Making Decisions with the Health Professional and Reconciling Less Involvement

In contrast, when patients felt involved in care decisions with health professionals that they liked and who they felt gave them the information they needed, they allowed the health professional to be included in making care decisions. If the patient were physically unwell or had a personal style where they desired less control of decision making, they reconciled less involvement in making care decisions by being pragmatic about their own abilities to make decisions and by recognising the expertise of those caring for them.

However, if the patients were physically and mentally able to and they had a decision role preference for collaboration; patients included the health professional by making palliative care decisions with them. Patients were able to make decisions with health professionals by building rapport with them, exchanging information and by compromising on decisions. Patients who perceived they were involved focused on making decisions in partnership with health professionals and described their decisions as mutual understanding or in terms of arriving at the decision together rather than in terms of who controlled the decision. Patients who made decisions with others in this way were most satisfied with and confident in their palliative care decisions.

The Relationship Between the Substantive Theory of Controlling Involvement and Existing Theory

The Concept of Patient Involvement in Decision Making

In chapter three, a similarity between patient participation analysed in the context of caring and patient involvement in decision making processes in this study was identified. Saino et.al (2001) used qualitative interviews of 34 hospitalised cancer patients to explore the meaning of participation in decisions found that patients interpreted activities of asking questions, obtaining information, communicating feelings and symptoms and complying with medical and nursing instructions were all

activities of participation. These are activities also identified by patients in this current study as activities of their involvement in decision making.

A concept analysis of patient participation by Cahill (1996) proposes a difference between participation and involvement. In the explanation of the differences between patient participation, involvement and partnership, Cahill (1996) placed these concepts in a hierarchical relationship, suggesting that although patient involvement and collaboration in care is a precursor to patient participation, it is a “one-way process ... as the patient’s voice is mostly ignored” (Cahill, 1996, p567). Furthermore, Cahill (1996) identified collaboration as involving intellectual pursuit for the purpose of decision making rather than care. The theoretical and hierarchical differences between involvement, collaboration, partnership and participation proposed by Cahill (1996) have not been verified by empirical means and failed to provide a plausible explanation for the involvement valued by patients in this study.

In this current study, involvement in making decisions occurred on a continuum of more or less involvement. In some circumstances, if patients felt their perspective was being ignored, they became more self reliant in decision making by excluding the health professional who had ignored them. However, if patients in this study were approached by health professionals who wanted to involve them and a relationship developed between them, opportunities arose for collaborating on decisions and working together in what patients described as a partnership in decision making.

The analysis of patient participation in the context of caring by Ashworth, Longmate and Morrison (1992) was more aligned with the examples in this study of patients perceptions of involvement. Ashworth, et al. (1992) described participation as a social interaction where the patient and health professional were emotionally and motivationally attuned to each other, where the patient believed they had a contribution to make to their care and where they felt confident their identity was not under threat.

Autonomy, Decision Control and Decision Involvement

The moral principle of autonomy describes the rights of people, to be self governing (Delbridge, 1986). Respect for the principle of autonomy is often referred to a right based on respect for the dignity of a person as a “rational chooser” (Johnstone, 1999, p88). Some authors (Husted & Husted, 1995) refer to the notion of autonomy as

an ethical standard as opposed to a principle, indicating that its status as a moral truth is impermanent and subject to claim in different societies. This view was supported by a 1995 study of 200 Americans belonging to four different ethnic groups (Blackhall et al., 1995). Blackhall et al. (1995) examined the differences in attitudes of elderly Americans of different cultural groups toward decision making related to end of life decisions. They interviewed participants using the Ethnicity and Attitudes Toward Advance Care Directives Questionnaire (Blackhall et al., 1995). In comparing attitudes to patient autonomy to demographics variables, they found that two of the four ethnic groups; the Korean-American and Mexican-American subjects, did not support individual responsibility for making health care decisions. These results indicate that respect for the principle of autonomy is culturally contextual.

In the context of this palliative care study, the World Health Organisation's definition of palliative care states that the purpose of palliative care is, "...to help people live as actively as possible" (World Health Organisation, 2002). Living actively includes being a rational decider of one's actions, within the limits of their illness. This interpretation is affirmed by Palliative Care Australia in its explanation of palliative care, claiming that palliative care "... aims to make the person feel in control of their treatment and their quality of life" (Palliative Care Australia, 2004). These widely accepted and contemporary understandings of palliative care indicate that encouraging patient choice is an expected standard of behaviour universally, regardless of particular societal debates on patient choice in health care. Patients in this current study indicated that involvement in decisions regarding palliative care was important. There was no distinguishable difference in this finding between patients in Australia where individual autonomy is an accepted standard and in Japan where individual autonomy is a debated standard (Levine, 1991).

The two broad components of an autonomous decision involve reasoning and choice. The component involving reasoning means the person is acting in accordance with his or her values. The choice component reflects that a person exercises an authorisation, free from coercion (Dalini, 2005). Because the principle of autonomy emphasizes that choices are free, when patients make an autonomous decision, they are in control of decision making.

In this current study, patients were less concerned with the control of decisions than they were about the control of who was involved in the decision, and how they were involved. So although a patient may not believe they have controlled a decision, they may still perceive they have been sufficiently involved and express some confidence in the decision and confidence in those involved. Patients in this study acknowledged that on some occasions, when they believed they did not have sufficient expertise to control decisions for example, it was not necessary nor was it in their best interests to control decisions. In these situations, they would defer to the health professionals' expertise and use this reason to reconcile their lack of control in the decision.

It might be claimed that an explanation for the lack of concern about decision control might be that palliative care patients are generally less autonomous because of their poor medical condition. Dalinis suggested that “[W]axing and waning capacity [for giving informed consent] is part of the human condition and the health experience in the medical encounter ...” (Dalinis, 2005, p56). However, a preference for involving others, particularly health professionals, in health care decisions has been determined in a range of health care environments (Cahill, 1998; Degner et al., 1997; England & Evans, 1992; Heyland et al., 2003; Kraetschmer, Sharpe, Urowitz, & Deber, 2004).

England and Evans (1992) studied patients in a cardiovascular risk management clinic. Despite the fact that the patients were invited to participate in treatment decisions, many perceived they had not much decision control. It was found that inviting patients to participate in decision making was not sufficient to ensure they would participate. Patient participation was influenced by the factors related to the health worker's role, for example; “the interests and information provided by a health worker have a significant impact on the choice of treatment ... ” (England & Evans, 1992, p1223).

In this current study, patient independence and self-reliance, though perceived by patients as decision control was also often the result of decision processes patients described as poor. A recent study exploring the affect of trust on patient preferences for participation in decision making suggested that autonomous patients had relatively low levels of trust in their health care professionals (Kraetschmer et al., 2004). However, in this study, where patients were self reliant in their decision making, their autonomy in

making those decisions was debatable. In most of those situations, patients' decisions were a result of a perception of lack of involvement, implying that they were coerced by the situation; frustrated by their health professionals' lack of understanding of them and a lack of information.

Findings from this study indicate that decision control was the end point of a process of decision making. Patients were often more concerned with the process (their involvement) than who actually made the decision. Decision control only became a means of obtaining control of the process if it were not the way the patient wanted it. Nevertheless, the free and informed elements of the ethical principle of autonomy were evident in the preferred strategies that patients used in making their palliative care decisions; involving others and reconciling lack of involvement. With both of these strategies, patients felt sufficiently informed and confident in those caring for them that they could relinquish some control of decisions. This mode of making care decisions might be explained as substantially autonomous, as opposed to fully autonomous (Dalinis, 2005). Dalinis viewed autonomy on a continuum and suggested that "the point at which actions are more understood and less controlled by others is the point at which intentional actions are substantially autonomous ..." (Dalinis, 2005, p55). This explanation implies that substantial autonomy may be a good enough, although not the best form of autonomy, but it fails to account for patients' preferences for substantial autonomy.

Paternalism and Decision Involvement

Paternalism involves making decisions for someone else, in their interests. Paternalism is generally only acceptable in circumstances where patients are unable to make a decision themselves and on the assumption that if the person were able to, they would make the same decision. In this research, most of the apparently paternalistic decision making occurred when patients were competent to make their own decisions. However, in describing decision making that engendered their confidence, they reconciled their lack of involvement, willingly allowed, and even encouraged their trusted health professionals to undertake decisions on their behalf. O'Neill, a British philosopher, suggested that it is impractical to suggest a moral requirement to obtain "consent to all aspects of descriptions of proposed treatments" (O'Neill, 1984, p176). She goes on to say that, "[I]n human contexts, whether medical or political, the most

that we can ask for is consent to the more fundamental proposed policies, practices and actions” (O'Neill, 1984, p176).

O'Neill's (1984) recognition of this type of paternalism supports this study's findings related to patients' pragmatic expectations that health care professionals will do what they need to, to help them. However, she qualified this permission by insisting that paternalistic decisions conform to patients' goals and further their patients' role in achieving those goals. To achieve this standard, health care professionals are required to establish a rapport and get to know the patient. The health professional must, by necessity come to understand patients' objectives in treatment and in their care. Only then would it be permissible for the health professional to make decisions on behalf of patients. Therefore, when a health professional understands that a patient wants to be made comfortable and has agreed to take narcotics to get comfortable, checking whether they would accept a particular dose is less material than being made comfortable. Further, a patient may not have the expertise required to evaluate the selection of a particular dose. If, however, the eventual dose required would sedate the patient, the health professional would have an obligation to return to the patient for a decision, because the decision now falls outside the original reasons for taking narcotic analgesics, agreed to by the patient. In addition, a decision to take a dose of analgesic that is likely to sedate the patient will interfere with the patient's ability to be autonomous, since the sedated patient is unable to reason or exercise choices. O'Neil (1984) describes decisions that might affect a person's autonomy as significant decisions that should not be undertaken by others. The decision to take an increased dose of narcotic to be comfortable though it would sedate the patient, as opposed to a decision regarding a dose that is unlikely to sedate, is a more 'fundamental' (O'Neill, 1984) decision, for which the patient's authority should be sought.

A paternalistic decision that would not be morally tolerated, according to O'Neill's standard and derived from the findings of this current study, would be a decision made without attempting to understand the patient's wishes and objectives regarding his/her palliative care. These circumstances, in this current study, resulted in patients perceiving a lack of involvement in their care decisions. When patients in this current study identified a lack of involvement, they were aware that the health care professionals associated with making the decisions were unaware of the patients' discontent and lack of confidence. That health professionals fail in some circumstances

to understand patients' perspectives is not new in the health professional literature. In 1993, Veatch, noted that "people often fail to grasp that it is just as hard for the expert to see the world as a lay person does as it is for the lay person to have the understanding of the expert" (Veatch, 1993, p1021).

It may be argued that patients in this current study were exhibiting a modern phenomenon where paternalism is less morally acceptable. Sixteen years after O'Neil's published standard of paternalism, Veatch suggested that increasingly, doctors have become less able to determine patient interests, and thus make paternalistic decisions, for three reasons. The first is that the balance of risk and benefit is no longer clear when medical technology is so complex and the perception of benefit and harm so individual. Veatch's view is that doctors have no choice in determining the balance of risks and benefits, but to ask patients their view. The second reason why doctors are less able to be paternalistic is because of competing moral duties such as the duty to respect for patient autonomy and the duty not to kill (Veatch, 2000). For example, in the face of patients who make decisions that are not in their interests, who may refuse a treatment that the doctor believes would save their lives, or who may be asked to be killed to prevent their suffering, the doctor also has a duty to avoid killing. Veatch cites the third reason for the decline of paternalism as the doctor's competing duties to benefit patients and to benefit society (Veatch, 2000). For example, a doctor faced with a decision to use an expensive drug that he or she believes is the best for a particular patient will struggle to ignore his or her responsibility to keep within the pharmacy budget for the unit in which he or she works.

Schneider (1998) reflected on why some patients were reluctant to take responsibility for making medical decisions, and suggested that they may be divided in their desires about particular treatments. He described this phenomenon where patients appeared to want to be manipulated into undertaking a treatment that might be abhorrent to them, but that they also wanted to pursue. Schneider gave examples where patients had been persuaded to have treatments they had not originally wanted, but were subsequently grateful they had, and questions the limits of such manipulation (Schneider, 1998). In this current study, patients also described decisions that had been made about options that they had not wanted, but acknowledged that the decisions had been the correct ones. In these situations, patients described the decisions as ones that did not involve a choice, or they were decisions made by the health professionals

because of their expertise. Like Schneider's examples, patients in this current study also were adamant they did not need to make those decisions; however, unlike Schneider's examples, these patients did not indicate that they had been manipulated.

There are many situations in palliative care where patients may not believe they have a choice to make, however this does not indicate that they were not exercising their autonomy or that health professionals were paternalistic. Patients in these circumstances understood the nature of the decision and its implications and authorised the decision made. Beauchamp and Childress (Beauchamp & Childress, 2001) indicate that an informed consent consists of the elements information, freedom and express agreement; the elements of an autonomous authorisation.

Decision Role Preference and Controlling Involvement

At the commencement of their participation in this current study, patients were asked their decision role preference. Most patients were able to indicate that they had a preference for one type of role over another in their care decision making with health professionals. As in other studies (Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Davison & Degner, 1998; Degner et al., 1997; Heyland et al., 2000; Heyland et al., 2003), many patients in this current study indicated a preference for the role of sharing or collaborating on decision making with their health professionals. However, when these patients discussed their experiences of making care decisions, they identified a range of roles they undertook, even in decision making processes they valued where they were involved.

Degner and Sloan's study of decision making during serious illness compared decision role preferences using a decision role card sorting procedure of over 400 newly diagnosed patients with cancer, with a group of over 400 Canadian householders without cancer (Degner & Sloan, 1992). Though majority (64%) of the householders in that study preferred to select their own treatment if they developed cancer, the majority of the patients (59%) wanted physicians to make treatment decisions for them. Degner and Sloan (1992) concluded that stress of a new diagnosis might impact on the decision roles people prefer.

A study in the United Kingdom of women with breast disease also noted that a new diagnosis of a life threatening disease such as breast cancer was a crisis situation,

influencing women to prefer to leave decision making to their doctors (Beaver, Luker, Owens, Leinster, Degner, & Sloan, 1996).

A later study that compared the decision preferences of patients at various stages of diagnosed colorectal cancer at a treatment clinic with the previous breast cancer patients, also found that majority of these patients preferred to let their doctors make treatment decisions (Beaver, Bogg, & Luker, 1999). This finding resonated in this current study where patients described their decision role at the time of their diagnosis and acute treatment as more dependent on their medical staff. However, in their reflections on the decisions made at that time, they did not indicate that their preference was to be more dependent. Rather, patients were resigned that circumstances, such as the manner of the health professionals, or their physical or emotional condition, meant that their decision making occurred in a more dependent way, despite their preference.

In the study reported here, the roles patients undertook in relation to a preferred style of decision making were not enduring but rather, their roles were contextual. The decision roles that people say are their preferences at any particular time may be static, although little evidence for this exists, as most studies have not been longitudinal. However, this study indicates that when patients are faced with the myriad of different circumstances influencing them and their decisions, they adopt different roles and may be quite satisfied with those decisions, though they have not used their preferred role. The study by England and Evans (1992), described earlier, illustrates that even when patients are offered an opportunity to exercise control of decision making, they will not necessarily take that opportunity. A later study by Kirk, Kirk and Kristjanson (2004) involved interviews with patient and family diads regarding their communication needs. This study proposed that these communication needs changed as the illness progressed and preferred roles in decision making also changed, with patients becoming more passive as they approached death.

Passive Decision Making Roles

Decision roles where doctors and other health professionals make decisions on behalf of patients are often described as roles where patients are passive (Beaver et al., 1996; Degner et al., 1997; Degner & Sloan, 1992). The Macquarie Dictionary lists the following definitions of the term passive, “1. not acting ... 2. inactive, quiescent, or inert. 3. suffering action, acted upon, or being the object of action.” (Delbridge, 1986,

p448). However, when patients choose to allow others to make decisions they are not necessarily choosing to be passive, to be 'inactive or inert' in the process leading to the decision. Beaver and her colleagues acknowledged that despite their finding that majority of women newly diagnosed with cancer wanted to take a passive role in decision making, many still "wanted some form of involvement in the decision-making process" (Beaver et al., 1996, p 18).

In this study, passivity as a decision role and lack of involvement were found not to be synonymous. Patients in this study, who acknowledged that they had not made particular decisions, and that they were satisfied with not making those decisions, disagreed when asked if that were a passive role. Those patients may have appeared to health professionals as passive, but the patients perceived themselves to be involved because they listened to and understood information. They may have felt it was not necessary for them to make the decision because they viewed the decision as not theirs to make, or because they trusted the health professionals as experts advising them or perceived there was no choice to make. The process patients engaged in during this deliberation was not passive, as even making a decision to let the health care professionals decide is active involvement in the process.

Schneider discussed the reluctance of some patients to make medical decisions and identified a number of factors evidenced by his own research, accounts from patient biographies and from other research (Schneider, 1998). Like patients in this current study, Schneider described the reluctance of some patients to make medical decisions was on the grounds that they felt less competent than their doctors. Patients' perceptions of lack of competence, Schneider (1998) explained, are not unrealistic because of the following factors: Firstly, medicine is complex requiring complex language to describe it and decisions are not always absolute, evidenced by differing opinions about the same test results. Euphemisms used to blunt the effect of bad news are often confusing. Secondly, patients do not feel competent to make medical decisions because they "know too little to assimilate what they have heard and to formulate questions" (Schneider, 1998, p59). Thirdly, the competence of patients to make medical decisions was affected by the bureaucratisation of the medical setting. Schneider noted that this meant that not only was the responsibility for decisions diffused among many people of different backgrounds and experience, but also the participants might not understand or agree with each other.

In this current study, when patients described the undermining of their confidence by doctors using language they did not understand, or language that was imprecise, or when their health professionals did not agree with each other, they became frustrated. However, in most of these situations, despite experiencing a lack of involvement in decisions, they responded by being reluctant to have these health professionals make their care decisions as opposed to being reluctant to make those decisions themselves. Only in situations where patients in this current study believed they were being involved in care decisions by health professionals they liked, when the patients were sick or when they had decided the decision was less significant for them to make, did patients relegate their decisions to the health professionals, and only then if they had relationships with the health professionals and believed them to be nice and caring.

Patient-Health Professional Relationship Theory and Controlling Involvement

Patients in the study reported here believed that the manner and niceness of the health professional was an important factor of their own involvement in decisions and influenced patients in how they involved health care professionals in decisions. The importance of the role of health care professionals in developing a relationship has been identified by a number of authors (Aranda & Street, 1999; Brody et al., 1989; Jarrett & Payne, 2000; Johns, 1996; Li, 2004; Luker, Austin, Caress, & Hallett, 2000; May, 1993; Peplar & Lynch, 1991; Thorne & Robinson, 1988; Ward-Griffin & McKeever, 2000; Wilson et al., 1998). The manner of the health professionals is further explained by Li (2004) who suggested that therapeutic relationships between nurses and patients are constructed collaboratively through the doing of what she calls, “symbiotic niceness” (Li, 2004, p2574). In her study, Li observed the psychosocial talk of nurses in two British palliative care units and one general hospital where there were patients diagnosed with terminal illnesses; mostly cancer. Using a grounded theory approach, she counted the incidence of various words used by nurses and compared the differences in the enacting of these terms in psychosocial care. Different categories of niceness were identified and defined, one of which was “Symbiotic Niceness” defined as “... the ‘niceness’ of nurses simultaneously requires, feeds on and ‘grows’ from the ‘niceness’ of nurses themselves and of patients and nurses. It is a symbiotic existence. It is mutually benefiting and sustaining” (Li, 2004, p2577). The similarity between Li’s findings and results of this current study are notable, in terms of the descriptions of

good decision making involving patients and health professionals being nice to each other as a way of accessing information about issues important to patients.

This current study found that patient personalities that were less likeable made involvement in decision making more difficult for both patients and health professionals. However, Li's entreaty that health professionals should "learn to 'do' niceness better" (Li, 2004, p 2582) ignores her own finding that when health professionals use measures of the niceness of others, particularly patients, some patients are judged as being undeserving of anything more than obligatory care.

Despite the fact that nurses and patients place so much significance on niceness as central to good decision making, niceness itself has the potential to undermine patient involvement in making care decisions. Concerns about niceness as a concept that threatens the ability of health professionals to challenge workplace practices and potentially fosters poor communication with patients have been expressed by others (Aranda, 2001; Street, 1995). Street refers to niceness as a tyranny within nursing cultures like hospital wards where nurses may be unable to express their concerns about their work because of a desire not to challenge the "unit stereotype of a 'nice, caring' person" (Street, 1995, p30). Street identified that patients and their family members were also less likely to challenge or question nurses who were being 'nice' with their concerns about their care and progress. Patients and family members would remain silent and frustrated rather than risk making the nurse unhappy. Thus, a culture of 'niceness' can be an impediment to real involvement in care decisions. In this current study, patients who were happy to let health professionals make decisions for them, did so because they believed the health professional was nice and knew sufficiently what the patient needed, and was sufficiently expert to make that decision on their behalf. None of these patients indicated they were unable to challenge health professionals because the health professional was too nice. In fact, some patients in this current study indicated that they could be honest with particular health professionals because of the rapport they had, including that the health professional was nice. Though no evidence was presented in this current study that patients were maintaining a culture of niceness as Street describes, health professionals in this current study expressed concern about the power they possessed when they had a good rapport with patients, to change decision making processes.

Despite health professionals' concerns about the power they had in good relationships with patients, health professionals and patients in this current study indicated that patient involvement was reliant on relationships built on nice and friendly rapport and that these relationships led to trust in the health professional. The relationship between a desired role for sharing decisions about medical treatment and trust in the recipient's doctor was investigated by a study undertaken in Canada in 1997 (Kraetschmer et al., 2004). The researchers provided patients with two vignettes, one referring to the participants' current health condition and one referring to the occurrence of chest pain. They asked respondents to identify their preferred decision role and their level of trust in both these scenarios. Patients (n=606) from three outpatient clinics at a large publicly funded hospital in Canada, were asked to complete a questionnaire consisting of two scales that measured problem solving and decision making roles and trust in the physician. They found that 67.3% of patients preferred a shared decision making role, and that this finding was strongly correlated to high levels of trust ($p < 0.0001$) (Kraetschmer et al., 2004). Blind trust, was more closely associated with preferences for passive decision making roles and low levels of trust with a preference for autonomous roles (Kraetschmer et al., 2004).

Though this current study used a different methodology, patients similarly described their preference for sharing or collaborating on health decisions as being dependent on a relationship with the health care professional that featured trust. These patients were also more likely to describe how they did not trust health professionals when they wished to exclude them from their health care decisions.

The conceptualisation of trust is complex and poorly understood (Kraetschmer et al., 2004; Pearson & Raeke, 2000). Kraetschmer et al. (2004) explains that the concept "includes both technical (expertise) and interpersonal (e.g. communication, respect) elements" (Kraetschmer et al., 2004, p318). However, in this current study patients explained their trust in various health professionals only in terms of their relationship with the professional. Patients chose their decision makers regardless of any particular assessment of professionals' expertise or membership of the palliative care team. Their limited perception of trustworthiness places an even greater responsibility on health professionals to meet the expectations of patients.

Theories of Balancing

The negotiation of care with health professionals is reported as the concept of 'balancing' in two other grounded theory studies that described the patients' responses to the difficulties they encountered in their care. These theories of balancing indicate that patients choose how to expend their energies in relation to their care. Findings from this current study support these theories.

Irurita and Williams (2001) undertook a study to examine patients' experiences of nursing care with a study from the nurses' perspective. The studies were undertaken concurrently in the same acute hospital setting in Western Australia, involving interviews and observations. The common concern identified for patients and nurses related to threats to their integrity. The basic social psychological process used by patients and nurses to preserve their integrity involved balancing and compromising. This process acknowledges that patients and nurses make rational justifications about care that did not meet their expectations and protected their integrity by trying to control the attention they gave (nurses) or received (patients) (Irurita & Williams, 2001).

The efforts patients made to understand and develop trust and to attract the attention of nurses in the Irurita and Williams' study is evidenced similarly in this current study, though the purpose has been identified differently. In this current study the focus of balancing and compromising was on care in general. In contrast, the focus in this current study was on a particular aspect of care; decision making. Evidence in this current study indicated that the threat to patients' integrity was the threat to their involvement in making care decisions and though their response involved strategies related to improving their involvement, elements of co-operating, rationalizing and justifying their compromise, identified in the Irurita and Williams' study, was also present (Irurita & Williams, 2001). Unlike the Irurita and Williams' study however, in addition to making efforts to 'attract' the attention of health professionals in this current study, patients would equally use strategies to 'repel' the health professionals they did not want involved in their care decisions.

The Canadian study by Bottorff, Steele, Davies, Garossino, Porterfield and Shaw (1998) which examined palliative care patients' experiences of every-day decision making, is more specifically related to this current study. Bottorff et al. (1998) observed the care of 16 patients and undertook in-depth interviews of 10 patients and 12 nurses in

two palliative care units. They indicated that even what appeared to be mundane choices were highly individual and held individual importance. Patients in that study strove for balance of their needs in the light of competing desires and unpredictability of their conditions. (Bottorff et al., 1998)

These findings are consistent with results from this current study, which found that balancing needs was an activity requiring significant energy and involvement. Patients were pragmatic about which decisions required their energy and involvement to control, and which decisions they could relinquish to others. Bottorff and colleagues (1998) reported that decisions to “let go of some decisions did not reflect a lack of control on the part of patients” (p15). This was also reported in this current study. Patients in both studies delayed decisions in order to optimise their participation.

Clinical Implications

Health Professional Behaviour

In clinical practice, the traditional difference in power and authority amongst health professionals, particularly doctors, and patients may enable otherwise difficult conversations and intrusive examinations (England & Evans, 1992). However, the establishment of a rapport and inviting patients to be involved in making care decisions does not ensure that the power difference is equalled. England and Evans (1992) suggested that health professionals have the capacity to control the choices patients have merely by restricting the choices they offer to patients. The manipulation of options given to patients was found in a study of Dutch patients with metastatic cancer and their consultations with their medical oncologist (Koedoot, Oort, de Haan, Bakker, de Graeff, & de Haas, 2004). In that study, 95 patients were interviewed, their consultations audiotaped and coded according to categories of information given. The analysis revealed that the oncologists spent more time on active treatment options and older and married patients received more information than younger single patients.

Other manipulations of patient choice by health professionals are reported in the literature. Paterson (2001) reported on a longitudinal study of 22 physician and self-referred patients with longstanding type 1 diabetes, who were considered to be expert self-managers. Participants were asked to keep a reflective audio journal of their self-care decisions during three randomly assigned one-week periods over a calendar year.

Focus groups confirmed the categories at the end of this period. Participants identified two strategies used by health professionals, including those with whom patients had a good rapport, which diminished their control over care decisions. The first strategy was identified as when the health professionals discounted the patients' experience by, for example, suggesting their strategy or reasons were not good and offering what they considered better strategies, or by questioning the patients about their knowledge of diabetes, particularly when that knowledge was derived from experience that differed from textbook cases. The second strategy used by health professionals to decrease patient empowerment was identified as the inadequacy of resources such as information, time and money. Participants used examples of the use of jargon and information irrelevant to their situation, the offering of strategies that did not consider the patients' lack of income and the lack of timely access to the health professionals, as disempowering (Paterson, 2001). Although not a focus of this current study, some participants acknowledged that they were aware when their health professionals used these strategies and despite the nice and caring manner of the health professional, the patients sought other health professional advice.

Participants in Paterson's study suffered a chronic condition rather than a terminal condition and thus, may arguably have had different concerns and influences on their participation in care decision making. However, many patients in palliative care have a history of a long period of illness. Patients in this current study did report situations where they believe health professionals undermined their involvement in care decisions by discounting their experiences and providing inadequate resources for making decisions.

However, the development of the type of relationship described by patients in this current study provides the circumstances where health professionals might unwittingly manipulate patients. Patients in this current study, who believed that they had a good rapport with health professionals and whose perception of involvement was dependent on that rapport, were less likely to doubt or question the advice given and choices offered by those health professionals. The assumption that health professionals may be innocent of knowing their influence over patients is justified. In this current study health professionals indicated that the relationship that patients valued was one in which they believed they were most effective in meeting patients' needs. Therefore, potential manipulations may have been subtleties in communications and actions of which neither party was aware.

One subtle manipulation relates to the language used in giving information to patients. Veatch (1993, p1023) claimed that “contemporary philosophers of science are now sceptical of the simple claim that there can be any value and concept-free facts even from the best of science”. He suggested that language and value frameworks shape even the medical facts given to patients and the way that patients interpret them. For example, two patients who have been told they have cancer in their throats, for which they will receive chemotherapy may each interpret the cancer in quite different ways, because of their value frameworks. One patient may have experienced a friend who developed cancer and had chemotherapy. His friend may have suffered terrible nausea during his chemotherapy. The patient, having seen the effects of chemotherapy on his friend (regardless of how related that is to his own situation), may not value the potential additional life span gained by the chemotherapy. The second patient, having had no similar experience to the first patient, and having a different value framework, may value additional life span regardless of the effects of chemotherapy he has to endure.

In another example, health professionals’ choice of language influenced the patients’ interpretation of information provided to them. A health professional explaining prognosis to a patient has the choice to present the information in two different ways. One way is positively framed; ‘you have a 20% chance of surviving for 5 years, or alternatively, more negatively framed, ‘you have an 80% chance of dying in the next 5 years. In a study testing the effects of positive and negative framing on goal setting, Krishnamurthy, Carter and Blair (2001), asked participants, to rate the likelihood of them talking to the doctor regarding variously framed treatment options. Some of the participants were otherwise well college students and their results were compared to a group of participants who were patients visiting a health care clinic. They found that negative frames were more effective motivators of decisions regarding health goals and positive frames were more effective motivators when describing the attributes of treatments (Krishnamurthy et al., 2001). They suggest that optimistic explanations of the performance of a treatment option preferred by the health professional will have more success in persuading the patient. On the other hand, if the health professional presents the negative aspects of a treatment they least prefer, the patient will be more likely to avoid or be more suspicious of that treatment.

The assumption underlying these recommendations from Krishnamurthy et al. (2001) study is that health professionals know what treatment options are unequivocally

better or worse for patients. However, a number of authors expressed concern about the framing of information according to the health professionals' values rather than patients' (Gillett, 2003; Scott, 1999; Veatch, 1993, 2000), and advise that the patients' context has a significant influence on how information is valued. In this current study, patients and health professionals acknowledged this issue and presented their solution as the relationship developed between them and the sharing of care decisions. However, the very relationship they advocate will improve communication and decisions, adds to the patients' vulnerability.

In the study reported here, the rapport that health professionals had developed with patients that enabled patients to share in making care decisions, left patients believing that the health professionals generally knew what was in their individual interests and also tended to leave health professionals with the impression that they knew the individual patients well. The relationship engendered a sense of knowing the patient, even though this knowing may have been significantly limited by time to get to know the patient and the context of only knowing the ill person. In an article expressing concern about disempowerment of patients in palliative care, Scott (1999) cautions health professionals not "to underestimate that profound vulnerability or to misperceive the disabling effect that entry to a foreign, controlled environment can have on an otherwise competent person" (Scott, 1999, p143). In developing relationships with palliative care patients that promote their involvement in care decision making, health professionals must consider the limits of the particular relationships developed with patients and the privileges and responsibilities this engenders. Decisions shared with patients that fail to acknowledge the patients' individual goals and needs, regardless of the perceived relationships with health professionals or the patients' perceived involvement, are still paternalistic decisions (O'Neill, 1984).

Communication in Care Decision Making

Hutton (2005) claims that effective communication is a core value of palliative care. Communication was a significant theme in this study, important to the development of relationships between patients and health professionals and for the purpose of sharing information, between patients and health professionals. In this study, the decision making process was affected by issues related to the content of information presented to patients as well as the process by which it was delivered. Both of these themes are well represented in the literature.

In this study patients expected to receive information regarding their disease and prognosis but they also expected information about the disease process and how it and the treatment would affect them and their lives. Kutner, Steiner, Corbett, Jahnigen and Barton (1999) conducted a mixed method study of terminally ill patients in the United States of America to describe the information issues important to these patients and the influence of the characteristics of these patients on their needs. They interviewed 22 patients and used these interviews to construct a structured survey which they applied to a further 56 terminally ill patients. Their findings describe two sets of needs common to most patients categorised as disease related needs and illness related needs. Disease related needs concerned information related to the diagnosis, prognosis and treatment and patients expected to receive this information from their medical staff. Illness related information related to how the “disease affects the individual personally and socially” (Kutner et al., 1999, p1349). Illness related information was obtained by these patients from a range of sources such as family, other health professionals, clergy, lawyers, insurers and financial advisors. Other studies (Bostrom, Sandh, Lundberg, & Fridlund, 2004; Williams & Irurita, 2004) also emphasise that patients require explanations about what to expect in terms of the process of their disease and the effects of treatments and what is expected of them in terms of their responses to the different experiences they will face. One study that investigated the factors influencing palliative care for patients with end-stage heart failure by interviewing senior registered nurses in South Australia acknowledged that a lack of focus on illness related information, particularly how patients might respond to the treatments offered, resulted in later referral to palliative care (Wotten, Borbasi, & Redden, 2005).

Kirk, et al. (2004) interviewed diads of patients and their primary family decision makers in Australia and Canada and also found that the content element of communication related to prognosis was important. In addition, patients in that study indicated that messages of hope were an important content area of communication. They described the importance of health professionals allowing them to preserve their sense of hope while still being realistic and honest about their ability to accurately prognosticate. The importance of honesty, hope and optimism in communication was also expressed in this current study and in other studies (Langley-Evans & Payne, 1997; Williams & Irurita, 2004)

In this current study, the process of communication was found to be important in assuring patients were involved in decision making. In particular, the time taken by

health professionals to chat with patients and the use of humour were important both in the exchange of information and in the development of a trusting relationship with health professionals. An early study by Greenfield, Kaplan and Ware (1985) used a treatment algorithm to increase patient involvement in decision making. They found that patients in the experimental group did not ask more questions than those in the control group, but were more effective at eliciting information by controlling conversations with health professionals indirectly by talking about the experiences of friends, for example (Greenfield et al., 1985).

Williams and Irurita (2004) interviewed 40 patients and observed interactions between nurses and patients to explore therapeutic interactions from the perspective of hospitalised patients. They found that the emotional comfort of patients in the hospital milieu was influenced by the interpersonal communication of hospital staff. They identified three conditions that influenced the emotional comfort of the patient; level of knowing, level of personal value and level of security. The provision of information increased the patient's level of knowing. Time taken to communicate, honesty, openness and nonverbal communication such as eye contact, spacial positioning, use of touch and facial expression were factors that left patients feeling valued by the staff. The use of chat, social conversation and getting to know patients were important communication strategies in ensuring the emotional comfort of patients by helping the patient to feel secure (Williams & Irurita, 2004). Light-hearted talk and humour were also found to be features in the conversations between patients and with health professionals in an ethnographic study of a palliative care day care centre in the United Kingdom (Langley-Evans & Payne, 1997). The researchers suggested that the open awareness of patients and staff about prognosis facilitated this type of chat and was an important feature of providing an opportunity for patients to seek information. They also suggested that humour and light-hearted chat served to distance patients from their disease and prognosis enabling them to maintain their optimism (Langley-Evans & Payne, 1997).

The study described earlier Kirk et al (2004) found, in addition to needs regarding communication content, needs regarding the process of communication. As with other studies mentioned previously, honesty and clarity of communication was important. In addition health professionals who used non-verbal demonstrations that they cared during communication were valued. The commitment of the health professional who gave extra time, paced information as the patient wanted it and who

indicated they would “not abandon the patient/family as the illness progresses” (Kirk et al., 2004, p3) was also important.

These studies all indicate that the information needs of patients require skills in communication. In this current study, when health professionals’ communication was not skilled, patients would attempt to exclude them from their decision making. This response, by patients seeking other advice was indicated in a number of other studies (Kirk et al., 2004; Kutner et al., 1999; Williams & Irurita, 2004), though the link to poor communication was not clearly made. However, a number of studies have identified that poor communication skills of health professionals working in oncology and palliative care interfere with the decision making of patients and their families (Georgaki et al., 2002; Hermesen & ten Have, 2004; Morita, Akechi, Ikenaga, Kizawa, Mukaiyama, Nakaho, Nakashima, Shima, Matsubara, Fujimori, & Uchitomi, 2004; Street & Blackford, 2001).

In Greece, in a study by Georgaki, et al. (2002) 148 nurses working in oncology departments completed a questionnaire that assessed their attitudes towards informing patients about their disease and their self assessment of communication skill. Despite over 75% of these nurses believing patients should be informed about their disease, over 66% found it difficult to engage patients in conversations about their disease or prognosis and suggested that this finding was due to over 66% of the nurses believing they were inadequately trained in communication skills.

A study of 318 bereaved family members who had received specialist palliative care in Japan (Morita et al., 2004), involved a questionnaire that focussed on perceived levels of emotional distress during communication about ending anticancer treatment for their relative. In addition, the family members were asked questions about different communication strategies used in the breaking of this bad news. The authors reported a “moderate but significant correlation between family-reported stress and necessity for improvement” in the communication skills of the health professionals giving information to family members and patients (Morita et al., 2004, p1553).

In Australia, Street and Blackford (2001) used a critical approach to study the communication patterns between community palliative care nurses and general practitioners. Interviews with hospital based consulting nurses and focus group interviews with self selected community nurses were conducted and the content analysis revealed situations of communication breakdown that affected patient care decision

making. The study was limited by the presentation of examples of communication breakdown by only one party in the communication process, some attempt was made to elicit opinion from general practitioners on the strategies recommended by the study and further research was recommended to develop better communication strategies in this field (Street & Blackford, 2001). Nevertheless, Street and Blackford notes that understanding each other's needs in the decision making process was important in improving the communication process.

In three intervention studies to improve decision making regarding the use of advanced supportive technology in the treatment of patients in intensive care units, improving communication processes between health professionals and patients were significant components of the strategies (Anonymous, 1995; Dowdy, Roberson, & Bander, 1998; Lilly, DeMeo, Sonna, Haley, Massaro, Wallace, & Cody, 2000). The first study involved an initial two year observation in five teaching hospitals in the United States of America, of over four thousand patients with life threatening diagnoses that revealed significant problems with communication, particularly the understanding of physicians about their patients preferences (Anonymous, 1995). In the second phase of the study, a similar number of patients were randomised into a control group and an intervention group. In the intervention group, a specifically trained nurse visited the patients and families regularly and had contact with the patients' care team to improve understanding of the patients' preferences and care outcomes and to facilitate care planning and pain management. The failure of the intervention to improve communication between the care team and patients or the outcomes of care in terms of resuscitation and bed days in intensive care, was attributed to a lack of "individual and societal commitment" (Anonymous, 1995, p22). However, the intervention did not seek the commitment of the patient and their care team to improving communication and no part of the intervention was designed to improve the relationships between the patients and the care team.

In a prospective, controlled study of 99 patients admitted to an intensive care unit, two control groups were compared with a treatment group where an ethics service intervened proactively with patients who had been ventilated for over 96 hours. The ethics consultation was conducted with the health care team and focussed on a standardised set of prompts to focus discussion on key aspects of decision making and communication in order to identify issues and recommend strategies. The study indicated that the treatment group received a better quality of communication, however

the sample size was small and the communication measures limited to evidence of communication content and the number of consultations requested with various counselling support staff.

In the third study, an intensive communication strategy used by doctors and nurses, was assessed before and after its introduction to a general medical intensive care unit (Lilly et al., 2000). Normal practice included a formal family meeting but only after the care team had reached consensus on the care plan. Communication of information relevant to those decisions was passed on to family members in informal ways. There were 134 patients who received the normal practice included in the study. The intervention commenced within 72 hours of admission and included multidisciplinary review of the medical facts and opinion, understanding of the patients' perspectives, consensus on the care plan and on the criteria used for measuring the success of the plan. The intensive communication strategy occurred in the context of multidisciplinary meetings with the family members and patients, where possible. Measures of the success of the intervention undertaken on 396 patients included diminished evidence of non-consensus in the team and with the families, decrease in bed stay days in the unit and decreased mortality rates attributed to better care planning. Though not concluded by the authors, this strategy was designed specifically to improve the communication between the care team, patients and families by sharing information and close collaboration on decisions, both features of the findings in this current study.

In the literature and in this current study, good communication in care decision making is dependent on the right information being shared and in the right process, a process where patients and their care providers are willing, skilled and committed, to being involved in making good decisions.

Family Involvement

The assumption that family members are natural surrogates for care decision making when patients are not competent, is often described as difficult (Abma, 2004; Curtis, Patrick, Shannon, Treece, Engleberg, & Rubenfeld, 2001; Luker et al., 2000; Norton et al., 2003; Panke & Volicer, 2002; Ward-Griffin & McKeever, 2000). Some patients in this current study indicated that they did not believe their family members should be involved in their care decisions, even if they were unable to be involved themselves. The involvement of family members in making care decisions remains

problematic, since the substantive theory of Controlling Involvement in this current study provides explanation of patients' perspectives rather than that of families. Davison and Degner suggest that the Decision Role Preference Card Sort (Degner & Sloan, 1992) used in this current study be adapted for patients to identify their own preferred role and how they would like their family involved (Davison & Degner, 1998). In simple terms, their proposed strategy is to ask patients at one point what their preference is for who should be involved in making care decisions and from then on, involve those preferred people. Although this strategy may improve communication between family members, patients and health professionals at one point in time, it fails to address the issue that preferences of decision roles are not static throughout a patient's illness.

The involvement of families in patient care decision making is complicated by the fact that family members will have different interests in particular decisions to that of patients. Mappes and Zembaty (1994) described cases where patients didn't respect family interests and where patients appeared to put too much emphasis on family interests in making their own decisions. In the first group of cases, they explored situations where what patients wanted infringed on the rights of family members. For example, an elderly dying man wishes to go home to be cared for by his frail and equally elderly wife. His wife, though she fears she may not manage, loves her husband, has spent years caring for him, and does not wish to let him down. The second group of cases related to dying patients deciding not to go home, because they did not wish to be a burden to their relatives, who might have been easily capable of their care (Mappes & Zembaty, 1994).

Where patients are able to develop relationships with health professionals and exercise their preference for sharing their health care decisions, health professionals may be able to assist patients in arriving at a decision that is respectful of family member needs and the patients' own needs. However, as evidenced in this current study, by virtue of their health and relationships with the patient, family members may interfere with the relationships developed with the health professionals and reduce the patients' ability to be involved in their care decisions. In this current study some family involvement in care decisions contributed to patients perceiving their own lack of involvement and exclusion from care decisions in situations to which health professionals seemed oblivious, or more significantly that health professionals seemed unable to influence. Paternalism is not justified, on moral grounds, in situations where family members simply do not agree with patients' decisions. In a discussion about the

evaluation of acceptable risk in home care situations, Tauer (1993) argues that the assessment of decision making capacity of a patient must “focus on her ability to make a decision about her care and her living situation, using a thought process that shows she understands the facts, the advantages and disadvantages, the alternatives, and the future possible consequences” (p50). She concludes that, although relatives should be encouraged to take an interest in patients’ care, their “expressions of concern in themselves should not lead [the health professional] to be more paternalistic towards [the patient] than would otherwise be appropriate and ethical” (Tauer, 1993, p52).

Summary

In summary, this chapter presented an overview of the substantive theory of Controlling Involvement, the related literature and clinical implications. This study described the response of patients to their perception of a lack of involvement in their palliative care decisions. This response was influenced by their relationships with health professionals, the information exchanged, their family relationships and the patients’ personal characteristics. When patients perceived a lack of involvement in their care decisions, they responded by excluding health professionals from care decisions. Excluding behaviours included evading care decisions and being self-reliant. When patients felt more involved in care decisions, they were more likely to include health professionals by making decisions with them and reconciling less involvement.

The literature related to this substantive theory clarifies the concept of patient involvement but fails to account for the preference of patients to share control of decisions with others involved in their decision processes. Decision making roles were further found not to be static but change in response to changing patient need, indicating that single assessments of preferred role will not reflect an ongoing preference for that role, although patients may be unable to determine their preferred role until they are experiencing the circumstances of particular decisions. The manner and niceness of health professionals was challenged in the literature as a potential threat to the ability of patients to question health professionals. However, the development of a trusting relationship, that often commenced with the patients’ assessment of the health professionals manner, was the basis on which patients could negotiate care with health professionals.

The clinical implications of this study focussed on the potential for health care professionals to unwittingly manipulate patients in decision making because of the importance placed on relationship. Further implications are related to the content and process of communication with patients and the importance of identifying the needs of family members as separate to the needs of patients in care decision making.

CHAPTER 7

Conclusions and Recommendations

The Study

This thesis reports on a study of care decision making in palliative care from the perspective of patients. The objective of the study was to develop a substantive theory to describe the social and psychological processes patients use to make decisions in the environment of palliative care. An initial literature review conducted at the commencement of the study in 2000 indicated that although the ethical principle of autonomy is widely accepted as the principle guiding the professional duty to respect and support patient choice, health professionals experience conflict in knowing when patients wish to make their own choices, when to involve family, when and how to undertake decisions on behalf of patients. There were no Australian studies investigating the process of decision making in Australian palliative care. A decision role card sorting exercise developed from a study by Degner and Beaton (1987) had been proposed as a technique for assessing patient role preference but no studies involving its use had been conducted in Australia. An updated literature review in 2005, confirmed the need for a study investigating the process of decision making used by palliative care patients.

Grounded theory was identified as most appropriate to describing the action and process orientations of this phenomenon. A grounded theory design was utilised to investigate the processes used by patients in making a range of everyday care decisions during the later stages of their advanced illness. Data was collected from patients, families and health care professionals in two Australian sites and one site in Japan. Data was collected over a period of three years and analysed concurrently using the constant comparative method. Two data collection activities were undertaken resulting in fifty-nine (59) individual interviews and over ninety (90) hours of field observations of decision making practices. The data were transcribed verbatim and managed using the Nud*ist Vivo computer software (Qualitative Solutions & Research, 2001). The findings were confirmed by four (4) further interviews with family members of people

who had died of terminal illness 2 to 3 years previously and experienced palliative care health professionals.

The Findings

The findings of this study describe a process where by patients respond to their perception of a lack of involvement in their palliative care decisions by attempting to control the involvement of others. Problems in their perception of control resulted in patients experiencing lack of confidence, distrust and uncertainty. Their response was affected by the relationship they had developed with health professionals, the type and process of information exchange, their relationships with family members and their own personal characteristics related to personality and stage of illness. A perception of lack of involvement in care decisions resulted in patients attempting to exclude particular health professionals by evading care decisions and by being self reliant. In contrast, when patients believed they were being involved in care decisions, they attempted to include the health professionals with whom they had developed a rapport in their care decisions by sharing decisions with them and reconciling less involvement when they felt it was appropriate for others to make the decisions.

Conclusions

The process of decision making in palliative care identified in this study that patients prefer, where decisions are shared with health professionals contradicts the ideal model of participation in health care where patients are independent decision makers. Furthermore, patients are pragmatic in their approach to making care decisions when circumstances leave them less able to exercise their preferences. Despite this pragmatism, patients find it difficult to communicate their decision making needs to health care professionals directly, using more subtle approaches imbedded in chatting with health professionals in the context of a relationship. The development of this relationship, which is determined by the health professional's manner towards them, forms the basis of the patient's ability to negotiate care with the health professional. Patients are willing to overlook expert advice from health professionals with whom they have failed to develop a relationship, in favour of advice from professionals with whom they are able to develop relationships in which a level of trust was involved. However, this same trusting relationship increases the vulnerability of patients to manipulation of their decision making, intentionally or otherwise, by health care professionals.

Limitations

The substantive theory of Controlling Involvement to Promote Confidence in Decisions in Palliative Care, is limited to the context of the patients in palliative care services in metropolitan Melbourne, Perth and in one inpatient service in Japan. However, support for the findings of this study was found in other studies undertaken elsewhere in the world. Although some attempt has been made to source some of the data from a cultural group other than Australian Caucasians, the small number of participants from Japan and limitations imposed by the need for translation by a third party meant that generalisation of the findings to this and other cultures cannot be made. The lack of research related to everyday care decision making in palliative care in cultures other than Western, Caucasian cultures has been noted and should be remedied to represent the decision making needs of all Australians, regardless of cultural background.

Recommendations

A number of recommendations can be made from the findings of this study. These recommendations are in relation to the education of health professionals, clinical practice and for further research in the area of decision making in palliative care.

Education of Health Professionals and the Community

Undergraduate, postgraduate and continuing education programs of all health professionals should explore the role of developing relationships with patients in care decision making in the context of sharing information and communication. Each program should include the development of clinical competencies related to developing rapport and informal and formal communication skills with patients. Communication competencies should include sharing of information and the facilitation of involvement in decision making with patients who have varying abilities to participate.

Health professionals should be encouraged in their professional development to undertake reflective practices in relation to the relationships they develop with patients. Reflective practice, with the aid of professional supervision should enhance self awareness regarding the influence that the health care professional has over patients and their involvement in care decisions.

The education of members of the community about developing decision making relationships with health professionals and about the communication strategies used to maintain involvement will assist in reducing the barriers to information patients experience when confronted with serious illness. Community education strategies should include community forums, audiovisual materials such as discussion vignettes, brochures and facilitated web-based discussion groups.

Clinical Practice

Clinical practice environments where there are patients with life-threatening diseases should include resource allocations that allow time for the development of relationships between health professionals and patients, for the formal and informal communication that needs to occur for patients to be involved in care decision making.

Assessment for the purposes of care planning should also determine the roles patients prefer to play in care decision making with some consideration given to the various circumstances that might change the patients' preferences, such as physical or mental incapacity. The patients' expectations of how their family members should be involved in decision making should be included in this assessment.

Clinical practice environments should also give consideration to how patients and their family members may gain access to information about illness, treatment, the care team, how care decision making occurs and how they can influence the agenda of care decision making forums. Information leaflets with photographs may explain the members of a health care team in a particular environment, the occurrence of medical rounds, times of consultations and team meetings. Similar information could appear on a dedicated channel on the televisions in patients' rooms in inpatient environments. Patients and family members could be directed to appropriate web based, textual or audiovisual material that provides general information about illness and treatment. However, this general information should never be substituted for face to face discussions with the health professionals trusted by patients, about individual disease patterns and treatment options and should only be used as a part of an individually planned information strategy.

In addition to the attention in clinical practice environments to the development of relationships with patients, assessment decision roles and information strategies, care

planning should attend to disease progression planning and the related decisions that should also be a component of that plan.

Further Research Directions

Further research should identify strategies to enhance the communication skills of health professionals to improve collaboration with palliative care patients in decision making.

The application of the substantive theory of Controlling Involvement to Promote Confidence in Decisions in Palliative Care should be explored in relation to care decision making in other clinical environments and within other cultural groups.

Further qualitative studies on the concept of trust in relation to collaboration with health professionals and care decision making are warranted in order to develop strategies that enhance patient and health professional trust.

An intervention study should be devised to test a decision making strategy that attends to aspects of the development of relationship, content and process of communication, disease trajectory planning and the documentation of an advanced decision plan and its outcomes in medical, oncology and palliative care environments.

Postscript

A little while ago, my dear mother was admitted to a hospital emergency department, in a very ill state. She was seen by a number of nurses and doctors, junior residents and specialists. Her panic-stricken family round her bedside turned to my sister (also a nurse) and me for interpretation of the tests, results and medical discussions. She was seen by a number of nurses and doctors, junior residents and specialists. At one point, my mother, my sister and I were comforting the family and ourselves that the care from one particular doctor was very good. “After all”, someone commented, “he seems very nice and kind and gentle”. We all agreed that it would be reassuring if he were responsible for mum’s ongoing care. Where others had breezed in and out, largely ignoring us, he seemed to take great care in ensuring mum understood what was happening and involved her in decisions. The doctor we trusted and wanted to be involved in decisions was the junior resident.

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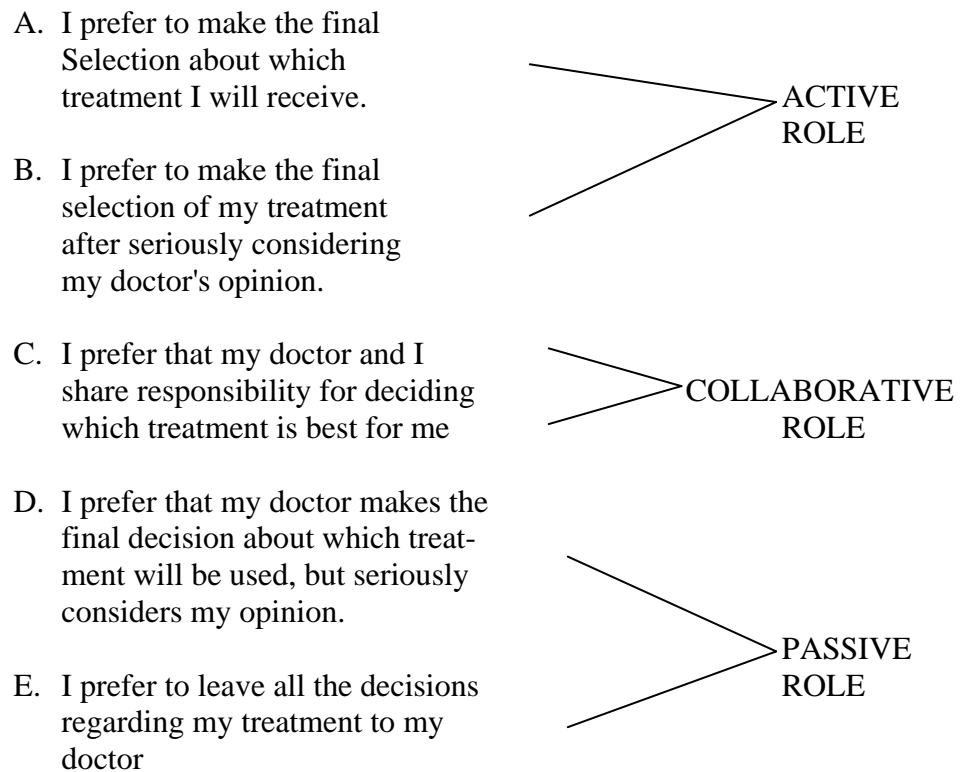
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Appendix I Decision Role Card Sort



Source: Degner, L.F. and Sloan, J. A. (1992). Decision Making During Serious Illness: What Role Do Patients Really Want To Play? *Journal of Clinical Epidemiology*, 45(9): 943.

Appendix II Setting 1 Patient and Family member Explanatory Statement

Research Project: Care Decision Making in the Context of Advanced Illness

My name is Susan Lee and I am a PhD Nursing student at Edith Cowan University, under the supervision of Professor Linda Kristjanson. My studies involve me doing a research project that looks at the way health care professionals, patients and their families, make decisions about care during advanced and serious illness. I hope that results from this research will help doctors and nurses to better assist patients and families in making decisions about their care.

This research project will be conducted over a period of 3 months and, if you would like to be involved, I will come to see you in hospital and at home every week. In order to help me understand you and your family, I will make a time to meet you and one family member for an interview that would take approximately 1 hour or we can break this into two sessions if you need. At this time we would discuss your situation, the structure of your family and complete a 5-minute questionnaire that helps me to understand how you like to make decisions. I will ask your permission to speak to your general practitioner and other community health providers about decisions regarding your care.

The rest of the research involves a process of observing and interviewing. While you are in hospital, I will be spending time with your health care teams (doctors and nurses) and with you and your family for 1-2 hours per week, observing patterns of decision making that occur. During these observations, I will be taking notes. After these meetings, I will be interviewing health care professionals, you and your family members about the decisions made and how they were made. These interviews will take approximately 30 minutes and will be tape recorded. You may find that during some of these discussions, thinking and talking about what is happening to you may be upsetting and if this happens, we can stop or postpone the interviews. You may also request that I not be present at times if you wish. I will also take some notes from your medical record about decisions made and who was involved.

When you go home, I would like to visit you for 1 hour per week to discuss the decisions you are making about your ongoing care. I will also be interviewing the health care professionals caring for you, in their offices, about the decisions they are helping you with. All these interviews will be tape recorded.

The tape recordings will be later transcribed, with all names and identifying information removed. These recordings and the field notes will be kept in a secure place for 5 years and then destroyed. You will not be identified in the final report. Your involvement in this project is completely voluntary and you can stop your involvement at any time by telling me. Whether you choose to participate or not, your care by the health care professionals involved will not be affected in any way by this research.

You should discuss this with your family and I will return on _____ to see if you would like to be involved and which family members I can also talk to. I would be happy to answer any questions you or your family have concerning the project and can be contacted on ph [number].

If you have any concerns about the project or would like to talk to an independent person, you may contact:

Ms Telephone: [number]
[Health Care Service] Customer Relations Manager

Appendix III Setting 1 Patient Consent Form

Project Title. **Care Decision Making in the Context of
Advanced Illness**

{PRIVATE}

<LEFT>

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I _____ (the participant) have been informed about all aspects of the above research project and any questions I have asked have been answered to my satisfaction.

I agree to participate in this activity, realising I may withdraw at any time.

I agree that the research data gathered for this study may be published provided I am not identifiable

I understand that I may cease my involvement in the research at any time by informing the researcher.

I give permission for the researcher to observe the health care professionals as they care for me, to discuss care decisions with them. I understand that I can request the researcher be absent from any particular observation if I wish. I give permission for the researcher to read my patient care record whilst I am in hospital and when I am at home. For this purpose, the researcher may also contact my local doctor:

Doctor _____

Participant _____ Date _____

Investigator _____ Date _____

Appendix IV Setting 1 Health Professional Explanatory Statement

Research Project: Care Decision Making in the Context of Advanced Illness

My name is Susan Lee and I am a PhD Nursing student at Edith Cowan University, under the supervision of Professor Linda Kristjanson. My studies involve undertaking a research project that examines the way health care professionals, patients and their families, make decisions about care during advanced and serious illness. I hope that this research will develop a framework that will help health care professionals' better assist patients and families in making decisions about their care.

Your participation would involve initial identification of potential patient subjects (1-2 at a time and up to 8 per site) for me to approach. The patient and their significant family members, having consented to being involved, will participate in an initial interview to gain an understanding of their situation, preferred decision roles and family functioning assessment. They will also be asked to identify community health care providers for later contact. Patients and their families may be involved in the project for up to 3 months.

The rest of the research involves a process of observing and interviewing. Whilst the patient is in hospital I will spend approximately 3 hours per week with the health care teams (doctors and nurses), the patient and the patient's identified family members. Observations will focus on the nature, scope and impact of decisions made and who was involved. During these observations, notes will be taken. At opportune moments after these observations, I may request short 5-10 minute interviews that will be audiotaped to clarify thought processes and background to decisions. Patients and families may also be interviewed. I will also take some notes from the patients medical record about decisions made and who was involved.

The tape recordings will be later transcribed, with all names and identifying information removed. The tapes and field notes will be kept in a secure place for 5 years and then destroyed. No individual or organisation will be identified in the final report. Involvement in this project is completely voluntary and you can stop your involvement at any time by informing the researcher. You may also request that I be absent at any particular time during observations.

If you have any questions regarding the project, I can be contacted on ph [number].

If you have any concerns about the project or would like to talk to an independent person, you may contact

Ms Telephone: [number].

[Health Care Service] Customer Relations Manager

Appendix V Setting 1 Family Member or Significant Other Consent Form

Project Title. **Care Decision Making in the Context of
Advanced Illness**

{PRIVATE}

<LEFT>

</left>

I _____ (the participant) have been informed about all aspects of the above research project and any questions I have asked have been answered to my satisfaction.

I agree to participate in this activity, realising I may withdraw at any time. I understand that the researcher will be observing my interactions with health care professionals and interviewing them and me about decisions made.

I agree that the research data gathered for this study may be published provided I am not identifiable.

I understand that I may cease my involvement in the research at any time by informing the researcher. I also understand that I may request the researcher be absent from any particular observation I wish.

Participant _____ Date _____

Investigator _____ Date _____

Appendix VI Setting 1 Health Care Professional Consent Form

Project Title. **Care Decision Making in the Context of
Advanced Illness**

{PRIVATE}

<LEFT>

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I _____ (the participant) have been informed about all aspects of the above research project and any questions I have asked have been answered to my satisfaction.

I agree to participate in this activity, realising I may withdraw at any time.

I agree that the research data gathered for this study may be published provided I am not identifiable

I understand that I may cease my involvement in the research at any time by informing the researcher. I also understand that I may request the researcher be absent from any particular observations.

Participant _____ Date _____

Investigator _____ Date _____

RESEARCH PROJECT



Susan Lee

*PhD (Nurse) candidate from Edith Cowan
University
is currently conducting an observational study
"Decision Making in Palliative Care" within the unit.*

Appendix VIII Setting 2 Explanatory Statement

INFORMATION SHEET

Research Project

Care Decision Making in Palliative Care

Researcher:

*Susan Lee, RN, DipNurse, BAdvNurs(ed), MBioethics,
PhD (Nursing) Candidate, Edith Cowan University*

THE RESEARCH PROJECT

The research project "Care Decision Making in Palliative Care" is currently being undertaken in the [Name of the Service] Unit. The researcher conducting this study is Susan Lee, a registered nurse with experience with working in Palliative Care, and who is currently a PhD student at Edith Cowan University, Perth. This study forms a part of the work towards her PhD Thesis.

OFFICIAL APPROVAL

This project has been approved by the Edith Cowan University Committee for the Ethical Conduct of Research, by the [Name of the Service] Ethics Committee and by the [Name of the Service] Unit. However, participation in this research is entirely voluntary and does not form part of the care delivered by the Unit. There is no obligation on staff of the unit, patients or their family members to participate in this research. Patient care will not be affected by not participating.

WHY THIS PROJECT

The aim of this research is to contribute to our understanding of the processes of decision making in advanced illness and to develop a decision framework for health care professionals who assist patients and families in decision making.

WHAT IT WILL INVOLVE

The researcher, Susan Lee, will be observing care decision making as it occurs on the ward and recording her observations in a notebook and on a tape recorder. During this time, she will assist the staff in activities around the ward, but will not provide direct nursing care to patients. Occasionally, at opportune moments, she may seek clarification of what she is observing by asking a few questions of the people involved. These short interviews will be tape recorded with permission.

The research will be conducted in such a way as to cause little disruption to the routine of the ward. Staff will not be observed in regard to clinical competence or any form of quality assurance. Susan Lee will not be involved in decision making in any way and any requests for clinical advice will be referred to the appropriate staff member.

WHO IT WILL INVOLVE

The study will involve patients and their significant family or friends, doctors, nurses and other allied health professionals involved in making decisions about patient care.

CONFIDENTIALITY AND PRIVACY

The researcher will keep confidential any discussion recorded as a part of the observation except under instruction of the person involved. The records kept by the researcher will not include any personal details that would identify a particular person. The final report of the research will not identify any participant nor will it identify particular hospitals.

TO FIND OUT MORE

If you have any questions, you can speak directly to Susan Lee, she wears an identification badge marked 'Nurse Researcher', or phone her on [phone number]. You can also phone her academic supervisor, Professor Linda Kristjanson on [phone number], or Doctor [Name], Medical Director, [name of the service] Unit [phone number].

IF YOU DO NOT WISH TO BE INVOLVED

Patients or their family members, not wanting to be involved in the study can notify the doctor or nurse caring for them, who will inform the researcher, or tell Susan Lee directly. Staff not wishing to be involved may notify Doctor [Name], (Medical Director), or the nursing shift manager. Whilst they still may be observed in the ward, no records will be made of these observations and they will not be approached to discuss issues.

Any patient or family member who wishes to withdraw from this study is free to do so without prejudice and without affecting the patient's current or future health care. Similarly, any staff member who wishes to withdraw from this study is also free to do so, without prejudice and without affecting their position at the hospital in any way. If you wish the researcher to leave particular observations, you may do so by telling Susan directly, or tell a staff member who will notify Susan. If you do not wish to answer particular questions or be interviewed at particular times, you can decline to do so.

If you have any concerns about this study or would like to talk to an independent person, you may contact:

[Name], [phone number]

Hospital Complaints liaison

Appendix IX Setting 3 Explanatory Statement

INFORMATION SHEET

Research Project

Care Decision Making in Palliative Care

Researcher:

*Susan Lee, RN, DipNurse, BAdvNurs(ed), MBioeth,
PhD (Nursing) Candidate, Edith Cowan University*

THE RESEARCH PROJECT

The research project "Care Decision Making in Palliative Care" is currently being undertaken in the Palliative Care Unit. The researcher conducting this study is Susan Lee, a registered nurse with experience with working in Palliative Care, and who is currently a PhD student at Edith Cowan University, Australia. This study forms a part of the work towards her PhD Thesis. Her translator is [Name].

OFFICIAL APPROVAL

This project has been approved by the Edith Cowan University Committee for the Ethical Conduct of Research, and by this Palliative Care Unit. However, participation in this research is entirely voluntary and does not form part of the care delivered by the Unit. There is no obligation on staff of the unit, patients or their family members to participate in this research. Patient care will not be affected by not participating.

WHY THIS PROJECT

The aim of this research is to contribute to our understanding of the processes of decision making in advanced illness and to develop a decision framework for health care professionals who assist patients and families in decision making.

WHAT IT WILL INVOLVE

The researcher, Susan Lee, would like to interview you for 30 minutes about the decisions you have had to make and how you have made them. [Name] will translate her questions and your answers. The interview will be tape recorded with permission. The interview can be held at a time that suits you and in a quiet place close to the unit.

Susan and [name] will not be involved in decision making in any way and any requests for clinical advice will be referred to the appropriate staff member.

WHO IT WILL INVOLVE

The study will involve patients and their significant family or friends, doctors, nurses and other allied health professionals involved in making decisions about patient care.

CONFIDENTIALITY AND PRIVACY

The researcher will keep confidential any discussion recorded as a part of the observation except under instruction of the person involved. The records kept by the researcher will not include any personal details that would identify a particular person.

The final report of the research will not identify any participant nor will it identify particular hospitals.

TO FIND OUT MORE

If you have any questions, you can speak directly to [name of translator] or Dr [name], Medical Director, [name of service] Palliative Care Unit on phone [number].

IF YOU DO NOT WISH TO BE INVOLVED

Patients or their family members not wanting to be involved in the study can notify the doctor or nurse caring for them, or tell [name of translator], who will inform the researcher directly. Staff not wishing to be involved may notify [name of translator], who will inform Susan Lee.

Any patient or family member who does not want to be interviewed is free to exclude himself or herself without prejudice and without affecting the patient's current or future health care. Similarly, any staff member who wishes not to be involved is also free to do so, without prejudice and without affecting their position at the hospital in any way. If you do not wish to answer particular questions or be interviewed at particular times, you can decline to do so.

If you have any concerns about this study or would like to talk to an independent person, you may contact:

[Name], [Phone number]

Hospital Complaints liaison (or other title)