NARRATIVES OF WOMEN'S HOSPITAL EXPERIENCES:

THE IMPACT OF POWERLESSNESS ON PERSONAL IDENTITY

Anne-Maree Polimeni BA (Hons.)

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QUOTATION

"The hospital is one of the few places where an individual forfeits control over virtually every task he or she customarily performs" (Taylor, 1979, p. 156).

ABSTRACT

Since women dominate the health care system as consumers, it is important to understand how women want to be treated by medical staff, and the factors that contribute to satisfactory hospital experiences. The present research comprised two separate but integrated studies exploring these issues. The first study adopted an atheoretical approach. Qualitative and quantitative methods were used to examine the importance of hospital experiences in the lives of women, and the role of power within those experiences. Closed answer items about hospital experiences were completed by 124 women who had had a hospital stay of at least one night. In addition, ten of the women provided open-ended oral and written comments about their hospital experiences, which were used as the basis of the qualitative data. The majority of the women were satisfied with their hospital stay, but a small group recalled experiences of powerlessness associated with the non-medical aspects of their treatment, such as behaviours on the part of health professionals that influenced participants' sense of control as hospital inpatients. The qualitative data reflected similar issues to the quantitative data and provided "process" information by demonstrating how health professionals' behaviour could contribute to patients' feelings of powerlessness. The results suggested that hospital experiences were a salient part of these women's lives. The richness of the qualitative data suggested that qualitative methodology would be a productive way to further study this area.

The second study was an extension of the first via in-depth interviews with 19 women who perceived their hospital experiences as life-altering. The interview content and the analysis were based on a narrative approach that used the theoretical framework of McAdams' (1993) Life Story Model of Identity. Using McAdams' methodology enabled the researcher to evaluate how women constructed meaning from their hospital experiences, and the main issues they faced. The life story interview also proved a useful way to explore issues of loss and self-growth in the face of traumatic hospital experiences. Transcripts of descriptions of positive and negative experiences were analysed according to McAdams' themes of agency (sense of power and control) and communion (relationships with others), and sequences of redemption and contamination. Redemption sequences involve the storyline moving from a bad, affectively negative life scene, to a good, affectively positive life scene. In a

contamination sequence, the narrator describes a change from a good, affectively positive life scene, to a subsequently bad, affectively negative life scene (McAdams & Bowman, 2001). Participants also rated their experiences according to Hermans' (Hermans & Oles, 1999) list of affects.

There was strong agreement between McAdams' coding of agency and communion and Hermans' agentic and communal indices: the women's hospital stories strongly emphasised the negative or opposite of McAdams' agentic theme "Self Mastery through Control", which indicated powerlessness, and Hermans' affects, which involved low self-enhancement. It may be useful for future studies to conceptualise McAdams' themes as bipolar by incorporating currently coded themes and their reverse; in particular, by expanding ideas of agency to incorporate powerlessness, as this theme was pervasive in women's hospital experiences. The rating of affects added to the findings as this showed a latent dimension of communion manifested as isolation.

The common agency and communion themes were apparent in the two distinct but related aspects of hospitalisation that affect patients' sense of control: the medical condition and the manner in which patients are treated by medical staff. The findings of the main study built on the pilot study by showing how ideas of control and powerlessness can inform better practice. For example, respectful, dignified and fair treatment by health professionals played a part in determining redemption sequences; women also indicated this was how they wanted to be treated. Due to the vulnerability of the "sick role", disrespectful or offhand treatment by health professionals had particularly distressing effects evident in contamination sequences, such as negative changes to sense of self and attitudes toward the health care system. In some cases, such treatment led to participants' avoiding subsequent interactions with doctors and to sustained feelings of helplessness. The present thesis demonstrates that doctors, nurses and other health professionals need to allow time to attend to the affective as well as the medical aspects of the encounter. Health professionals need a good bedside manner, compassion, and communication skills, as these characteristics play a part in maintaining female patients' sense of self and their faith in and satisfaction with the health care system.

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This thesis is dedicated to the lives and memories of Gelsomina DiBlasio, for being a strong and inspirational woman – the type of woman I aspire to be – and Cesare DiBlasio, who loved to learn.

DECLARATION

This thesis contains no material which has been accepted for the award of any other degree or diploma, except where due reference is made in the text of the thesis. To the best of my knowledge, this thesis contains no material previously published or written by another person except where due reference is made in the text of the thesis. Where the work is based on joint research or publications, I have disclosed the relative contributions of the respective authors. This thesis has been professionally edited. The editing has addressed only the style and grammar of the thesis and not its substantive content.

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Anne-Maree Polimeni

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CHAPTER ONE

INTRODUCTION AND OVERVIEW OF THE THESIS

1.1 Introduction

A newspaper article appeared in the Melbourne Herald Sun in June 2001 (Ross, 2001) describing the case of a woman who went into hospital as a day patient for a cystoscopy after suffering from bladder cancer for several years. When she awoke after the surgery she discovered that her clothes and personal items had been stolen.

> When it was discovered her clothes were missing, staff gave Mrs Duffy, 64, a boy's pyjama jacket and a sanitary pad and told her to go home.… Mrs Duffy pleaded to be able to at least keep on the hospital gown or have a blanket but her requests were refused … She was taken shamefaced and squirming with embarrassment in a wheelchair through public areas to her friend's car, trying desperately to pull the flimsy jacket over her breasts.… "I felt like a third rate citizen, and like I'd been absolutely violated", said Mrs Duffy … She was sent home half-naked from the hospital and nearly two years later she suffers nightmares and distress (Ross, 2001, p. 8).

Cases in which health service providers treat patients with discourtesy or in an undignified manner are relatively rare. However, the above account demonstrates they exist and serves to highlight the important point that hospital stays do not simply involve treatment for a physical affliction. Hospitalisation is also made up of psychosocial aspects, such as the manner in which hospital staff treat patients. Other personal accounts of hospitalisation also reveal a distinction between the experience of the physical affliction and the manner in which health professionals treat patients (e.g., Cross, 1986; Sack, 1984). This aspect is reflected in the Annual Report of 2001–2002 of the Victorian Office of the Health Service Commissioner (Health Services Commissioner, 2002), which states that communication failure is a feature of nearly all complaints about medical treatment. Complaints about communication involved rudeness and lack of interest, inadequate quality and quantity of information provided about the treatment, risks, outcomes and prognosis, and inconsiderate or undignified

service. The most frequently mentioned communication issue was poor attitude and discourtesy. Mrs Duffy's experience reflects this, as she was provided with undignified service, and there was a clear absence of caring. Researchers, educators and health professionals are in a position to ensure that no patient is treated in this manner. Research shows that unsatisfactory hospital experiences have important implications for patient satisfaction, health outcomes, and litigation (Frankel, 1995; Phillips, 1996; Stewart, 1984; Winefield, Murrell, & Clifford, 1995).

1.2 The Importance of Hospitalisation

People can feel particularly powerless when they are placed in the vulnerable position of being ill. Sickness conjures up images of passivity, anxiety and dependency. Additionally, the role of the hospital patient is to be compliant. Just as legislation promotes a civilised and lawful society, hospitals need rules and routines in order to run efficiently. Patients are expected to abide by hospital rules and routines, but in doing so, some patients may feel that their daily life is not quite their own and that they are at the mercy of staff. Such feelings may invoke a general sense of reduced power, control or agency[1] (Brown, 1963; Lupton, 1994; Roth, 1972; Tagliacozzo & Mauksch, 1972; Wilson, 1963). Medical staff can also exacerbate a lack of power. For example, the high social and professional status of doctors may intimidate patients (Todd, 1989). In addition, the manner in which health service providers treat patients may play a part in engendering a feeling of powerlessness in patients. For example, clinical detachment and the suppression of emotion is a basic requirement in medical work, in routine examinations, emergency situations and when diagnosing disease (Crossley, 2000). However, an unintended consequence is that the patient may feel "invisible", like an object to be worked upon by the doctor. The emphasis is then on cure rather than care and this can cause patients to feel dehumanised and disempowered. Furthermore, if patients are treated insensitively and also have to undergo invasive and painful procedures, their general sense of reduced power may be compounded, a situation that has the potential to produce traumatic and long-lasting effects (Shapiro, Prislin, Shapiro, & Lie, 2000).

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[1] The terms "power", "control", and "agency" are used interchangeably throughout this thesis. The definition includes the ability to do or act; to exercise restraint or direction over; the state of being in action or exerting power (Macquarie Australia's National Dictionary, 1983)

Research has also shown that hospitalisation temporarily disrupts patients' lives and can contribute to a loss of self when patients are dislocated from their normal environment and lack normal social interaction (Warren, Holloway, & Smith, 2000). Psychology has explored the idea that control is an important factor in everyone's lives, but has not directly examined the role of control in patient hospital experiences. The majority of research that has explored the experience of hospitalisation from the patient's perspective examines the child patient's perspective, the antenatal experience, or that of the psychiatric patient. Very little research has been conducted on the views of the adult patient with a physical illness and on the impact of hospitalisation on the sense of self.

1.3 Overview and Objectives of the Thesis

The present research consisted of two separate but integrated studies. The first was a pilot study which took an atheoretical approach and explored women's oral and written comments on, and their responses to, specific questions about their hospital experiences. The main study extended the first through a qualitative analysis of in-depth interviews with women who perceived that their hospital experience had altered their lives. The interview content and analysis were based on a narrative approach that used McAdams' (1993) life story procedure. Interviews primarily explored the main issues women faced in hospital and sought to answer the question "How do women understand a change in their identity after a life-altering hospital experience?" Although narrative psychology has been used to explore life narratives of people with an illness, such as stroke (e.g., Ellis-Hill & Horn, 2000), no previous studies have specifically used McAdams' methodology as a way of exploring the impact of a hospital experience.

The general aim of this thesis was twofold. The first aim was to explore female patients' perspectives of hospitalisation by examining their perceptions of power as inpatients and by assessing the relevance of such issues. The second aim was to examine the impact that hospital experiences have on the lives and identities of women in terms of their sense of self and their attitudes towards the health care system. The researcher also attempted to document specific examples of how female inpatients want to be treated by health professionals. This was achieved by exploring women's

inpatient experiences of "good" and "poor" quality service in their interactions with health professionals during their hospital stay.

1.3.1 Rationale for using Female Participants

The current study focused on female patients' hospital experiences. The reason female participants were chosen was threefold: they constitute the majority of health consumers, they belong to a low power group in society (Nathanson, 1975; Taylor, 1999), and they have a close relationship with their bodies (Gergen, 1992, 1994). Results from the National Health Survey conducted by the Australian Bureau of Statistics (2001), which included approximately 27,000 people from all states and territories in Australia and across all groups, revealed that women were more likely than men to consult most types of health professionals (Australian Bureau of Statistics, 2001). There are a number of reasons for this: women live longer than men, their reproductive capacities bring them into contact with medical services more often, and they are more likely to act as providers and negotiators of health care for others (Horsley, Tremellen, & Hancock, 1999). Therefore, it is likely that they hold strong views about the health professionals with whom they come into contact (Nettleton, 1995).

Nettleton (1995) believes that doctor–patient relationships both reflect and reinforce wider social relations and structural inequalities, especially those of gender[2], ethnicity, and class. She states that the negative effects of perceived lack of control in the medical setting may be exacerbated if the patient also belongs to a low power group, for example, young people, women and minority cultures. As men constitute the majority of medical practitioners, women infrequently receive health care from a provider of the same sex, unless they make a specific effort to do so (Horsley et al., 1999). Gender inequality and power are likely to be just as important in a hierarchical social structure such as a hospital as they are in wider society, and may have a particularly significant effect on women's inpatient experiences (Swan, 1992). All these factors may work towards increasing the vulnerability of female inpatients and

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[2] Sex is generally described in terms of biological or physical characteristics related to being male and female, and gender is defined in terms of roles or characteristics culturally assigned to sex (Moradi & Yoder, 2001). West and Zimmerman (1987) argued that gender is a social and cultural construction, and is conceptualised as a dynamic understanding produced through everyday interactions and social arrangements, rather than as a set of fixed roles or traits.

may make it difficult for women to act as autonomous, confident and capable adults in the hospital setting (Webster & Wilson, 1993).

The vulnerability attached to the sick role may yet again be intensified in a female inpatient. Gergen (1992, 1994) found that women refer to their bodies as an integral aspect of their identity; they refer to their bodies, characteristics and processes using "I", "me", "my", and "mine", rather than "it" as men do. Women describe themselves as deeply embodied; to have a certain bodily condition is to be "oneself". Thus, violations of the body represent invasive negations of identity. Considering women's close identification with their body, their sense of self may be more vulnerable to violations in the hospital environment where their body is potentially at risk or under threat.

Very little research has been conducted on women's experiences of the health care system. It is important for women and health professionals alike to understand the roles which gender and power issues play and the way women wish to be treated, so that they are satisfied with their care.

1.3.2 Combining Qualitative and Quantitative Research Methods

The present research employed qualitative and quantitative methodologies with the aims of (1) achieving convergence and confirmation of results across different methods, and (2) gaining a comprehensive picture of power within women's hospital experiences from a number of different research standpoints. In this research, the pilot study involved qualitative and quantitative aspects. This helped to determine the factors that were important to participants during hospitalisation, and prepared the ground for the more extensive qualitative data collection in the main study. Also, within the pilot and main studies, triangulation of research methods contributed to verification and validation of analyses by allowing the exploration of the consistency of findings generated by the two methods.

There are arguments that a combination of qualitative and quantitative methodologies is useful when researching an area for which there is little previous research or for which there is no theoretical framework (Cohen & Manion, 1994; Reinharz, 1992), such as the exploration of women's hospital experiences. There now appears to be a trend towards research on the role of power and control in doctor–patient interactions, but this means that there is an accompanying need to more properly

and carefully define the concept of power and control in the hospital context and explore its significance. Power and control in women's hospital experiences appears to be an ambiguous concept because it can be manifested in very subtle ways; therefore, this research attempted to access such subtle material through a range of methods, ranging from very personalised case material to a survey.

1.4 The Significance of the Present Study

To understand the significance of hospital experiences to the lives of women, it is helpful to look back to the nineteenth century and examine the development of the medical system in relation to women, and the ways in which women have been perceived within the health care system. Many commentators argue that women have not been treated fairly and equally in the medical arena, either as health professionals or as patients. Although female patients may be at a disadvantage in the health care system, health psychology has done very little to clarify the nature of their experience and the extent of their difficulties.

1.4.1 The Historical Context of the Health Care System

In Australia, the modern medical profession emerged when the 1858 Medical Registration Act unified previously distinct types of medical practitioners into an alliance (Hardey, 1998; Pringle, 1988; Ross, 1953; Witz, 1992). Some authors state that, at this time, the field of professional medicine was defined as masculine territory and doctors attempted to exclude women from access to its ranks (Pringle, 1988; Witz, 1992). Women were not excluded from the medical register by law; rather, they were excluded from medical education and examination in all the Australian universities which were the means of entry to the medical register (Hockey, 1993; Pringle, 1988; Witz, 1992). In the 1870s, women began to be accepted into the medical profession; however, their education and examination was conducted separately from men (Stacey, 1994; Witz, 1992). Pringle (1988) reports that women encountered many obstacles to practising medicine, such as refusals of entry to universities, the hostility of male medical students, the refusal by medical staff to allow women on the committees of medical schools, and the examining bodies themselves. In addition, medical qualifications did not guarantee that women would receive hospital appointments as hospitals were reluctant to employ women (Pringle, 1988).

Witz (1992) believes that the establishment of medicine as an allied profession, together with the development of industrial capitalism, were two fundamental factors in explaining women's exclusion from medicine in the 1800s. First, in the pre-industrial period, Witz believes that the practice of healing generally took place in the domestic context, and was overwhelmingly provided by women. After the industrial revolution, the market for medical services rapidly expanded, as did the middle class and their incomes. Therefore, people sought medical care from (mostly male) medical practitioners rather than in the domestic context, which contributed to the demise of women's role in caring for the sick (Witz, 1992). Second, in the pre-industrial period, families (including wives and daughters) were involved in market-orientated medical services (Hockey, 1993; Witz, 1992). After the establishment of the medical profession, medical practice was no longer a part of the market-orientated activities of the family business (Hardey, 1998; Witz, 1992). As women were excluded from specialised sites of education and training outside the family context, they were therefore excluded from the emergent specialised medical profession (Witz, 1992).

Other writers have a different perspective on history. Pringle (1988) states that the events of the 1800s are often portrayed as an attack on women healers, and believes that such writers have "romantic notions about the place of women in medicine before 1858" (Pringle, 1988, p. 25). She argues that women's healing activities were already being significantly reduced before the formal establishment of the medical profession. Pringle appears to believe there was nothing sinister about the lack of a role for women in medicine. Rather, 19th century modern society demanded more from medical practice and, consequently, midwives began to be displaced as medical men saw the opportunity and had the ability to set up a new medical establishment.

Since the mid-1970s, the proportion of female medical students has rapidly increased in most Western countries. In Australia, in 1974, the University of Melbourne changed its entrance requirement for medicine to include an English grade, in recognition of the need to improve doctors' ability to communicate (Pringle, 1988). This development contributed to the increase of female medical students. Today, in Australia, the proportion of female medical students has reached 50% and it continues to rise. This change will take some time to be reflected in the proportion of male and female doctors in practice. Presently in Australia, men continue to dominate the health care system as doctors, with women accounting for just 26% of all private practice

medical practitioners (33% of general practitioners and 14% of specialists) (Australian Bureau of Statistics, 2002).

1.4.2 The Medical Profession's View of Women

There have been powerful arguments put forward by both psychologists and sociologists that sickness is linked to the feminine role, and that medicine tends to perceive women's normal state as "sick" by virtue of their stereotyped role in society as the "weaker sex" (Broverman, Broverman, Clarkson, Rosenkrantz, & Vogel, 1970; Foss & Sundby, 2003; Phillips & Ferguson, 1999). Some empirical research lends support to the idea that medical professionals are more likely to consider male patients as physically and mentally healthier than female patients, who tend to be characterised as weaker, less healthy, and more given to complaint (Broverman et al., 1970; Phillips, 1964; Phillips & Segal, 1969). Research has also shown that health care providers tend to discriminate against females (Calderone, 1990; Colameco, Becker, & Simpson, 1983; Foss & Sundby, 2003; McDonald & Bridge, 1991; Pittman, 1999; Wallston, DeVellis, & Wallston, 1983). For example, nurses and doctors have been shown to plan less ambulation, pain relief and emotional support for female patients, and to also perceive women more negatively, for example as demanding and difficult. Such findings appear to reflect traditional gender role stereotypes. Furthermore, women may be less stigmatised for expressing vulnerability and weakness, and are perhaps more willing to express such characteristics by being prepared to see a doctor when ill. However, judging women against a different standard of health or relying on traditional feminine gender role stereotypes and holding incorrect perceptions may interfere with the quality of patient care.

1.4.3 The Lack of Empirical Work on the Psychosocial Aspects of Women's Hospital Experiences

Health psychologists' examinations of the doctor–patient relationship have focused on patient compliance[3] and adherence to medical treatment, and interventions which increase compliance (e.g., Cecil, 1998; Falvo & Tippy, 1988; Frankel, 1995; Leirer, Morrow, Pariante, & Sheikh, 1988; Ley, 1986; Schraa & Dirks, 1982). Crossley

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[3] Compliance is defined as the degree to which the patient's behaviour (in terms of taking medication, following diets or other life-style changes) corresponds with medical or health advice (Ogden, 1996).

(2000) states that there are two main problems with the focus by health psychologists on compliance and improving patient adherence to medical advice. First, this focus fails to take into account the changing social context of health care; that is, the rise in the consumerist health movement. Concentrating on patient adherence to doctors' advice in a time of "consumerism" implies an uncritical acceptance of the medical standpoint, and places little value on the patient's role in the health care process. The second problem refers to a failure to take account of the emotional and often irrational nature of the doctor–patient relationship. Diagnoses of illness are intense events which raise strong emotions, including the fear of death and the desperate desire for a cure. Medical degrees do not usually prepare doctors for such intense emotions, and to cope, they generally tend to emotionally distance themselves from patients (Crossley, 2000). This may help the doctor, but it can be upsetting to the patient. Emotions are also likely to run high as doctors essentially dominate the doctor–patient relationship; therefore, conflicts between the patient's desires and the doctor's recommendations are usually resolved in the doctor's favour. Thus, much emotion can arise from both the power-related as well as the illness-related aspects of the situation (Parsons, 1951). The emphasis that has been placed on compliance in the study of health psychology undervalues the patient's role in the health care process and the emotional aspects of the medical encounter. This emphasis may in itself contribute to maintaining the dehumanising aspects of medical practice (Crossley, 2000).

To add knowledge to the area of hospital experiences and the role of power, researchers in health psychology need to acknowledge social change, and take into account patients' desire for collaboration and increased access to information, and the importance of their emotions. The present research is located within the contemporary social context of medical care in that it acknowledges the importance of the patient's role, it acknowledges that medicine is more than the cure of illness, and explores the patient's view of hospitalisation. Implicit in this approach is the acknowledgement of emotions, not only connected to the powerlessness which may be felt when one is sick but also to the potential powerlessness of inpatients within the hospital system.

1.5 The Following Chapters

Chapter Two contains a review of empirical studies from the psychological literature on women's health experiences. It includes factors which affect the power

differential between the doctor and the patient, the impact of that power differential, as well as a summary of the literature regarding what women seek from their relationship with their doctor and with the health care system.

Chapter Three describes the conduct and analysis of the pilot study, which involved the exploration of the importance of power and control for female patients in hospital. This study provided a rationale for the further study of women's hospital experiences which focused on the hospital experience as a life-changing event. In addition, from the richness of the qualitative data, it appeared that a qualitative methodology would be a productive way to further study this area.

In Chapter Four the need for a theoretical framework to understand and explore issues of power and control in women's hospital experiences is addressed, as a prelude to a larger qualitative study of women's hospital experiences. McAdams' Life Story Model of Identity (1993) is introduced. The theory is relevant as it addresses the two fundamental aspects of the present research. First, it provides a method of examining themes of control, power or agency within a person's life narrative; second, it enables the exploration of the way in which people construct "life stories" to make sense of their lives. In Chapter Four there is a discussion of the Life Story Model of Identity, including the evolution of the theory, and the development of identity. Chapter Four concludes by addressing the manner in which McAdams' Life Story Model of Identity can be applied to the analysis of women's hospital experiences.

In Chapter Five the main study is introduced, which used McAdams' methodology to explore the stories the women told about significant hospital experiences. Specifically, the chapter includes the research aims, information about the female participants, details of the interview and the questionnaire, and the manner in which the interview transcripts were coded, including McAdams' agency and communion themes which were used to code the data. Chapter Six presents an in-depth qualitative analysis of the interviews with women who perceived their hospital experiences as life-altering. It explores themes of power, McAdams' communion and agency themes, his conceptualisation of redemption and contamination scenes, participants' ratings of how they felt during their hospital experiences, and examples of good and poor quality service on behalf of service providers. The findings reflected and built on the results of the pilot study by illustrating the different sources of power and powerlessness for female patients in hospital.

In Chapter Seven there is a general discussion, which draws together the results of the two studies, highlights the main findings, and places them within the theoretical context of power and control in women's hospital experiences. Also addressed in this chapter are limitations and implications of the present research and suggestions for future research.

CHAPTER TWO

WOMEN IN HOSPITAL: THE ROLE OF POWER AND GENDER

2.1 Overview of the Chapter

Chapter Two is organised into three sections. The first section discusses past and present research on the psychosocial experience of hospitalisation. Past researchers tended to examine hospitalisation from a different angle to present researchers. The latter examined the individual pathology of patients as a way of looking at disruptive or misbehaving patients. On the other hand, contemporary researchers have argued that patients' behaviour is a result of the interaction between health professionals and patients, thus they have explored the patient's experience of hospitalisation and their interactions with medical staff. Common to each approach is the impact of patients' perceptions of control on their behaviour. Specifically, when patients lack control it can adversely impact on their behaviour. The second section concentrates on the empirical studies of control in health care, with a focus on women's health care experiences. Specifically, this section discusses patients' desire for control, the health benefits of perceived control, and the factors that can impact upon the power differential in doctor–patient relationships, either to the detriment or improvement of patients' wellbeing or the doctor–patient relationship itself. The final section reviews studies examining what patients seek from health care providers.

2.2 Research on Hospitalisation: Different Perspectives
2.2.1 Research on Hospitalisation Prior to 1980

In the 1960s and early 1970s a handful of social scientists (Brown, 1963; Roth, 1972; Wilson, 1963), psychiatrists (Kornfeld, 1972) and other researchers (Tagliacozzo & Mauksch, 1972; Volicer, Isenberg, & Burns, 1977; Wilson-Barnett, 1976) published innovative commentaries and studies that explored the hospital experience from the patient's perspective. These writers described the experience of hospitalisation as disruptive, confusing, "destructive to the psyche" (Roth, 1972, p. 429), and producing conditions conducive to feelings of powerlessness, helplessness, dependency and passivity (Brown, 1963; Roth, 1972; Tagliacozzo & Mauksch, 1972; Wilson, 1963).

American researchers Tagliacozzo and Mauksh (1972) conducted interviews with 86 cardio-vascular and gastro-intestinal patients which highlighted that patients

were aware of "good patient" and "bad patient" roles. Good patients are concerned with doing exactly what they are told and following instructions of the hospital staff (Lorber, 1975; Tagliacozzo & Mauksch, 1972). Bad patients complain, demand attention, and insist on their rights as autonomous individuals. In the aforementioned studies, patients were eager to appear co-operative, considerate, and did not want to be labelled "bad". They believed that staff had the power to withhold services, and that being labelled bad would increase the likelihood of this occurring. Tagliacozzo and Mauksh commented that these ideas make it difficult for patients to play the "consumer role" openly and without fear of criticism.

Roth (1972) asserted that hospital disrupts one's life plan, not only as a result of illness or treatment but because the hospital routines and environment are designed for the convenience of hospital staff. Researchers acknowledged that whereas some patients were satisfied with, and appreciative of, the care they received while in hospital (Wilson-Barnett, 1976), a substantial proportion were not only dissatisfied but were also disturbed by their time in hospital (Brown, 1963). Some early writers perceived hospitalisation as a source of psychosocial stress for most patients (Kornfeld, 1972; Mason, Sachar, Fishman, Hamburg, & Handlon, 1965; Pride, 1968; Strumpfer, 1979; Volicer, 1978; Volicer et al., 1977). For example, Mason et al. (1965) examined 90 American adults and found that the experience of entering hospital resulted in significantly higher urinary corticosteroid levels for many research participants during the first several days of hospitalisation compared to later in hospitalisation. Generally, higher urinary corticosteroid levels reflect higher stress levels. The researchers attributed these corticosteroid changes (in part) to the participants' psychoendocrine response to environmental change.

Other American survey studies indicate that distress can stem from several factors related to hospitalisation, such as a lack of information about one's medical condition, financial worries, isolation from family and friends, time away from work, concerns about the illness (Volicer et al., 1977; Wilson-Barnett, 1976), and being in a strange environment where one has little control (Affleck, Tennen, Pfeiffer, & Fifield, 1987; Johnson & Leventhal, 1974; Pennebaker, Burnam, Schaefer, & Harper, 1977). Wilson (1963) argued that when patients enter hospital, their identity and social roles in the outside world lose much of their meaning. Other writers emphasised that patients experience a restriction of freedom (Roth, 1972; Volicer et al., 1977; Wilson, 1963).

For example, they have little choice of bed allocation, roommates, the time and manner of waking, going to bed, and eating.

In a review of this line of research, Taylor (1979) suggested that the hospital creates a depersonalising environment that forces the patient to relinquish control over his or her daily existence to the staff. Taylor clarified that hospital staff do not intentionally depersonalise patients; instead, the control is simply for reasons of efficiency and self-protection. Depersonalisation of the patient can occur in a number of ways. For example, routine procedures (e.g., diagnostic medical tests, x-rays) that treat all patients the same may facilitate a patient's loss of identity (Roth, 1972; Tagliacozzo & Mauksch, 1972; Wilson, 1963). Also, disrespectful treatment, such as a lack of basic courtesy, may cause patients to feel depersonalised (Cartwright, 1964). Taylor's review focused on evidence supporting Lorber's (1975) idea that patients adjust to depersonalisation by assuming either good patient or bad patient behaviour. Taylor also argued that good patients might in fact be depressed or showing anxious helplessness, whereas bad patients may be exhibiting anger and reactance against the perceived arbitrary removal of freedoms. An analysis of the research on the behavioural, cognitive, affective and physiological correlates of helplessness and reactance, as well as the behaviours they elicit in staff, suggests that both good and bad patients sustain health risks such as detrimental consequences for treatment and recovery (Taylor, 1979). It is also argued that an informed and participative role for the hospital patient can contribute to a healthy physical and psychological state, and can offset adverse side effects that the loss of control-reactance-helplessness cycle creates (Affleck et al., 1987; Johnson & Leventhal, 1974; Pennebaker et al., 1977).

2.2.2 The Importance of the Patient's Perspective

Taylor's (1979) review and others (e.g., Lorber, 1975) were important contributions, as they acknowledged patients' reactions to hospitalisation and highlighted the importance of patients' perceptions of control. However, such researchers were primarily concerned with the individual pathology of patients such as questioning what was wrong with a patient if he/she misbehaved in hospital. In contrast, the present thesis investigated how the system impacts on the patient by examining individuals' experiences of the system.

Kelly and May (1982) reviewed the nursing, sociology and psychology research on so-called good and bad patients. They found that much of the literature was deficient from empirical, methodological, epistemological and theoretical viewpoints (Kelly & May, 1982). The researchers proposed an alternative theoretical framework of an interactionist perspective. According to Kelly and May, patients are labelled as good or bad patients, not because of anything innate in them or in their behaviour, but as a result of the interaction between staff and patients. Roles are not simply a rigid list of traits that instruct behaviour, but exist and have meaning only in relation to other roles with which they interact. Therefore, it can be argued that the role of the caring nurse may only be possible with the presence of an appreciative patient. Similarly, the disruptive patient may only be possible with the existence of a controlling doctor or an inattentive nurse.

2.2.3 Recent Research on Hospitalisation

In recent times, few studies have explored the patient experience of hospitalisation. Those that exist show that today's experiences of hospitalisation are not as negative as studies of earlier decades and reflect changes in the normative expectations of doctor and patient roles. For example, patients are no longer expected to be passive, but to express their views and take some responsibility for managing their condition. Nevertheless, there are some similarities between current findings and those prior to 1980. For example, in the field of nursing, Warren and colleagues (Holloway, Smith, & Warren, 1998; Warren et al., 2000), have published qualitative research on the emotional experience of hospitalisation in order to gain a better understanding of what it feels like to be a patient. The data were collected from 11 patients of varying ages admitted to the acute medical ward of a hospital in the south of England. Holloway et al. (1998) explored patients' experiences of time in hospital and revealed findings consistent with the writings of Roth (1972). As in the earlier research, patients keenly felt that their normal way of life was disrupted by time spent in hospital. These findings also highlight the idea that time can be perceived as a basis of power and control. Patients perceived a loss of control over time because staff and hospital routines largely determined how time was spent. Also, patients likened being discharged to being "released" and "let out", phrases usually associated with prison.

Warren et al. (2000) aimed to gain an understanding of the patient culture. Patients' stories confirmed that while hospitalisation eased suffering caused by an illness, in some cases it also caused distress. The study's findings were consistent with those of Tagliacozzo and Mauksh (1972), in that patients expressed the need to "fit in" to the patient culture. This involved being co-operative and acknowledging the right of the professionals to control. Although patients were aware of their rights and responsibilities, they rarely challenged the system. They accepted their care and treatment with few complaints, as they did not want to be labelled "disruptive". The researchers also found that conforming to the social rules of the patient culture minimised the threat to the patient's sense of self. When social rules are broken, patients can feel embarrassed and this can threaten their sense of self.

In summary, Warren's (Holloway et al., 1998; Warren et al., 2000) findings suggest that the manner in which health professionals' power and patient dissatisfaction are manifested is more subtle today than was reflected in the writings of the 1960s and 1970s. The research points to the importance of control for hospital patients. Namely, control over time and maintenance of the sense of self were two important aspects of the hospital stay. The findings implied that some control over time and hospital timetables would give power to patients and would reduce the negative effects of loss of time. Additionally, hospital staff can provide a compassionate and understanding hospital culture, and they can assist patients who wish to complain about their treatment or who are unable to "fit in" to the patient culture by supporting and validating their sense of self. The next section focuses on the role of power in the doctor–patient relationship.

2.3 Power in the Doctor–Patient Relationship

"Power is an inescapable aspect of all social relationships, and inherently is neither good nor evil" (Goodyear-Smith & Buetow, 2001, p. 449).

The doctor–patient relationship is one example of a professional–client relationship, and as such it involves a power relationship (Haug & Lavin, 1981). Parsons (1951) argues that doctor–patient relationships are inevitably characterised by asymmetry because of the doctor's professional competence and professional concern. Professional competence is characterised by the doctor's level of skill and knowledge,

founded on formal training and experience. Professional concern refers to the doctor's role as a "general trustee" of the health interests of the population.

Traditionally, the power differential between doctors and patients has been reinforced by social mores. Western medicine has given prominence to what could be described as a paternalistic value system, in which doctors take charge of making decisions about what is best for their patients (Weitz, 1996). But in contemporary society, more than ever before, most people have a wealth of information at their fingertips. As individuals become more knowledgeable and less dependent on health professionals for information, research shows that the so-called paternalistic value system has given way to a more consumer-orientated system. This is reflected in the larger numbers of patients who seek greater agency and involvement in decisions about their treatment (Coulter & Magee, 2003). Such a change is also evident in the recently founded multi-disciplinary international journal called *Health Expectations*. The journal focuses on public participation in health care and health policy.

Today's doctors need specialised knowledge and skills, not only to facilitate the healing process, but also to help them understand their patients' needs, to share information, and to help patients make informed decisions about treatment. Doctors are often expected to be their patients' advocates, and to interact with patients in a sensitive and compassionate manner, while maintaining professional integrity (Goodyear-Smith & Buetow, 2001). To optimise the doctor–patient relationship, patients also need power to express their values, to realise and communicate their health needs, and to meet their responsibilities (Goodyear-Smith & Buetow, 2001). This shift in the balance of power is important because patients who perceive themselves as having an active role in their health care have significantly improved health outcomes (Lerman et al., 1990). The next section continues the discussion of this argument by examining patients' desires for control in medical encounters and the benefits of patient control.

2.3.1 Patients' Desire for Power

The psychological literature indicates that most individuals place great importance on control in their lives (Gatchel, 1980; Shapiro & Austin, 1998; Syme, 1989; Thompson & Spacapan, 1991), and illness is one situation where the sense of control can be disrupted. American and British quantitative and qualitative research demonstrates that hospital patients want more control over their care (Deber,

Kraetschmer, & Irvine, 1996; Dennis, 1987; Gotlieb, 2000; Haskell & Brown, 1998; Litva et al., 2002; Walker, Arnold, Miller-Day, & Webb, 2001), although the type of control differs. Deber et al. (1996) administered a questionnaire to measure the desire for information and participation in medical decision-making to 300 patients undergoing angiograms at a Toronto hospital. The research revealed that patients had a high desire for information, and although the patients did not wish to be involved in problem solving tasks, such as deciding whether a particular diagnostic test would be performed, few were willing to hand over total decision-making control to their doctor (Deber et al., 1996).

Dennis (1987) conducted a combined qualitative and quantitative study of 30 medical and 30 surgical patients admitted to a large military medical facility. The findings identified three types of patients with respect to need for control. Type one patients wanted to have information about diagnostic tests and treatments but did not reveal a desire to be actively involved in decision-making related to those events. Type two patients tended to be those diagnosed with cancer and wanted to take part in decision-making. They were also less concerned about having control over daily activities and the physical environment. Type three patients were more concerned with having staff meet their needs. This included staff providing pain medication when asked, as well as giving explanations and generally supporting behavioural independence and integrity. The researchers concluded that the control phenomenon is complex and the identification of the kinds of persons who desire certain types of control remains elusive. Other American research involving observational data from 72 patients' clinical visits to one female family practice physician, revealed that patients wanted to share the control with the doctor by allowing the doctor to guide the interaction but also by engaging in active questioning, giving their opinion, and asserting their status as the informed decision maker (Walker et al., 2001).

Buetow (1995) revealed that Australian patients appear to have similar needs to their American counterparts. Buetow conducted a review of the Australian literature in the course of examining what Australian patients want from their general practitioner. The review showed that, although the amount of information patients want remains uncertain, most patients want more information than they are currently receiving in order to make informed decisions (Law Reform Commission of Victoria, 1989). The review also stated that in recent years there has been an increase in patient decision-

making. However, Buetow emphasised that it is still unclear under what circumstances sharing of authority and responsibility is acceptable to both general practitioners and patients.

The few studies that specifically examine women's perceptions and desire for control in medical encounters mirror the previous findings. Primarily, women want more control over their health, desire access to information, and to be treated as partners in their relationships with health care professionals (e.g., Annandale, 1987; Ellingson & Buzzanell, 1999; Kasle, Wilhelm, & Reed, 2002; McKay, 1991; Taylor & Dower, 1997). For example, one study conducted focus groups in southern Arizona with women receiving community services, providing community services, and developing health programs and policy. The findings showed that the women considered themselves to be treated unequally, and that they wanted to be treated with respect and as partners (Kasle et al., 2002). Furthermore, interviews with Lebanese (Kabakian-Khasholian, Campbell, Shediac-Rizkallah, & Ghorayeb, 2000) and American women concerning their experiences of childbirth (McKay, 1991) revealed similar sentiments: women reported that the medical system dominated their health and reduced their level of participation in decisions related to their care.

Ellingson and Buzzanell (1999) interviewed 14 women diagnosed with breast cancer living in suburban or rural midwestern United States. The interviews determined that the participants envisioned their patient roles as equal, but not identical, to their doctors' roles. They relied on the doctor to have all the latest information and treatment options, and to be able to communicate with them. They believed their role involved making assisted decisions. The researchers asserted that when control is shared, participants feel they are in partnership, and they understand why actions are taken or decisions made. Thus, through information sharing, the patient acquires the knowledge needed to play a role in her care. Australian research also indicates that women, across different age groups and geographical regions, want to be treated with dignity and respect, and desire access to informed decision-making (Victorian Ministerial Women's Health Working Party, 1987). The outcomes of the Ministerial Working Party's extensive consultation with approximately 7000 Victorian women suggested that women desire a more collaborative role in their relationship with the health system.

In summary, the research shows that both men and women want an active role in their health, but that the extent of the role clearly depends on the individual. Notably,

requirements can range from wanting more information about a diagnosis, medication and its side effects, treatment and prognosis, to wanting to participate in decision-making about treatment. Taken together, these findings point to a definition of the patient's perception of control as the degree to which patients believe that they can influence the care they receive from the hospital (Gotlieb, 2000). The literature also emphasises the importance of communicating health information, as accurate information allows patients to interact with health professionals and maintain a degree of control over the care process, thus alleviating fear (Haskell & Brown, 1998).

2.3.2 Benefits of Patient Control

An increasing amount of literature emphasises the beneficial effects of increased personal control over life events (Seeman & Seeman, 1983). The advantages of increasing a person's sense of control have been dramatically revealed in earlier studies of hospitals and nursing homes conducted by Langer and colleagues (Langer, Janis, & Wolfer, 1975; Langer & Rodin, 1976; Rodin & Langer, 1977). For example, Langer et al. (1975) assessed the effectiveness of stress reducing strategies in 60 surgical patients. An analysis of nurses' ratings showed that control-enhancing manipulations, such as cognitive reappraisal of anxiety-provoking events, effectively reduced both pre- and post-operative stress. Langer and Rodin's (1976) field experiment involved 91 nursing home residents who were assigned to either the experimental or control group. The experimental group was given enhanced personal responsibility (behavioural and decisional), such as the opportunity to control meal and visitor times and the responsibility of caring for a plant, whereas the staff's responsibility and control were emphasised in the control group. Questionnaire ratings and behavioural measures demonstrated that in comparison to the control group, the experimental group showed significantly more improvement on happiness, activeness and a general sense of well being. In a follow-up study, nurses' ratings and health and mortality indicators suggested that the experimental group had sustained beneficial outcomes (Rodin & Langer, 1977). Seeman and Seeman's (1983) interview study of approximately 1200 adults also showed that a sense of control was associated with more self-initiated preventative care, less pessimism concerning the efficacy of early treatment, greater self-rated health, fewer illness episodes, less bed confinement, and less dependence upon the doctor.

Other quantitative research in America also suggests that an enhanced perception of control can have positive effects on patients. For example, among a sample of 92 patients with rheumatoid arthritis, Affleck et al. (1987) found that a greater perception of personal control over medical care and treatment was associated with better mood and psychosocial adjustment. Also, Thompson and colleagues (Thompson, Sobolew-Shubin, Galbraith, Schwankovsky, & Cruzen, 1993) addressed a sample of 71 cancer patients and found that patients with greater perceptions of control were better adjusted, even when physical functioning, marital satisfaction and negative affectivity were controlled, than patients who believed they had lower levels of control. The study also showed that even patients who were physically or psychosocially worse off were better adjusted if they had higher perceptions of control.

Studies of the interactions between physicians and patients, in which the level of patient satisfaction was assessed, indicate that patient satisfaction increases when doctors exercise less control over the encounter (Cecil, 1998; Flocke, Miller, & Crabtree, 2002; Roter, Stewart, Putnam, & Lipkin, 1997). The majority of patients in these studies wanted to share the control of the consultation, and valued the doctor's openness to the patient's agenda and his/her willingness to negotiate options. The studies concluded that such characteristics might facilitate good communication and convey an understanding of patient preferences and values regarding health. This pattern of results points to a collaborative model of exchange between the doctor and the patient, in which a sense of partnership is emphasised (Cecil, 1998; Flocke et al., 2002; Roter et al., 1997).

2.3.3 Misuses of Power

Studies of the doctor–patient relationship and women's experiences of health care reveal many aspects of the misuse of power and control which may not be traditionally perceived as such (e.g., Ellingson & Buzzanell, 1999; Johansson, Hamberg, Lindgren, & Westman, 1996; Taylor & Dower, 1997). Often researchers have not recognised these elements as working in the interest of the power play within the health care system. Traditionally, researchers have conceptualised "control" within the doctor–patient relationship as the ability to make decisions about the process of health care (Annandale, 1987; Goodrich & Wang, 1999). As has been acknowledged in the literature, the main element of informed decision-making lies in having adequate

knowledge (Waitzkin & Stoeckle, 1976). However, Annandale's (1987) study of the experiences of Scottish women in a midwife-run birth centre identified many more components of patient control, including control over one's own response to procedures, treatments, health maintenance, information exchange and the balance of control between patient and midwife. She recognised that control needs to be defined by the participants in the health care process; therefore the concept of control is much more complex than has been previously conceptualised. The following sections outline some of the general and subtle factors which contribute to the power differential between patients and the health care system, and show how power can be misused when these factors come into play.

2.3.3.1 General Factors Contributing to the Power Differential

Evidence indicates that variables which both patient and doctor bring to the encounter (e.g., sex, age, ethnicity/race, socio-economic status and education), plus social and cultural factors, can influence the power differential between doctor and patient. In general, the power differential is accepted by patients and doctors, but sometimes it can result in conflicts if either party behaves in a way that is unexpected or disapproved by the other (Cline & McKenzie, 1998; Danziger, 1981; Waitzkin, 1985; Waitzkin & Stoeckle, 1976). For example, if a patient expects to play an active role in decision-making but the doctor has a paternalistic working style, they may conflict. Thus general factors, which impact on the power differential, underlie the more subtle manifestations of the misuse of power. To place discussion of the subtle misuses of power in context, the more general factors in the doctor–patient encounter are discussed.

2.3.3.1.1 *Gender.* The sex of the patient and/or doctor may impact on the power differential within the relationship. The overall pattern of the literature on doctors and female patients suggests that female patients are often treated as subordinate within the health system. That is, their lower power status as patients is exacerbated by the (often) lower status of their gender. Some authors (Broom, 1995; Candib, 1995; Ehrenreich & English, 1979; Lupton, 1995; Matthews, 1984; Todd, 1989) maintain that illness is characterised as feminine, claiming that sickness, frailty and inferiority have traditionally been linked to the feminine role. For example early research shows that "vulnerable" or "emotional" behaviour is more accepted in women, while self-assertion,

aggression and demonstrations of vigour and strength are more permitted among men (Nathanson, 1975; Phillips, 1964; Phillips & Segal, 1969). According to some studies (e.g., Phillips & Segal, 1969), it may be because of these different social expectations of the sexes that women are more likely than men to report psychological distress and to ask for medical care. However, results are inconsistent on this point (e.g., Eisenthal, 1971; Yamamoto & Dizney, 1967).

Broom (1995) and colleagues (Ehrenreich & English, 1979; Matthews, 1984; Nathanson, 1975; Todd, 1989) believe that within the medical profession there has been a conflation of femininity with weakness or illness, such that women's normal state has been characterised as sick. The higher incidence of morbidity among women is one basis for this association; however Broom (1995) argues that the idea is based on deeper roots, linking it to Western society's patriarchal culture. Broom (1995) and Todd (1989) maintain that modern Western society has historically conceptualised women as inferior. To support her case, Todd (1989) uses examples from philosophers such as Aristotle, "Women are constitutionally unfitted for public life" (Todd, 1989, p. 28), and from contemporary psychological theories about development, "In the life cycle, as in the garden of Eden, the woman has been deviant" (Gilligan, 1982, p. 6). Todd also states that medical institutions share this view, arguing that they perceive the male body as the norm, and the female body as a deviation from the norm.

Studies by Broverman et al. (1970), Foss and Sundby (2003), and Phillips and Ferguson (1999) support the argument that health professionals perceive the male body as the healthy norm. Broverman et al. explored the effect of gender role stereotypes on judgments made by psychiatrists, social workers and psychologists about mental health. Seventy-nine health professionals completed a gender role stereotype questionnaire, consisting of bipolar adjectives, with one of three sets of instructions: to describe a healthy, mature, socially competent adult (sex unspecified), a man, and a woman. The professionals' ideas about mental health were shown to differ for men and women, and paralleled traditional gender role stereotypes, showing a positive bias toward men. Interestingly, professionals' ideas about a healthy adult, sex unspecified, did not differ from their concept of a healthy man, but differed greatly from the perception of a healthy woman. Results of a recent qualitative study by Foss and Sundby (2003) showed consistent results, but were not as explicitly sexist. Foss and Sundby found that Norwegian physicians and nurses consistently described female patients in a negative

manner. The researchers inferred that men appeared to constitute the norm, whereas female patients were considered deviant. These findings are consistent with Woodward's (1999) argument that, until this century, women were overtly characterised as inferior, but that current manifestations of sexism are less readily obvious.

Hicks (1999) and Woodward (1999) distinguished between gender stereotyping and prejudice among hospital staff. Gender stereotyping does not necessarily have to reduce the quality of care received by patients, and can in fact be useful in initial interactions. For example, based on expectations or general knowledge about certain groups in society, most people have ideas on how to open a conversation with an elderly person, an athlete or an adolescent. In contrast, gender prejudice occurs when the stereotyping is rigid and/or expectations surrounding gender are incorrect, and are maintained in the face of inconsistent evidence. Thus prejudice creates a problem, and can interfere with the quality of care, whether it involves female or male patients (Hicks, 1999; Woodward, 1999).

Research has identified prejudicial gender stereotyping in both medical care (Colameco et al., 1983; Foss & Sundby, 2003) and nursing (Calderone, 1990; Foss & Sundby, 2003; McDonald & Bridge, 1991; Pittman, 1999; Wallston et al., 1983). For example, American researchers McDonald and Bridge (1991) presented 160 female nurses with patient vignettes containing the same medical history but differing on patient sex. The nurses were asked to construct a care plan for each patient. Nurses planned significantly less ambulation and emotional support time and fewer painkillers for female patients. The results of Calderone's (1990) study of medical records of male and female patients matched on medical and demographic variables also showed that female patients were administered pain medication less frequently than were male patients. Other quantitative studies of American physicians (Colameco et al., 1983) and nurses (Wallston et al., 1983) also showed gender stereotyping. Health professionals judged female patients less positively, as less mentally healthy (Wallston et al., 1983) and more emotional than male patients (Colameco et al., 1983). These results suggest that health providers may devalue the female patient, which can have implications for the quality of care delivered. Qualitative studies involving interviews with physicians and nurses in Norway (Foss & Sundby, 2003) and Argentina (Pittman, 1999) also show that some health care providers have attitudes about women which reflect the traditional

female stereotype, such as perceiving women as demanding and difficult, and may reinforce this stereotype.

Some recent research (e.g., Hosoda & Stone, 2000; Twenge, 1997) suggests that the social roles of men and women are evolving. Hosoda and Stone (2000) studied the evaluative content of gender stereotypes in a sample of 230 American university students. One hundred and seventy-three participants assigned 300 different attributes to masculine or feminine gender stereotypes, while a second independent sample of 57 participants evaluated the favourability of the attributes. The results showed that although the traits assigned to gender stereotypes seem to have remained unchanged, the value attached to them has changed, thereby creating a more negative masculine stereotype (Hosoda & Stone, 2000). Such changes can also be found in health care. Phillips and Ferguson (1999) surveyed 75 medical students in a Canadian university when they entered medical school in 1994, and 54 were resurveyed at the beginning of their final year in 1997, to determine whether there were any changes in their stereotyping of gender roles, their willingness to control the decision-making of female patients, and their conceptualisation of men, women and adults. First year students at two other Canadian universities were also surveyed in 1994, and these 166 participants formed a comparison group. Although there were no direct comparative data from the past, less stereotypical thinking regarding the sex of patients was evident at the beginning of medical school. The comparison group confirmed this finding. Three years of medical education, which is considered a traditionally socially conservative influence, did not reverse this attitudinal trend, but rather seemed to enhance it. After three years of training, students showed that they were somewhat less accepting of gender role stereotypes, and were more open to seeing women as equally vulnerable to diseases that are not sex specific. Findings also showed that the participants were less likely to be paternalistic toward female patients and more willing to acknowledge patient autonomy. However, this study showed that the sample continued to equate adults with men and to perceive women as "not adult" or as "other". Although it appears that progress has been made, sexism has not been eliminated in medicine.

To conclude, the studies summarised above lend support to the idea that women are sometimes judged against a different standard of health than are men. Judging women according to a lower standard of health may lead to reduced quality care, including incorrect diagnoses and treatment.

The interaction between the sex of the patient and doctor can affect the power differential (Waller, 1988; Weisman & Teitelbaum, 1985). Weisman and Teitelbaum (1985) reviewed the empirical evidence, and tentatively concluded that same-sex doctor–patient interactions may be characterised by more effective communication, including more self-disclosure and joint decision-making, stronger rapport, and thus more favourable outcomes than in opposite-sex dyads. It was argued that sex is a major component of social status, and that male doctor–female patient dyads are assumed to result in greater status incongruence between the health professional and the patient than do female doctor–female patient dyads, thereby affecting the power differential (Weisman & Teitelbaum, 1985).

Literature reviews (e.g., Roter & Hall, 1998; Roter, Hall, & Aoki, 2002), as well as Danish and American empirical studies of audio and video tapes of medical consultations (Hall, Irish, Roter, Ehrlich, & Miller, 1994; Meeuwesen, Schaap, & Van Der Staak, 1991) examining communication differences between male and female doctors, show that female doctors facilitate more open and equal exchange than male doctors. West (1984) transcribed and analysed 21 dyadic encounters between doctors and patients of a variety of ages and backgrounds in a family practice centre in southern United States. She found that in doctor–patient interactions, male doctors interrupted far more often than did the patients. However, patients interrupted their female doctors as much or more than did the female doctors. The above findings indicate that medical consultations with female doctors may result in less power asymmetry.

2.3.3.1.2 *Social class.* Social class can also adversely impact on the power differential between patient and doctor. Australian (Zadoroznyj, 2001) and Lebanese (Kabakian-Khasholian et al., 2000) analyses of birthing experiences revealed that women of lower social class were characterised as exhibiting "passive" patient attitudes and behaviours. In comparison, women of higher social class (who were distinguished as having private health insurance) were more likely to show "consumerist" attitudes and behaviour, and felt less subordination to the medical team. In addition, a study involving telephone interviews of 1205 urban women in Washington, DC found that women from lower socio-economic backgrounds had poorer primary care experiences compared with their higher paid and better educated counterparts (O'Malley & Forrest, 2002). The literature suggests that middle-class women are more likely to demand

personal choice and less professional dominance over their health care compared to low social class women, who focus their concerns on continuity of care (Lazarus, 1994).

2.3.3.1.3 *Attitudes and expectations.* Patients' and doctors' general attitudes and expectations about the doctor–patient relationship can be related to the amount of control they have in the relationship (Waitzkin, 1985). For example, Haug and Lavin (1981) conducted a survey study of 466 members of the American public and 86 primary care physicians. They noted that some patients adopted a consumerist approach to the medical encounter, which undoubtedly affected the power differential, as these patients were more likely to challenge the doctor's authority. Similarly, theoretical and empirical evidence shows that doctors with a "paternalistic" working style are more likely to control the medical encounter. Conversely, doctors working within an informative or consumerist model are more likely to provide the patient with relevant information, which allows the patient to autonomously decide which medical intervention should be made (Botelho, 1992; Emanuel & Emanuel, 1992; Falkum & Forde, 2001).

2.3.3.1.4 *Talk during consultations.* Generally, a medical consultation involves the doctor questioning the patient to determine their medical condition, providing medical information and giving medical or health advice. The consultation also involves the patient giving information about their medical condition and asking questions. However, some researchers believe that if the doctor asks too many questions and gives inadequate medical information this can adversely affect the power differential in the doctor–patient relationship because the doctor is perceived as taking control. Furthermore, some researchers have suggested that these behaviours may be a way for doctors to gain control over the medical encounter (Beckman & Frankel, 1984; Bourhis, Roth, & MacQueen, 1989; Walker et al., 2001; West, 1984; West, 1993). Yet, the same can be said for patients. For example, Goodyear-Smith and Buetow (2001) state that patients can also misuse their power by providing the doctor with misinformation (e.g., falsely claiming compliance with treatment) or by withholding information (e.g., denying alcohol use).

2.3.3.1.5 *Nonverbal behaviours.* Many observational and survey studies conducted in Britain (Heath, 1984; Robinson, 1998) and America (Pendleton, 1983; Walker et al., 2001) have examined the nonverbal behaviour of the doctor, such as body orientation and tone of voice. It emerged that doctors commonly use non-verbal behaviours such as standing, sitting or turning of the back to show different levels of engagement with the patient. Some researchers suggest that nonverbal behaviours can directly or indirectly lead doctors to actively take control of the interaction (Heath, 1984; Pendleton, 1983; Robinson, 1998; Walker et al., 2001). Similarly, patients may also draw on their assertiveness or sense of confidence, displayed in their body language, to directly or indirectly pressure or manipulate doctors (Goodyear-Smith & Buetow, 2001).

2.3.3.1.6 *Situational factors.* The power differential in the doctor–patient relationship is also affected by the situation in which the encounter takes place. This includes factors such as the length of interaction, the diagnosis and the reason for visit. For example, American researchers Beisecker and Beisecker (1990) studied the factors which impact on information seeking behaviours in communication with doctors in a sample of 106 rehabilitation patients aged 17 to 85 years. A variety of measures were used such as surveys, observational and audio taped data of doctor–patient encounters. They found that patients' information-seeking behaviours were more directly related to situational variables (such as length of visit, diagnosis, reason for visit) than to their attitudes or sociodemographic characteristics. Another important situational factor may be the setting of the interaction. Sankar (1986) interviewed 18 American medical students, who reported that patients exerted greater control when an encounter occurred at home rather than in a hospital or a doctor's office.

In summary, factors such as sex, social class, attitudes, expectations, behaviour and the situation in which the medical encounter takes place can impact upon the power differential between doctors and patients. These factors form a backdrop against which more subtle manifestations of the use of power can come into play.

2.3.3.2 Subtle Factors Contributing to the Power Differential

Subtle manifestations of power, empowering and disempowering behaviours have been touched on in the empirical literature. Empowering behaviours include

doctors treating patients with respect, acknowledging them as independent individuals, giving adequate information about heath matters, and treating patients as persons. In contrast disempowering behaviours include doctors treating patients with disrespect or in a depersonalising manner, and giving inadequate or inaccurate information. Other subtle manifestations of power include the manner in which doctors interact with their patients and the values and beliefs underlying medicine. These factors will be discussed in turn.

      2.3.3.2.1 *Respect*. Research has demonstrated that female patients wanted doctors to respect them as intelligent and autonomous human beings (e.g., Annandale, 1987; Kasle et al., 2002; McKay, 1991; Taylor & Dower, 1997). Women perceived "respect" in terms of their doctor talking in a straightforward manner when giving information about diagnosis, prognosis and treatment options, and being treated as knowledgeable and autonomous individuals (Ellingson & Buzzanell, 1999). Being treated as an intelligent and independent human being can reduce the power differential, as patients are more likely to feel informed and active participants in the health process, and thereby feel empowered. Ellingson and Buzzanell's (1999) study involved interviews with 14 women diagnosed with breast cancer, aged 33 to 70 years. One female participant in the study remarked that when doctors spoke to her in a straightforward manner she found it comforting and empowering. Another woman in the study stated that giving information about tests, diagnosis and treatment can be a sign that the doctor thinks the patient is intelligent enough to be proactive in the treatment (Ellingson & Buzzanell, 1999). It should be noted that the "act" of a doctor giving a patient information may be perceived as empowering, and thus distinct from the information per se. However, information concerning diagnosis, treatment, and outcomes is another important aspect of ensuring an empowering health care experience.

      2.3.3.2.2 *Information*. Many interview and focus group studies have shown that when women are inaccurately or inadequately informed about health issues, they are unable to be active participants in their health care process, and that this can be experienced as disempowering (e.g., Ellingson & Buzzanell, 1999; Kabakian-Khasholian et al., 2000; McKay, 1991; Taylor & Dower, 1997). The outcomes of

limited and insufficient information can mean that women feel unnecessary fear and anxiety about their condition or illness, or medical procedures (Kabakian-Khasholian et al., 2000; McKay, 1991). For example, in the aforementioned studies, numerous procedures were applied to women during labour and delivery without their permission or understanding. The procedures included episiotomy, perineal shaving, use of enemas and labour-inducing drugs. The women in the sample expressed extreme discomfort and embarrassment, and considered these experiences the most disturbing in their lives (Kabakian-Khasholian et al., 2000). Another example comes from a study by Ellingson and Buzzanell (1999) who described the experience of a woman who had breast cancer. As the woman was not told that after the needle biopsy her breast would be wrapped in surgical tape, she took the tape off as soon as she could and ended up badly bruised. Health information educates patients, which enables them to be responsible, active and confident participants in their health care (Candib, 1995).

2.3.3.2.3 *Caring.* Many researchers have identified that female patients perceive the act of caring on the part of doctors as another important aspect of the doctor–patient relationship (Ellingson & Buzzanell, 1999; McKay, 1991; Taylor & Dower, 1997). Caring can also be considered another factor in the power differential. For example, being treated with care can be empowering. Conversely, being treated in a depersonalised manner can be a disempowering experience. Interviews with American women have identified that aspects of caring include (a) nonverbal behaviours such as touching, eye contact and facial expressions, (b) expressing concern verbally, and (c) willingness to spend time speaking with patients personally (Ellingson & Buzzanell, 1999; McKay, 1991). These aspects of caring emphasise the importance of being treated as a person rather than as a problem to be solved or a disease to be treated (Candib, 1995; Ellingson & Buzzanell, 1999). Specific examples include doctors making eye contact with the patient, exhibiting appropriate expressions when discussing a negative prognosis, offering comforting messages and assurances, and speaking directly to a patient rather than communicating via a nurse (Ellingson & Buzzanell, 1999). Hedstrom and Newton (1986) surveyed the literature across different cultures and found that the effects of physical touch on labouring women have been shown to decrease anxiety and increase ability to manage contractions, while their responses indicated that the women felt supported and cared for (Hedstrom & Newton, 1986).

Women have identified the importance of doctors and nurses taking the time to communicate and openly discuss feelings and concerns (Kabakian-Khasholian et al., 2000; Zadoroznyj, 2001). Being treated as a person is seen to be empowering because it reflects the partnership aspect of the doctor–patient relationship, and that the patient is involved in his/her health care as an active participant. The reverse of this concept is to feel dehumanised and alienated from one's own treatment.

McKay (1991) interviewed American women regarding their childbirth experiences and found that women can feel dehumanised and alienated from the health care process when procedures and technology are used extensively, and when women perceive they are not seen as individuals but are treated "all alike". For example, in an obstetric situation, a woman may feel that she is not needed as a source of information if electronic foetal monitors do a better job, or that she is unable to offer anything to childbirth if an epidural has removed her ability to feel her body (McKay, 1991). McKay stated that many of the women who were interviewed played a passive part in their childbirth processes and gave the control to the obstetric health providers. Howard (1975) described the concept of dehumanisation as "thinging", where people are perceived and treated like objects of actions instead of individuals, and are "done to" rather than being active participants. Feeling patronised, unheard, ignored, and insensitively treated can all lead to a sense of powerlessness (Taylor & Dower, 1997).

2.3.3.2.4 *Culturally entrenched interaction patterns.* Broom (1995) and colleagues (Foss & Sundby, 2003; Sebrant, 1998) argued that doctor–patient relationships are characterised by patriarchal interaction patterns, which can take control away from patients. One example of this is the traditional authoritarian doctor–patient relationship, which represents a relationship marked by stereotypical masculine characteristics such as dominance, control, rationality and objectivity (Candib, 1995). Other researchers believe that in the last 20 years, a competing model of the doctor–patient relationship has begun to gain some popularity, one based on consumerism, challenge of authority, and negotiation, rather than acceptance of authority (Buetow, 1995; Emanuel & Emanuel, 1992; Haug & Lavin, 1981; Hayes-Bautista, 1976; Zadoroznyj, 2001). However, although there has been change, research suggests that Broom's "masculine interaction pattern" may manifest itself in more subtle ways in contemporary society. Research has shown that men and women have different values

regarding the importance of different aspects of care (Bjoerkman, Hansson, Svensson, & Berglund, 1995; Larsson, Larsson, & Starrin, 1999; Pittman, 1999). Research has also revealed that values expressed by health providers appear to be more similar to those expressed by male patients than by female patients (Pittman, 1999). For example, in Pittman's (1999) interviews with patients and doctors, most health care providers referred to the concept of "talk" as a means of ensuring patient compliance and communicating instructions for treatment. Similarly, male patients perceived talk to entail diagnosis or information about disease. In contrast, the female patients described talk as being listened to, and a central function of the medical visit. The findings show that the differences between men and women tend to reflect gender roles and the dominant view of providers tends to be closer to the values expressed by male patients than by female patients. If this is the case, women may be at a disadvantage in the doctor–patient relationship, as their needs may not be met.

     2.3.3.2.5 *Ideology.* Broom (1995) argued that values and beliefs underlying the practice of modern medicine embody qualities closely associated with stereotypical masculinity, for example, "active" intervention and "combating" disease, and may be detrimental to patients' health care. Broom stated that an active response is a fundamental component of traditional medical education, and she argues against too much of an active response, or excessive interventionism. Some people involved in maternity care and alternative childbirth have also criticised excessive interventionism as they believe it does not promote heath and may in fact cause suffering (Reiger, 2001). Broom argued that this type of training reinforces the notion of the doctor as a hero, and promotes a picture where the doctor is the central character and the patient's health is secondary. Crossley (2000) stated that promoting the doctor as a hero can be problematic for patients, as it encourages patients to have unrealistic expectations of doctors, and to assume a passive demeanour. A contrasting perspective could be that using words such as fighting and active intervention may, for some people, reflect a confident, enthusiastic and optimistic attitude toward medical treatment. Although there is little doubt that such language is aggressive, it may be that this is what patients want to hear in order to maintain hope and faith in the medical profession. Therefore, a masculine ideology does not necessarily have to reduce the quality of care received by patients, and can in fact be useful in some situations.

This section has described the subtle factors which may impact upon the power differential in doctor–patient relationships either in empowering or disempowering ways. The next section reviews empirical studies which examine the implications for female patients when doctors misuse their power.

2.3.4 Outcomes of the Misuse of Power

Research shows that when doctors misuse their power within the doctor–patient relationship, this can adversely affect patients' attitudes towards doctors, health care and in how they perceive themselves (Annandale, 1987; Gridley, Moore, Higgins, & Johnson, 1998; Taylor & Dower, 1997). Melbourne researchers (Gridley et al., 1998) conducted semi-structured interviews with 13 women who had experienced an intimate medical examination which they felt was inappropriate or abusive. The interviews revealed that the negative experiences were detrimental to subsequent relationships with health professionals, and in some cases led to continuing psychological suffering, with implications for the women's future health. Most of the participants chose to see a female practitioner in the aftermath of their negative experience with a male practitioner. An American qualitative study also revealed that women's experiences of doctors' abuse of the power differential led them to avoid visiting a doctor, which clearly could adversely affect the health of women (Taylor & Dower, 1997).

Some people believe that childbirth has been overly medicalised; that is, it has become subject to excessive medical intervention (Reiger, 2001), which may in turn be perceived as taking the power away from women and misusing it. An extension of this argument is that excessive medical intervention can lead to the dehumanisation of women's birth experiences (Hodnett, Gates, Hofmeyr, & Sakala, 2003; McKay, 1991). Annandale (1987) explored the concept of patient agency in a Scottish birth centre managed by midwives which emphasised patient-controlled childbirth. The research was longitudinal in design, and specific methods included participant observation, interviews with 46 patients, and quantitative analysis of approximately 1000 medical records. Many of the participants stated that the ability to have control over decision-making was a pivotal reason for choosing to give birth at the birth centre rather than a hospital. However, the results revealed that over the course of their pregnancies, the participants remained uncertain about the birthing centre being the safest option for childbirth (Annandale, 1987). These results suggest that the health care system may

have instilled in women the idea that childbirth is "dangerous" and medical intervention necessary. This message may have led women to distrust their own instincts and natural abilities in childbirth. An article in the Melbourne Herald Sun newspaper reflected similar attitudes: a Professor of Midwifery stated that medical intervention in the birthing process is so common in today's delivery rooms that women are doubting their ability to give birth naturally (Call for Natural Births, 2002).

2.3.5 The Patient's Power

Research indicates that patients act on their own preferences, and are not completely passive consumers of health care (Edgman-Levitan & Clearly, 1996). The sick role may be synonymous with passivity, but research and reviews show that patients often take an active role in their health care. However, this is more likely to occur outside the doctor's office rather than inside it (Beisecker, 1990; Hayes-Bautista, 1976; Reed, 2000; Warner, 1981). Warner (1981) conducted telephone interviews of 551 predominately female consumers of general practice and family medicine in Canada. Patient complaints appeared to take the form of silent rebellion, such as non-compliance, changing practitioners, seeking alternative health therapies, or by relying on their own ideas, rather then direct confrontation (Warner, 1981). Reviews of the empirical and theoretical literature on patient power in doctor–patient communication indicate that whereas non-compliance with doctors' orders may reflect a lack of understanding of the treatment, it may also be a way for the patient to assert his/her own independence and power (Beisecker, 1990; Hayes-Bautista, 1976).

A study involving 117 interviews with women in rural and urban areas in Lebanon on their obstetric experiences found that the women expressed dissatisfaction with some of the procedures during childbirth, for example episiotomies and perineal shaving (Kabakian-Khasholian et al., 2000). However, instead of actively challenging these procedures, the women passively challenged the system and minimised the time spent in hospital by perineal shaving at home prior to the delivery, and changing unsatisfactory health care providers between pregnancies (Kabakian-Khasholian et al., 2000).

Todd (1989) suggested that women's passivity in the medical encounter is due to the powerful status of doctors, which may inhibit direct confrontation. She argued that society has been socialised to believe that the doctor "knows best", and although

patients may question this belief outside the doctor's office, they are less sure once in the doctor's presence. The doctor's role is essentially a helping and healing role, and it therefore may seem inappropriate for a patient to question their help (Todd, 1989). In support of this assertion, a study by Gridley et al. (1998) found that female patients who had had a negative medical examination felt unable to take action at the time or afterwards. The participants described their inability to act as twofold: they felt afraid and powerlessness in the face of the doctor's status and behaviour, and they lacked the knowledge of their rights or of complaints procedures (Gridley et al., 1998).

2.4 What Patients Seek from Health Care Providers

According to analyses of audio taped doctor–patient consultations (Levinson, Roter, Mullooly, Dull, & Frankel, 1997) and survey studies (Dunfield, 1996) with patients of family practice offices, American men and women want their doctors to respect them as independent persons and to be treated with care and consideration. Australian research also highlights that most doctors and patients appreciate doctors' being friendly and sensitive and having good listening skills (Buetow, 1995). Research shows an increase in patient satisfaction, patient compliance and a low risk of malpractice when physicians show less control and more psychosocial exchange in the patient–doctor consultation (Cecil, 1998; Flocke et al., 2002; Roter et al., 1997).

Examining the studies of women's hospital experiences reveals an additional element in the doctor–patient relationship: women want to be viewed in their social, cultural and life contexts (Ellingson & Buzzanell, 1999). American researchers Ellingson and Buzzanell (1999) analysed 14 women's narratives of their breast cancer treatment in order to explore conceptualisations of patient satisfaction with doctor–patient communication. According to the narratives, women do not want to be perceived just as a patient; they want to attend a medical consultation and be perceived in the context of their lives. They want doctors to ask about their partners, their children, and their jobs. This finding implies that women want their doctors to "step into their shoes" and understand them, not simply as patients, but as women in contemporary society. The findings emphasise that female patients want warmth, friendliness and humanity from their doctors (Ellingson & Buzzanell, 1999). Furthermore, this study emphasised that women's health and wellbeing is related to the social context in which women live. Similarly, another American qualitative study

revealed that women would like to be treated as partners, and appreciate having choices in health matters (Kasle et al., 2002). For example, Zadoroznyj (2001) explored the birthing narratives of 50 women in a major Australian city. The women wanted a provider who had similar social values and a shared vision of the doctor–patient relationship. They perceived the encounter between them and the provider as more than a simple exchange of services; it was an exchange of services where the participant's identity as a woman and her feelings about the process were critical to the experience. The women's narratives about their relationships with their health care providers showed that trust was important and was built on by having time to talk with providers. This was seen as more influential than the doctor's perceived technical competence (Zadoroznyj, 2001). Other Australian research mirrors these findings, according to a report by the Victorian Ministerial Women's Health Working Party (1987). These findings highlight that women's social and cultural position in society can mediate and define their experience of health (Victorian Ministerial Women's Health Working Party, 1987).

2.5 Summary of the Chapter

Early researchers described patients' perceptions of hospital as largely negative, and characterised hospitalisation as a source of psychosocial stress and disempowerment. These early writings are important as they highlight the significance of the patient's perspective. However, they tended to focus on patient pathology as a way of making sense of non-compliance and disruptive behaviour. In contrast, this thesis examines the patient's perspective of the hospital environment and the manner in which the hospital system may impact upon the individual.

Research shows that control is important in people's lives, and this importance is increased when people are sick. Empirical evidence involving patients shows that control is beneficial; for example, patient satisfaction increases when doctors show less control and involve the patient in the health care process. According to such research, the concept of power and the behaviours that affect patients' sense of control appear to be manifested in a variety of forms. An important factor that may influence the power differential between doctor and patient is the sex of the patient. Research shows that some health professionals may discriminate against female patients by judging them against a different and perhaps more negative standard of health than men. Judging

women against a different standard of health or relying on traditional feminine gender role stereotypes can lead to reduced quality care.

There are also more subtle factors affecting the power differential, which have not been labelled as such but appear to be important factors for female patients. For example, research implies that when doctors treat female patients as intelligent and independent adults, and give accurate and adequate information in a caring manner, the women feel empowered and involved in their health care. Additionally, when doctors are prepared to negotiate with female patients, and meet their needs in terms of the type and extent of medical intervention, the women are more likely to feel empowered and receive quality care which places their health at the forefront of the medical consultation.

Existing research implies that men and women want to be active partners in the doctor–patient relationship; they want more information to enable them to make informed decisions; and they value friendly, sensitive doctors with good listening skills. Research exclusively involving women shows that health is not a stand-alone area in their lives; it is inextricably linked to other areas, such as relationships, career, and children. Therefore, visiting the doctor is more than a simple exchange of services: women's identity and feelings are critical to the health care process.

The next chapter describes the pilot study. The study involved a combination of qualitative and quantitative methodologies to describe perceived control/powerlessness in women's hospital experiences, and to assess the salience of loss of power among female inpatients.

CHAPTER THREE

PILOT STUDY

3.1 Introduction

The earlier chapters have described some key elements of hospitalisation and women's hospital experiences. In an extensive array of laboratory and naturally occurring situations, both real and perceived lack of control has been shown to have a significant negative impact on participants' psychological and physical health, behaviour and motivation (Gatchel, 1980; Shapiro & Austin, 1998; Syme, 1989; Taylor, 1999; Thompson & Spacapan, 1991). However, there appears to be a paucity of information regarding participants' perceptions of power and control as hospital inpatients. This chapter reports a pilot study in which both qualitative and quantitative methodologies were used to explore the relevance of power and agency issues for women in hospital. The rationale for this approach is first discussed, followed by a description of the aims of the pilot study, the methodology, the study results, conclusions and decisions about further directions for the research.

3.1.1 Methodological Overview

Some researchers (e.g., Patton, 1980; Reinharz, 1992) suggest that a multiple methodological approach is suited to research undertaken in poorly understood areas as it adds layers of information and data can be cross validated. Therefore, this study included both qualitative and quantitative methodologies because of (a) the desire to more fully describe women's hospital experiences from women's points of view, and (b) to assess the extent to which women expressed feelings of disempowerment and dissatisfaction with their hospital experiences.

3.2 Research Aims

The first aim of the pilot study was to describe women's experiences of power and control in hospital. A large sample of women who had experienced hospital stays completed a questionnaire, and of those women, a small number volunteered to be interviewed. The objective of the interviews was to gain a sense of participants' experience of power and control as hospital inpatients. In addition, hospital experiences were described through women's responses to a list of closed answer items about power

and control in hospital, presented in the form of a survey questionnaire. Factor analysis was used to identify thematic groupings among the closed answer items that represent different aspects of power and control experienced as a hospital inpatient. Additional information regarding the closed answer items has been reported in Polimeni and Moore (2002). Briefly, the researchers described how the closed answer items were developed into the Perceived Control in Hospital Scale, designed to provide a measure of participants' perceptions during their hospital stay, and of their ability to exercise control over their day-to-day care and the management of their condition. Polimeni and Moore also included the assessment of the psychometric properties of the scale; in particular, internal consistency and underlying factor structure and initial construct validation. This information is not included here, as it does not directly relate to the descriptive aims of the thesis.

The second aim was to evaluate the importance of hospital stays in the lives of women and of power issues within those experiences. This aim was achieved through both the interviews and the questionnaire by asking women to reflect on the importance of their experiences and their understanding of power and agency issues.

3.3 Method

3.3.1 Participants

The closed answer items were completed by 124 women, with an age range of 17 to 70 years (*Mean* = 31.98 years, *SD* = 12.40 years). The sample comprised undergraduate and postgraduate psychology students and their acquaintances who had experienced a hospital stay of at least one night. The majority of participants were of Anglo background (84.2%), 6.4% were of Southern European background, 4.0% were of Central European background, 3.2% were of Asian background, and one participant was of South African background.

The majority of the participants had been inpatients in a private hospital (52.1%) within Australia (94.4%). The lengths of the participants' hospital stays ranged from one to 70 nights (*Mean* = 5.70, *SD* = 9.38), and occurred when they were aged from 16 to 68 years (*Mean* = 25.20, *SD* = 9.92). The majority of the sample (49.9%) had a minor condition (e.g., childbirth, extraction of wisdom teeth, appendectomy and tonsillectomy), 38.2% had a serious but not life threatening condition (e.g., childbirth with complications, surgery, accidents), 8.9% had a serious and life threatening

condition (e.g., asthma, cancer-related, heart attack), and the remaining participants (3.3%) were classified as having a chronic condition such as multiple sclerosis, chronic fatigue syndrome, or epilepsy.

Of the 124 women who completed the survey, 36 wrote general comments in a section at the end of the questionnaire which invited participants to comment on any aspect of the questionnaire. Seven of those participants wrote comments in regard to the power and control they experienced in their hospital stay, and the remaining comments were in relation to the content of the questionnaire. In addition, three women were individually interviewed. The comments from the seven women, plus the material available from the three interview transcripts, were used as the basis of the qualitative section of this study.

3.3.2 Materials

3.3.2.1 Survey

The survey comprised a demographic section which included items to ascertain age, level of education, occupation, ethnic background, and religious affiliation. The demographics also included the details of the participant's hospital stay such as type of hospital, age participant was in hospital, length of the stay, and nature of the illness/condition for which the participant was admitted. Participants were asked to indicate the perceived seriousness of the illness/condition for which they were admitted on a 7-point scale, where 1 = minor and 7 = life threatening, and to indicate the perceived significance of their hospital experience on a 10-point scale, where 1 = not at all significant and 10 = extremely significant. In addition, participants gave a global rating of their satisfaction with the medical encounter on a 10-point scale, where 1 = not at all satisfied and 10 = extremely satisfied.

The survey contained 38 closed answer questions designed to augment descriptions of participants' perceptions of power/control issues as hospital inpatients. The ideas concerning the types of items to be included were drawn from three main sources: (a) the ideas for five items were developed from an inspection of the content of existing health care evaluation measures, (b) eight items from informal discussions with individuals who had been in hospital, and (c) 25 items from pamphlets of patient rights and responsibilities from various hospitals in Melbourne, Australia.

Thirty-eight statements were constructed concerning patients' beliefs about the degree of control they experienced as inpatients. Examples of the items included "If I wanted to make decisions about my health care I believe I was well informed to do so", "Health care workers treated me in a patronising manner" and "The health care workers did not respect my privacy when I was examined". Participants were required to rate their agreement or disagreement with each statement using a 5-point scale, where 1 = strongly disagree and 5 = strongly agree. A full list of the statements, the information sheet and consent form are included as Appendix A.

3.3.2.2 Interview

The objective of the interview was to understand women's thoughts about their hospital experiences and their ideas of power and control in hospital. The interview began with the researcher giving the participants a consent form explaining the interview, and then introducing the purpose of the study. The researcher invited the women to discuss their hospital experiences, asking them to focus on day-to-day experiences in hospital rather than the nature of their illness. Topics of discussion covered those aspects of the hospital experience which were enjoyed or not enjoyed, aspects perceived as meaningful or significant, and relationships with health care professionals including doctors, nurses, and physiotherapists. Interviewees were also asked to discuss their understanding of power and control in hospital, and any situations they had experienced as inpatients where they felt out of control, in control, powerless, helpless, and/or powerful.

3.3.3 Procedure

Participants were recruited from large lecture classes at a Melbourne university. The researcher attended undergraduate and postgraduate lecture rooms to speak about the study and left questionnaires and reply paid envelopes for interested students. Advertisements, questionnaires and reply-paid envelopes were also left at strategic places within the university such as the Women's Room. Participants were asked to complete the questionnaire anonymously and either return it to a box on campus or post it in the reply-paid envelope. There was a 64% return rate.

Women were given the opportunity in the questionnaire to volunteer to be interviewed further about their hospital experiences. If they were interested, they wrote

their first name, a contact number and contact times on the survey (the invitation and consent form for the interview are presented as Appendix B). Six participants volunteered, but only three were finally interviewed due to difficulties in arranging appropriate times. The duration of the interview was 45 minutes to one hour. Interviews were taped and transcribed.

3.4 Results

3.4.1 Nature of the Hospital Experience

Ratings of the personal significance of the hospital stay ranged from 1 to 10; the average level of significance being moderate (*Mean* = 5.62, *SD* = 3.07). Perceived seriousness of the condition for which the women were admitted to hospital ranged from 1 to 7, with a mean rating representing moderate seriousness (*Mean* = 3.48, *SD* = 1.86). Overall ratings of satisfaction with the medical encounter ranged from 1 to 10; the mean represented an average to relatively high level of satisfaction (*Mean* = 7.11, *SD* = 2.22).

3.4.2 Qualitative Data

Qualitative interviews and comments on the surveys were read and re-read with a view to developing themes or categories of responses concerning perceived lack of control (McLennan & Miller, 2000). Four broad themes emerged: disrespect/ insensitivity, diminished patient rights, lack of acknowledgment, and "not listened to". These themes were prominently and consistently reflected in the data, and appeared to have the underlying concept of power and control in common. An independent rater read the transcripts and showed 100% agreement with the categorisation of the themes. The category "examples of good practice" was also sought, because of the importance of acknowledging and describing positive inpatient interactions with health care professionals. A description and examples of each of these themes follow. Within the following section, participant numbers refer to the coding of participants' questionnaires. The comments from the seven women, plus the three interview transcripts are presented as Appendix C. The page numbers, which appear following participants' quotes, refer to the page number of Appendix C. Key words relevant to each theme are highlighted.

3.4.2.1 Disrespect and Insensitivity

In three accounts the medical staff were portrayed as lacking sensitivity and courtesy. For example:

> I had been in bed all day and was told not to wash because my surgeon had drawn on me for the operation. It was a boiling hot day, my room had huge windows so I got really sweaty and this **one nurse made a negative comment about my personal hygiene when obviously there was not a thing I could do about it** (Participant 3, p. 243).

Another participant commented on a nurse who had acted in an insensitive manner when she had an ultrasound. She recalled that she was in pain and had consumed a large amount of liquid in preparation for the ultrasound:

> (The nurse) just sat there and I had to hoist myself out of the wheel chair onto the bed and she said come on, hop up (onto the bed) ... OK get out, out you go ... I was so full of liquid, I felt like I was going to wee myself ... and I thought you know what sort of situation (this is) ... so you would be nice to someone ... and **she was completely undervaluing my pain** (Participant 97, p. 241).

These accounts of medical staff being insensitive do not align with public expectations of health care professionals, which are that they will express compassion and empathy. Participant 97 commented, "**What are you going to say, they're health care professionals**, and they're devoted serving members of the community ... they're doing a good job, by definition ... they're noble" (Participant 97, p. 241). When an inpatient is treated with insensitivity by medical staff, there may also be a sense of helplessness in that the patient can feel powerless to rectify the situation. One woman felt that the insensitivity made her feel trapped, "**You end up feeling squashed** ... how dare you boss me around and how dare I let myself get bossed around, **but you realise that there's nothing you can do in the circumstance**" (Participant 97, p. 242). These feelings of helplessness in the face of insensitivity can highlight the enormous gap of power and control between patient and medical staff.

The accounts show that it may be the nature of the hospital environment which contributes to patients' feelings of powerlessness, yet the hospital staff appear to expect patients to have control over their situation in areas such as personal hygiene and pain. The responses of the medical staff suggest that they did not understand the patient's lack of control, or at least did not express empathy towards it. Their focus was (rightly) on medical procedures, yet it might not be difficult to ensure these procedures were carried out with interpersonal sensitivity.

3.4.2.2 Diminished Patient Rights

When patients enter hospital, they enter the medical world, which can seem like another world removed from the reality of "physically well" people. "Sick" people have little or no control over when they eat or sleep, the clothes they wear, and the level of noise or light to which they are exposed. Many patients feel that it is difficult to be treated like a person and taken seriously when lying in a hospital bed in only a hospital gown. As patients are removed from their daily life they may feel that they lose their status in society, such as the status attached to their occupational roles. In five women's accounts, this disruption of the "norm" resulted in diminished status. For example:

> I felt about two years old and I was 21 so I should have been able to (assert myself when I did not agree with the way I was treated) **but that's the thing about hospitals, everyone is reduced to a 12 year old person ... you have no power** (Participant 97, p. 241).

This treatment reduces patients to a child-like state, where they have diminished self-responsibility and independence, and where they may seem stripped of their adult rights and adult status.

One woman noted that she was "finally **allowed** to return home" (Participant 6, p. 243). To some extent, patients are treated in such a way that they need to be told what to do by the "experts", and the experts treat patients as though they cannot be trusted to be responsible for their own health. One participant, who was in hospital for childbirth, and had a background in herbal medicine recalled, "One nurse was very rude about me taking a herbal mixture and demanded to know who prescribed it" (Participant 73, p. 244). Although there are undoubtedly important reasons why health professionals

keep track of patients' prescribed and non-prescribed medications, it may not be necessary to take the high-handed approach of the nurse described. It appears that patients are sometimes subject to control by the hospital in ways which are over and above that necessary for medical treatment.

Some accounts also portrayed the medical staff as treating patients like "naughty" children. One woman who, after a tonsillectomy, continued to vomit for three days, recalled:

> (When the doctor) came in (three days after the operation) and said well how are we and I said go away I feel awful and he said ... **I am going to come back and we are going to start that conversation again** (Participant 97, p. 240).

Another woman was "**reprimanded** by a nurse for refusing medication" (Participant 17, p. 243).

Women's experiences in hospital also highlighted a feeling of diminished status in the sense of feeling shame at not conforming to the norm of physical wellness; in other words, the patient was responsible for her illness. Participant 19 commented that throughout her hospital stay she was "sometimes made to feel as though it was **my fault**" (Participant 34, p. 244). Participant 97 agreed:

> You're the loser who happens to be sick. That's the feeling, **almost slightly ashamed of yourself for not feeling better**, obviously she (nurse) expects me to get from the wheel chair to the bed without any trouble, so therefore I must be able to, **it must be my problem** (Participant 97, p. 241).

3.4.2.3 Lack of Acknowledgment

Some participants said that they felt invisible when they entered hospital. Two women's accounts portray the medical staff as treating the patient as an inanimate object or piece of machinery. One described this as like "being in a science experiment" (Participant 97, p. 240). Participant 17 recalled the negative treatment by a doctor in the emergency room when she was first admitted to hospital:

> The doctor who examined me initially **didn't introduce himself, he did an internal examination, without telling me what he was going to do**, even when I was in unbearable pain, it was almost like I was inconveniencing him by having said that I was (in pain) ... even though he probably should have been asking me a lot of questions, he tended not to, he read the doctor's letter and then did what he did ... so it was **very much that they were in control of me once I was there** ... **I felt like I was ignored** (Participant 17, p. 237).

Another woman who went to hospital for her third child reached the labour ward and "was **never spoken to** by any of the staff ... **I was on my own** ... **No empathy**" (Participant 31, p. 243). Such accounts emphasise the alienation, loneliness and vulnerability that can be experienced by hospital patients.

3.4.2.4 Not Listened to

Three women's accounts showed that they felt ignored, that their thoughts or feelings were not considered important, and that the medical world held the belief that "doctors, they know best" (Participant 97, p. 241). It appears that some medical staff are hesitant in trusting the patient and may ignore the patient's knowledge about their own bodies. They may give the impression of not wanting to work cooperatively but to control the situation, and in doing so take the control away from the patient and treat the patient as if their knowledge is not good enough. Three women reported that doctors ignored them to the perceived detriment of their health. Participant 17 explained how the medication she was given made her sick and she thought she was allergic to it. She requested that the medication be changed but her requests were ignored:

> Finally said that I wouldn't take it anymore ... when they changed my medication it did make a difference, so I was annoyed that for three days I had been so sick, whereas **if they had of listened to me straight away, that could have been avoided** (Participant 17, p. 238).

This negative experience led this woman to become more assertive with health professionals, "I am now more assertive and I will tell people what I think and if I am

not happy with something **I will make sure that they will listen**" (Participant 17, p. 239).

One woman was admitted to hospital at 36 weeks of pregnancy because she was vomiting blood, was dehydrated, and was experiencing extreme back pain. She was ignored when she told doctors that the baby was "too big for my body" (Participant 60, p. 244), which she felt could have led to a potentially life threatening outcome. This may be an unsophisticated way of expressing felt symptoms, but it is a comment that expresses a high level of fear and anxiety. It deserves to be at least acknowledged, listened to, and accepted as the stimulus for the provision of further information or an alternative "diagnosis". The woman commented:

> **If the doctor had listened** they would have done a caesarean instead of **almost losing both myself and the baby**. My own diagnosis was correct ... (and this was proven when) the placenta came out, the baby had kicked a hole in it near my ribcage (Participant 60, p. 244).

This experience of not being listened to has now led this woman to avoid doctors: "These days I nearly never go to the doctor's office unless very ill" (Participant 60, p. 244), but she has also developed "an excellent relationship" with her family doctor.

3.4.2.5 Examples of Good Practice

Women commented on a variety of examples of good practice. Several examples of good practice corresponded to the power themes reflecting bad service. For example, Participant 97 said she experienced a good interaction with a doctor as she was treated with respect and sensitivity and was listened to:

> He was a very **good listener**, and he wasn't loud, he just **sat next to my bed** and asked me how I was feeling in a perfectly normal nice way ... **not at all patronising** ... instead of standing there, he sat next to the bed and **chatted at my level**, and that's obviously a very good trick, in terms of physically they are on your level, they are **not standing over you while you are lying flat on your back in a hospital bed** (Participant 97, p. 242).

She also appreciated that the doctor came to see her every day after the operation because she felt that it "gives you a feeling of control because you can ask questions and you can get feedback" (Participant 97, p. 242).

Many of the participants recalled good experiences with nurses which corresponded to the power theme of disrespect and insensitivity, as they were treated with respect and sensitivity. One woman stated: "They **talk to you as a person**, rather than a science experiment" (Participant 97, p. 240). Another woman agreed, and recalled that when talking to the nurses she was "**respected as a person** rather than just a patient" (Participant 30, p. 232).

Participant 97 recalled a positive experience with a nurse who tried to help her stop vomiting by offering her options such as peppermint tea and an anti-nausea injection: "**Being presented with choices makes the fundamental difference** between feeling crap about what's happening, and **at least you have choices** even if they are crappy" (Participant 97, p. 242). The woman felt that the idea of being presented with options gave her a feeling of control over what was happening, rather than of things being done to her.

One woman was able to put a positive slant on circumstances which may usually connote powerlessness. For example, she recalled that when the medical students came to see her, instead of feeling intimidated and "just lying there and being surrounded by all these people" (Participant 30, p. 234), she used the time to ask them questions so she was able to learn more about her condition. She saw them as "specialists of the future ... maybe they will be the person that finds a cure" (Participant 30, p. 234). This woman also described a "self preservation" mechanism which she has since developed in order to regain control of situations where her personal dignity or privacy might be compromised:

> **You need to learn that the body is separate from the mind** …
> If you are having things done to you and it hurts you have to say
> this is the body and they can do what they like but **it won't
> affect me as a person** … I am not really a part of it … you
> really have to **strengthen your own personal view point of
> yourself** (Participant 30, p. 231).

3.4.3 Quantitative Data

The 38 closed answer items were subjected to a factor analysis with varimax rotation to identify underlying aspects of power and control. Factor analysis was justified as the number of participants was more than three times greater than the number of variables (Kline, 1986; Kline, 1993). The factor analysis resulted in seven factors with Eigenvalues greater than one, accounting for 68.7% of the variance. However, an inspection of the Scree plot suggested a 3-factor solution, as did an examination of the factor loadings, which indicated factors four to seven had few unique loadings and were difficult to interpret in terms of content. The initial 7-factor solution and the Scree plot are included as Appendix D.

A second varimax analysis was conducted to produce a 3-factor solution. This solution accounted for 54.1% of the variance. Items with factor loadings greater than or equal to .4 on more than one factor were removed (6 items) in an attempt to develop factors which were relatively independent. A further factor analysis was then conducted. This procedure was repeated (a further two times) until the 3-factor solution contained no factor loadings which were equal to or greater than .4 on more than one factor, to ensure that each factor was relatively independent. The final factor solution of three factors across 26 items accounted for 57.1% of the variance (the final 3-factor solution is presented as Appendix E). The first factor comprised 30.4% of the variance and involved items relating to sensitive and clear communication of medical information and listening to the patient. It was labelled Respect/Communication, and contained 14 items with loadings between .59 and .81. The second factor (14.3% variance) contained seven items, with factor loadings between .44 and .76. It was labelled Lack of Dignity and concerned feelings of lack of dignity or privacy during the hospital stay. Factor three (12.5% variance) had five items with loadings between .54 and .71, and concerned the patient's sense of control over the day-to-day activities in hospital. This factor was labelled Day-to-Day Control. Table 1 shows the percentage agreement with each of the 26 items (shortened version of items only shown) and their loadings on Factors one, two and three (loadings over .4 only shown). The full version of the 26 closed answer items is presented as Appendix F.

It can be seen from Table 1 that the majority (about 80%) of women agreed that during their hospital stay, the health care professionals listened to them when they explained their symptoms and concerns about their condition. However, about 15% did

Table 1

Percentage Agreement with the Closed Answer Questions and Item Loadings on the

Three Factors

Item	Disagree (%)	Uncertain (%)	Agree (%)	Factor loadings
Factor 1: Respect/Communication				
Listened to when explained symptoms	13.7	4.8	81.5	.81
Listened to when explained concerns	13.7	11.3	75.0	.79
Satisfied with the way I was treated as a person	16.1	4.0	79.8	.78
Explanations about diagnosis were given sensitively	17.1	13.0	69.9	.78
Satisfied with medical treatment	22.1	4.9	73.0	.76
Explanations about health were given supportively and empathically	19.4	10.5	70.2	.73
Explanations about condition were given clearly and accurately	19.5	9.8	70.7	.71
Listened to when asked about medical treatment	11.3	11.3	77.4	.71
Treated in a patronising manner	68.0	9.0	23.0	-.68
Medical care was compromised as I was discriminated against	83.9	7.3	8.9	-.67
Explanations about future health were given sensitively	21.3	13.1	65.6	.67
I was understood when I explained symptoms	8.9	5.7	85.4	.66
Clear information was given prior to any medical treatment	20.2	6.5	73.4	.67
Received quality care regardless of lifestyle	9.0	14.8	76.2	.59
Factor 2: Lack of Dignity				
Not asked for my permission when interviewed	47.6	23.4	29.0	-.76
Not asked for my permission when examined	62.6	14.6	22.8	-.70
Privacy was not respected when examined	79.5	10.7	9.8	-.67
Privacy was not respected when interviewed	82.3	8.9	8.9	-.63
Privacy was not respected while bathing and dressing	86.3	7.3	6.5	-.62
Dignity was not respected while bathing and dressing	83.7	7.3	9.7	-.56
Felt embarrassed when examined	58.9	8.9	32.3	-.44
Factor 3: Day-to-Day Control				
Able to decide when to eat meals within reason	36.9	4.9	58.2	.71
Felt comfortable to access my medical records	41.5	21.1	37.4	.69
Felt comfortable to refuse presence of professionals not directly involved in my care	25.8	24.2	50.0	.67
Felt free to have someone with me throughout hospital stay	20.2	13.7	66.1	.54
Able to decide to have showers within reason	13.7	10.5	75.8	.54

not feel they were adequately listened to. A small but significant proportion of the

women (about one-fifth) did not believe that health care professionals explained health-

related issues to them clearly, accurately and sensitively. Similarly, about one-fifth of women were not satisfied with their medical treatment, and/or believed they were treated in a patronising manner. Nearly one-third indicated that health care professionals did not ask their permission prior to an interview and, perhaps more disturbingly, over one-fifth said that health care professionals did not ask their permission prior to a physical examination. Larger percentages noted a lack of day-to-day control, with 37% not experiencing the freedom to decide when to eat meals "within reason" and over 40% feeling that they could not comfortably access their medical records. Therefore, the majority of women expressed satisfaction and perceived control on most items; however, a substantial core of respondents had not experienced, during their hospital stay, conditions conducive to maintenance of a sense of personal control.

Table 2 shows the correlations between the three factors, the one-item satisfaction measure, and the demographic items. To enable scales to be developed from the three factors for correlation analyses, the negatively worded items were reversed and the item ratings were added. The factors were moderately related to each other, and moderately to highly related to satisfaction, as would be expected. Higher satisfaction was associated with greater levels of respect, communication and day-to-day control and lower levels of perceived lack of dignity. The correlations between the factors, perceived seriousness, perceived significance, and length of stay were all significant. Overall, higher perceived control was associated with less serious conditions and shorter and less "significant" hospital stays, which suggests that lack of control is more likely to manifest itself in situations where the patient is sicker. Cronbach's alpha for the three scales were as follows: Respect/Communication 0.95; Lack of Dignity 0.81; Day-to-Day Control 0.73.

3.5 Discussion

The qualitative and quantitative data show that the majority of the women reported experiencing a sense of control as hospital patients. However, a proportion of the sample experienced feelings of powerlessness associated with the non-medical aspects of their treatment. The quantitative results show that inpatients' perceptions of being treated with respect and feeling listened to, preservation of dignity and privacy, and control over everyday events, were more likely to be related to satisfaction with the

hospital stay. Perceptions of control in hospital were also more likely to be related to less serious conditions, less significant experiences, and a shorter hospital stay. This finding appears logical as, for example, being seriously ill may render a patient incapable of showering alone, therefore making it difficult to maintain privacy.

Table 2

Correlations between the Three Factors and Other Variables

	Factor 1 Respect	Factor 2 Lack of Dignity	Factor 3 Day-to-day Control
Factor 1: Respect/Communication			
Factor 2: Lack of Dignity	-.64**		
Factor 3: Day-to-day control	.57**	-.53**	
One-item measure of satisfaction	.80**	-.66**	.48**
Seriousness of condition	ns[a]	-.18*	-.17*
Significance of hospital stay	-.24**	ns[a]	ns[a]
Length of hospital stay	-.20	-.21**	ns[a]

** $p < .01$. * $p < .05$. [a]ns = not statistically significant.

The experiences of not being listened to by health professionals, loss of privacy and dignity, and loss of day-to-day control were present in the sample, however, they were relatively uncommon experiences affecting between 10% and 40% of the participants. For example, about one-fifth of the women had the feeling they were not being listened to by health professionals when they spoke about their condition, and that health professionals were not giving adequate, jargon-free explanations of their condition. Approximately one-third of the sample reported feeling a lack of dignity or privacy during their hospital stay because health care professionals failed to ask their permission prior to interviews and examinations. Nearly half of the participants had experienced a lack of control over day-to-day activities in hospital such as meal and shower times, and access to personal medical records.

The qualitative data reflect similar issues to the quantitative data, and provide more detailed accounts of both negative and positive experiences. These data also add "process" information by demonstrating how different types of behaviour on the part of health professionals could contribute to patients' feelings of loss of power or control over their health care. For instance, the closed answer items showed that some patients

experienced a lack of sensitivity in terms of the communication of medical information. The qualitative data also showed that patients felt a lack of sensitivity on a more personal level in terms of courtesy and respect. Consistent with research reviewed in Chapter Two (e.g., Annandale, 1987; Ellingson & Buzzanell, 1999; Kasle et al., 2002; McKay, 1991; Taylor & Dower, 1997), when a patient is treated with disrespect, she may feel powerless to respond assertively due to the power differential between her and the health professional.

Women also emphasised that they experienced insensitivity in terms of feeling invisible or ignored; they felt that the health professionals were treating the "parts" (the patient's body/the illness) and ignoring the "whole" (the person). Women's comments showed that their experiences of insensitivity increased the feeling of vulnerability attached to being an inpatient, and emphasised that health professionals sometimes do not treat patients as people. This finding is consistent with the research reviewed in Chapter Two (e.g., Ellingson & Buzzanell, 1999; McKay, 1991; Taylor & Dower, 1997) emphasising the importance of empowering patients, treating them as individuals, and as autonomous and active partners in the health care process.

The quantitative data showed that participants often felt health professionals were not listening to their concerns about their condition, or to their accounts of symptoms. The qualitative data suggested that this lack of listening was interpreted by patients as health professionals' not recognising the advantages of working cooperatively. Instead, the health professionals were perceived as wanting to be in full control of the course of the medical treatment. Such control is illusory, given the importance of patient adherence, trust and motivation in the outcome of treatment (e.g., Byer & Myers, 2000; Walitzer, Dermen, & Conners, 1999). A more effective model of treatment is likely to involve an alliance between patient and health professional, in which both are aware and respectful of the contribution of the other to outcomes (e.g., Benbassat, Pilpel, & Tidhar, 1998; Buetow, 1995).

Some women felt a lack of control over their daily experiences such as showering, eating, and interacting with visitors, as well as a lack of dignity and privacy during their hospital stay. The qualitative material shed more light on what the participants meant by a lack of day-to-day control and dignity: participants' accounts emphasised feeling stripped of their public and professional rights and status simply by virtue of being a patient and of not conforming to the norm of physical wellness.

Maintenance of individual identity during times of stress is a form of adaptive coping (Smith, Wethington, & Zhan, 1996; Zayne, 1997). Strategies which facilitate this form of coping, such as use of own night wear, encouragement of maintenance of grooming standards while in hospital, or even menu choice have long been a feature of modern Western hospitals. These efforts may be undermined if there is an attitude among professionals which allows the treatment of patients as "things" rather than people.

The closed answer items were partially developed from pamphlets of patient rights from various hospitals in Melbourne, Australia. Such documents reflect a desire on the part of hospital administrators to increase the level of respect and dignity afforded to patients, and to increase patients' sense of control over their own health. However, it appears that patient rights are sometimes ineffectively implemented. Patients may be unaware of what they have the right to expect, especially when something goes wrong. Patients may want to voice their concerns, but may feel intimated due to the hospital environment, or they may feel not listened to even if they try. It is in the interest of better health care that patient rights are readily available, and it is a system responsibility to ensure that processes for encouraging patient rights are supportive rather than intimidating (Anonymous, 2001). No matter how assertive or articulate the patient, the health care system has the greater power to dictate the terms of the medical experience, by controlling information about the condition or the treatment, ignoring patient descriptions of their problems, disregarding patient concerns, and working "in control" rather than "in cooperation" with patients. It is perhaps not surprising that some women felt that their illness had become the "significant other" in the medical relationship, and that they were simply the "science experiment". Words used by the women to describe their hospital experiences, such as "controlled", "bossed around" and "science experiment", all imply recognition of the power differentials of the health care system as described by Broom (1995). Broom calls this the "masculinisation" of health care, which indicates her belief that the power differentials between patients and health care professionals reflect gender role power differentials.

Descriptions of good practice showed that the participants wanted health professionals to listen to them and treat them with respect and sensitivity. These examples of good practice reflected the power themes as they showed the reverse of disrespect and insensitivity and not listened to. Additionally, the participants wanted to

be treated in a humanised manner, and to have more control in their hospital experiences as they appreciated playing a role in treatments and making choices.

3.6 Contribution of the Pilot Study to the Main Study

The quantitative and qualitative data showed that the experience of powerlessness as a hospital inpatient was a shared experience among this sample of women. Specifically, the data highlights the dimensions of control that are important to women inpatients: disrespect/insensitivity, diminished patient rights, not being listened to by health professionals, loss of privacy and dignity, and loss of day-to-day control. Although the qualitative data were derived from a small number of female participants, and the majority of examples illustrating power themes came from a few participants, women readily shared their experiences and provided useful and moving information. This suggested that hospital experiences are a salient aspect in the lives of women, and such experiences have the potential to shape the sense of self. The results also support the importance of such a study. The richness, breadth and detail of the qualitative data also suggested that qualitative methodology would be a productive way to further study this area.

Overall, results show that perceived lack of control in hospital is more likely to manifest itself in situations where the patient has a serious illness, lengthy stay and views the experience as a significant one, implying that in such circumstances the concept of control plays a major role. These findings raise questions of how women "reclaim" their rights, dignity and sense of power after such experiences, and whether the experience can change them and their attitudes towards the health care system. The next chapter presents a theoretical framework for understanding these phenomena, as a prelude to a larger interview-based study continuing the exploration of the role of power and agency in women's hospital experiences.

CHAPTER FOUR

NARRATIVE PSYCHOLOGY: THEORY AND METHODOLOGY

4.1 Overview of the Chapter

Earlier chapters have described some of the key elements of hospitalisation and women's hospital experiences. The picture that emerges is that a hospital stay can often be perceived as a life-changing experience, not only in terms of dealing with an illness and the fear and anxiety associated with it, but also of the way in which patients are treated by medical staff, and of the need for patients to learn and conform to the hospital culture. Thus, hospitalisation has the potential to disrupt individuals' lives and cause them to reflect and question basic assumptions about themselves and the world, thereby potentially altering the sense of self. Chapters One and Two also highlighted the important role that power can play in the doctor–patient relationship and how this has the potential to affect how patients feel about themselves, especially female patients. Additionally, the pilot study described in Chapter Three showed the importance of power issues to female inpatients, in particular the relevance of powerlessness to women with serious conditions, who were experiencing lengthy stays, and who perceived their hospital stay as significant. This chapter presents a methodological framework to further explore issues of power and control in women's hospital experiences, in particular those which involve major life transitions.

The chapter begins with the theory and methodology of narrative psychology. The assumptions, characteristics and usefulness of the approach are explored. A narrative represents what the individual believes is important about an event, and allows meaning and a sense of coherence to be made (Bruner, 1990; Sarbin, 1986). It is argued that narratives are relevant to hospital experiences, as traumatic events such as hospital stays can impact upon the characteristics of narratives, and thus have the potential to change and influence the sense of self. In the second section of the chapter, the history of the narrative approach is traced, influential narrative theorists discussed, and their contribution to the field briefly described. The works of Tomkins, Hermans and McAdams are introduced, as they were the first narrative theorists to note the importance of the "story" itself. McAdams' Life Story Model of Identity is presented as the theoretical framework of choice for the present study, and a rationale is provided. McAdams shares assumptions with many of the early narrative theorists and has built

on that work to develop the Life Story Model. In the third section, the components of the Life Story Model of Identity are explored, and how they relate to theories of human development discussed. Empirical support for the theory is also presented. In the third section, the particular components of the Life Story Model of Identity relevant to the main study are identified. The theory is useful as it is comprehensive and adaptable and it provides a method of examining the issues facing women inpatients and how women deal with a life-altering hospital experience.

4.2 The Life Narrative Approach

The life narrative approach is based on the belief that one's sense of self is created through life narratives or stories told to oneself or others (Gergen & Gergen, 1988; Polkinghorne, 1988; Sarbin, 1986). A narrative can be defined as the "re-creation of events and actions in a symbolic structured way so that the motives of the actors and the morality of the situation can be understood by self and others" (Hill, 1997, p. 132). Telling stories either about certain experiences or about whole lives contributes to a sense of daily existence (Bruner, 1990; Sarbin, 1986) and creates a sense of order, unity and meaning in an uncertain world. Narratives put life events in their place within the life story, so that there is a sense that life flows. They allow individuals to learn from their past and predict aspects of their future (Baumeister, Stillwell, & Wotman, 1990; Freeman, 1993; Gergen & Gergen, 1988; Heatherton & Nichols, 1994).

The study of autobiographical narratives has expanded in recent years. Some authors have examined entire life stories (McAdams, 1988b), while others have focused more narrowly on stories about specific events (e.g., Baumeister et al., 1990; Harvey, Flanary, & Morgan, 1986; Heatherton & Nichols, 1994; Weber, Harvey, & Stanley, 1987). Like any eyewitness accounts, these autobiographical stories may not be absolutely true. For example, people often selectively construct, retrieve and distort narratives to fit their self-concepts (McGregor & Holmes, 1999). However, narratives are considered particularly useful in representing what the person believes is important about a particular event (Baumeister et al., 1990).

4.2.1 Narrative in Everyday Life

Researchers have stated that there are four main interrelated characteristics which have been attributed to narrative: a sense of temporality, identity, understanding

of the world, and unity (Bruner, 1990; Sarbin, 1986). These four elements are discussed in turn so that comparisons can be made when trying to understand how the sense of self can be threatened by the experience of hospitalisation.

In the case of temporality, researchers have asserted that narrative is the main way in which individuals organise time (Carr, 1986). Although people live in the present, the past and the future can still be accessed. The main way to access past and future actions is through thought and language. For example, if an individual is asked what they did yesterday or what they will be doing tomorrow, they will explain it in words. Ricoeur (1984) also explored the relationship between narrative and time, and like Carr (1986), he agreed that the events of the past and future are linked to the present through the use of narrative. In addition, he proposed the idea that human experience is not based on linear or clock time: the past is not remembered as a fixed list of events. Rather, narrative implies a sense of fluid time, flowing and adaptable. Perception and interpretation of a past event is guided by narrative, and importantly, is affected by why it is being remembered. Therefore, completely different stories may result at different times from the same events. These accounts are not fixed, nor are their meanings. There are many possibilities, bounded only by personal and societal limitations (Hill, 1997).

The second characteristic is identity. People tend to create stories which reinforce and demonstrate their sense of self. Certain elements of the past are selected in biography to support present identity (McAdams, 1993). Gergen and Gergen (1988) explain that present identity is not sudden or mysterious, but a result of a coherent connection of life events. For example, seeing oneself as suddenly and momentarily "aggressive", "gregarious ", or "dependent" would seem strange. However, when aggression follows longstanding and intensifying resentment, it appears logical. Similarly, being gregarious or dependent can be understood when placed in the context of life events (Gergen & Gergen, 1988).

People use stories to understand the world and to understand the motives of others. Hill (1997) explains that generally people rarely reflect on life and experience. Typically, life and experience are taken for granted, and there is a sense of being a particular person in a predictable and controllable world. When one understands their experience and life, he/she is not consciously aware of the narrative process. However, when life is disrupted by an unexpected or traumatic event, and there is a threat to the

sense of predictability and control, people try to make sense of their experience; they reflect on themselves and their lives and narration becomes conscious (Hill, 1997). This experience is well described by Oliver Sacks (1984) as occurring after a traumatic injury:

> To be full of strengthened vigour and virtually helpless the next … with all one's powers and facilities one moment and without them the next – such a change, such suddenness, is difficult to comprehend, and the mind casts about for explanations (Sacks, 1984, p. 6).

Narratives are only brought to attention when meanings cannot be found; thus the focus of the story is to make sense of the incomprehensible (Bruner, 1990).

The fourth characteristic is unity. When a story is told, several events are linked to form a complete and whole story: a beginning, middle and an end. McAdams (1993) believes that narratives are able to place order and unity onto an otherwise random and chaotic experience of everyday life. The orderly flow of past events enables predictions to be made about the future.

Having discussed the four underlying themes of narrative, and their importance to daily life, the next section explores the experience of life disruptions and how hospitalisation may impact on narrative.

4.2.2 The Experience of Biographical Disruption

The experience of hospitalisation itself, whether it is due to an emergency appendicitis, a planned hip replacement, or a stroke, can be frightening and shocking. Patients not only have to deal with their medical problem, but they also have to conform to the often unfamiliar social rules of the hospital. In addition, distress may arise if patients' self-perceptions change after hospitalisation. For example, patients may continue to see themselves as mother or daughter, but other parts of identity such as "assertive", "independent" or "in control" may be challenged. As their life narratives are threatened or shattered, patients' lives become disrupted; they may experience a loss of consistency and control, and a loss of the aspects of self that are often taken for granted (Charmaz, 1983).

Sociological and psychological research suggests that a chronic illness interrupts one's preferred life story and undermines the sense of coherence, so that the future becomes uncertain and unpredictable (Radley, 1994). This process has been termed "biographical disruption": the diagnosis of a chronic illness separates the person in the past from the person they were expecting to be in the future (Bury, 1982). Bury (1982) proposed the concept of biographical disruption as a way of defining the sense of an individual's life course being undermined. For example, suffering a heart attack at the age of 35 can have a considerable effect upon the self-perception of a young, healthy, fit and able person. Critical incidents, which may cause individuals to question basic life assumptions, can be seen, metaphorically, as rips in the fabric of life. Williams (1984) argued that the way individuals maintain meaning in life is through narrative, the story that connects the different events and experiences that make up life. He proposes that the "rip" in biography raises questions such as "How have I come to be like this, because this isn't me?" and the person attempts to answer such questions through "narrative reconstruction" (Williams, 1984). A narrative reconstruction attempts to make sense of the disruption and connect it with the life story so the story maintains its coherence. For instance, after a heart attack, patients may reconstruct the incident to make it fit in with their life story, so it may be seen as the "obvious outcome" of an unhealthy diet. Therefore, narrative reconstructions serve as repairs to life's so-called disruptions. "Repairing" life's disruptions is not simply a case of re-establishing personal meaning or re-attaining a positive perspective; it is also a way of devising a future of living as a "changed" person (Radley, 1994).

The idea of using narratives as a way of understanding the impact of trauma and physical health is not new. James Pennebaker and colleagues (e.g., Pennebaker, Kiecolt-Glaser, & Glaser, 1988) proposed some innovative research on the health benefits which stem from writing or speaking about trauma. It appears that one way in which people make sense of potentially devastating experiences is by sharing the experience with others (Pennebaker, 1997; Pennebaker et al., 1988). In doing so, stories have the power to reduce anxiety and guilt, and give coherence to the self (Stein & Apprey, 1990). This emergence of the narrative approach as a methodology to explore life-change or disruptions to the life path extends to many research areas. For example, rheumatoid arthritis (Bury, 1982), Parkinson's disease (Marr, 1991), head injuries (Nochi, 1998; Tyerman & Humphrey, 1984; Wright & Telford, 1996), strokes

(Doolittle, 1992; Ellis-Hill & Horn, 2000; Ellis-Hill, Payne, & Ward, 2000; Wyller & Kirkevold, 1999), and other traumatic life experiences (King, Scollon, Ramsey, & Williams, 2000). In addition, social and personality psychologists have begun to examine the different types of narrative accounts that adults devise to cope with personal problems and explain difficult and challenging life events (Baumeister et al., 1990; Harvey, Flanary et al., 1986; Harvey, Weber, Glavin, Huszti, & Garnick, 1986; King et al., 2000; Kirkman, 1999; Leonard & Burns, 1999). Participants' stories attempt to make sense of experiences and represent explanations of the onset of the illness or the traumatic event (Borkan, Quirk, & Sullivan, 1991; Mathews, Lannin, & Mitchell, 1994). The research emphasises the notion that participants' lives may never return to normal and highlights the importance of returning to the life led prior to the onset of the illness or traumatic event (Doolittle, 1992; Wyller & Kirkevold, 1999).

Research shows that a range of critical incidents perceived as traumatic, which shatter one's self-perception or life beliefs, may also evoke biographical disruption. Some hospital experiences can be perceived as an interruption, an event that can undermine the coherence of the life story. Therefore, a narrative psychology approach can be used in exploring hospital stays, as the experience needs to be understood or contextualised within the wider concept of life-change. Kirkman (1999) used the narrative approach to explore the role that infertility played in the lives of women, the idea being that these women needed to construct new narratives for and about themselves to accommodate the unexpected event of infertility.

> If we accept that our lives are constituted through narrative, not
> merely described by narrative – that is, if we accept narrative as
> the very structure of life – we can comprehend the profound
> challenge confronting a person whose identity, narratively
> constituted, has been disrupted. This is what confronts a woman
> whose identity is that of a mother, but who discovers that she
> cannot fulfil that identity by giving birth to a child (Kirkman,
> 1999: http://www.latrobe.edu.au/www/aqr/offer/confeen.htm).

The research conducted in this thesis borrows this description of the necessity of narrative in understanding life disruptions. However, applying this idea to women's hospital experiences, perceived as life-changing, is not simple. The life-changing aspect

of being in hospital can be positive or negative, and can be caused by the illness for which one is admitted, the way in which one is treated by hospital staff, or a combination of these. Regardless of the change and what caused it, if a woman perceives the experience as life-altering, then she will not leave hospital the same person as when she went in. It is this point that is the focus of the present study: how do women understand this change in their identity after a life-altering hospital experience? The narrative approach is compatible with the intention of the present study to explore narratives of women's hospital experiences, and to understand how they constructed the meaning of this event within their life story.

4.2.2.1 The Relationship between Hospitalisation and Narrative

Time is disrupted when one enters hospital. People are isolated from daily life and have to conform to hospital rules. Holloway et al.'s (1998) findings highlight that time, which is normally taken for granted, becomes a significant problem for patients. Health professionals determine the way that time is spent in hospital; therefore patients may feel that they lose control over time. The participants in Holloway et al.'s study attempted to keep track of time and found ways of passing it, while believing that valuable personal time was lost to them.

Identity can also be affected by hospitalisation. Charmaz (1983) states that the threat to a person's sense of self can be termed "a temporary disruption of self". The usual validation of identity by interactions with family and friends and by playing roles such as wife and teacher, in addition to the familiarity of everyday life, is temporarily disrupted. Warren et al. (2000) found that one of the consequences of being hospitalised was the threat to a person's sense of self, not only through pain or loss of bodily functions, but also because of the dislocation from one's normal environment and the lack of normal social interactions. When a person becomes a "patient", she may feel disconnected from her identity or discouraged from expressing her individuality and talking about her hobbies or interests. The person is given the biography of a patient. Furthermore, a patient's privacy is sometimes not respected. For example, curtains can be pushed aside without warning, hospital gowns leave little to the imagination, and invasive tests and procedures are sometimes unexplained and attended by hospital staff who remain unknown to the patient (Cross, 1986). Staff can treat patients in a depersonalised manner; for example during ward rounds doctors tend to

talk among themselves in the presence of the patient while revealing personal information about the patient. Charmaz (1983) interviewed 57 chronically ill adults and found that discrediting definitions of the self (such as when someone is tacitly devalued or discounted) contributes to a loss of self. The cumulative effects of undignified experiences, disempowering treatment and medical conditions may combine to threaten a patient's sense of self. On the other hand, positive hospital experiences can also impact on a person's sense of self in empowering ways. For example, some patients are proud of being able to cope with the pain associated with illness or procedures, which may increase their self-esteem and alter their self-perception to that of a "strong" person. Furthermore, patients facing the possibility of dying may discover a renewed perspective on life and find an improved way of living. Charmaz (1983) found that patients who had particularly lengthy episodes of illness, and had later improved, had time to reflect on their lives. The extended periods of illness provided freedom from the ordinary restrictions of routine existence and raised their consciousness of who they were and who they wished to become, thereby providing an important time of self-development.

There can be a disruption to patients' relationships with their physical and social world. Research on survivors of illness and trauma have suggested that people have fundamental assumptions about the world, such as that they are worthy, that the world is a good place, and that life makes sense (Janoff-Bulman & Berg, 1998). In the aftermath of traumatic victimisation, some victims discover that these assumptions are illusions. For example, the assumption that the world is fair and predictable is replaced by the recognition that the world is not always a good place and sometimes life events do not make sense. Similarly, during hospitalisation, people's understanding of their physical and social world may change. There can be a challenge to personal assumptions about oneself and the world, and one's ability to change, predict and understand it.

Finally, unity can be disrupted during a hospitalisation, in that the unity of one's life narrative is threatened. This in turn threatens the flow or coherence of the life story. Patients may try to connect their medical condition or the manner in which they are treated in hospital to previous experiences in an attempt to understand the cause, thereby asking "Why me?" Hill (1997) noted that the difficulty with many chronic illnesses and traumatic events is that there rarely is an answer or a direct cause, which makes it difficult to incorporate the hospital experience in a meaningful and coherent life story.

The disruption of time, identity and relationships also plays a part in the loss of unity by adding further interruptions to the flow of the life narrative.

4.3 Narrative Psychology

4.3.1 Early Narrative Theorists

Life span theorists maintain that the narrative is a form of explaining adult lives. Such theorists believe that the adult life course should not be perceived simply as a systematic developmental progression or as a predictable expression of stable personality traits, but rather as an evolving narrative, situated in culture and history (McAdams, 2000). The development of a narrative perspective on the life course can be traced back to the first psychobiographies, such as Freud's of Leonardo da Vinci and Erikson's analyses of Martin Luther and Mahatma Gandhi. The narrative perspective is also evident in Erikson's subsequent conceptualisation of the stages in psychosocial development and the influential writings of Murray who attempted to interpret the content of biography in terms of motives (McAdams, 1988a, 1997). These early psychobiographies and biographies reflect a narrative approach because they involve the systematic use of psychological (especially personality) theory to aid in the process of collecting life narratives and transforming a "life" into a coherent story (McAdams, 1988a).

Three influential representatives of narrative psychology are Theodore Sarbin (1986), Donald Polkinghorne (1988), and Jerome Bruner (1986). They maintain that narrative is useful in understanding adult lives and the nature of human beings. These authors explain that narrative provides a framework for understanding past events and planning for the future (Polkinghorne, 1988). Therefore, they suggest that the manner in which human beings arrange their psychosocial world to provide their life with unity and purpose is best addressed through the language of narrative (Bruner, 1986; Polkinghorne, 1988). Furthermore, Sarbin perceives the narrative to be the "liberating metaphor" for psychology, and argues that stories provide an understanding of lives in their social and cultural contexts (McAdams, 1994). Bruner (1986) states that human beings are intentional agents: they act on their desires and beliefs to achieve goals. Correspondingly, stories are essentially about the organisation of human intentions and convey sequences of motivated action and the accomplishment of intentions over time. Therefore, stories complement the nature of human beings as intentional agents.

4.3.2 The Importance of the Story

Beginning with Tomkins' (1987) Script Theory, personality psychologists began to consider the possibility that the story itself is important. Tomkins maintained that from the early years of life onwards, the person approaches life as a storyteller, unconsciously constructing self-defining scenes and arranging them into a story. Following Tomkins' lead, researchers such as Hermans and McAdams generated new narrative approaches to life stories. These approaches are embodied in Hermans' view of the dialogical self and McAdams' Life Story Model of Identity.

4.3.2.1 Tomkins' Script Theory

Tomkins' Script Theory is essentially a cognitive affective perspective on personality (Carlson & Carlson, 1984; Carlson, 1988; Singer & Salovey, 1993; Tomkins, 1991). Tomkins sketches a broad theory of personality, connecting scenes and scripts to fundamental human affects. He adopts a narrative approach to the meaning of human life, viewing the person as a storyteller who narrates life while living it (McAdams, 1988b).

Tomkins' "scene" is viewed as an idealised memory of a specific event in the life story, which consists of at least one affect and at least one subject of that affect (Carlson & Carlson, 1984; Singer & Salovey, 1993; Tomkins, 1991). Scenes which have the same affective pattern are linked or "psychologically magnified" through the basic human desire to increase positive affect and minimise negative affect (Carlson & Carlson, 1984; Singer & Salovey, 1993; Tomkins, 1991). For example, people seek and link scenes containing positive affect so that positive memories are reinforced.

The different types of scenes include transient, habitual, positive and negative scenes. Transient scenes contain brief bursts of affect but are not linked to other scenes. Examples are a rush of pain when burning oneself while ironing, or a momentary fright when one trips when walking. Habitual scenes are recurring and linked scenes involving minimal consciousness, thought and affect (Carlson & Carlson, 1984; Singer & Salovey, 1993; Tomkins, 1991). Examples are brushing one's teeth each morning and night, or walking down the street without incident. Positive scenes are pleasurable and linked with other pleasurable scenes with similar content (Tomkins, 1991), for instance the feeling of being understood and accepted in encounters with different close

friends. Negative scenes are characterised by unpleasant affect and are linked with different events which are of a similar negative tone. For example, a stranger may be reminiscent of a childhood bully. Singer and Salovey (1993) believe that positive and negative affect scenes rely on different psychological magnification or linking processes, as individuals want to find positive affect at all times and are always trying to generate new variations or possibilities of enjoyable experiences. With negative affect scenes, people are motivated to avoid situations that bring more negativity; ironically, people also seek out negative affect scenes in order to gain control over the bad scene and work through them (Carlson & Carlson, 1984; Singer & Salovey, 1993; Tomkins, 1991).

As key positive and negative scenes are continually repeated or magnified mentally, similar sets of scenes that are imagined as specific events or episodes in memory become blended into scripts. The script is an individual's template or set of rules for expectations, affective responses and suitable behaviours in a magnified set of scenes. Magnification of particular scenes into scripts is only determined by the ongoing experiences in an individual's life that involve repetition of similar thematic and affective patterns. Two important scripts identified by Tomkins are commitment scripts and nuclear scripts. Commitment scripts involve a sense of positivity and optimism, the willingness to pursue goals or long term activities, even in the face of obstacles, and the anticipation of a happy ending (Tomkins, 1987). Nuclear scripts capture a person's most central, unresolved and enduring problems and concerns (Carlson, 1981, 1982). These generally reveal confusion about life goals and the repetition of sequences in which good things turn bad. In Section 4.4.5.1, Tomkins' Nuclear Script is discussed in more detail. Understanding a person involves an analysis of the recurrent affects, scenes, scripts and different modes of psychological magnification that the person manifests throughout their life.

4.3.2.2 Hermans' Valuation Theory

Hermans is a contemporary personality psychologist who draws upon both idiographic and nomothetic methods to understand how people make sense of themselves through stories (Hermans, 1987, 1988, 1992a; Hermans & Hermans-Jansen, 1995). The basic units of life stories are valuations, which refer to people, events or experiences which a person finds to be important when thinking about his or her life.

Through the process of self-reflection, people organise their valuations into narratives, some of which are constant and some are changing, depending on the person's life stage. Valuations may be classified in terms of positive and negative affect and of agentic S- (self-enhancement) motives and communal O- (contact and union with the other) motives. It is expected that the assessment of the pattern of affects and motives will reveal hidden aspects of the valuations.

Hermans developed the Self-Confrontation Method for gathering and evaluating valuations. The method was designed to assess the connection between valuations and affects and motives, the manner in which these variables are organised into a system, and how the system changes over time (Hermans, 1987, 1988, 1992a; Hermans & Hermans-Jansen, 1995). It can be considered an idiographic instrument that allows for nomethetic generalisation (Hermans, 1988).

In terms of nomothetic research, Hermans explored how particular patterns of valuations characterise certain groups of people (Hermans, 1992b; Hermans & Oles, 1999). From the idiographic perspective, Hermans suggests that inspection of valuations gives researchers a glimpse into an individual's uniquely positioned dialogical or multivoiced self (Hermans, Kempen, & van Loon, 1992). Philosophical-phenomenological thinkers such as William James and Maurice Merleau-Ponty inspired Hermans' view of the dialogical or multivoiced self in which he distinguishes between the senses of self as "I" and "Me". A valuation is an interaction between the I and Me, between that which organises and interprets experiences, and that which defines and articulates such a process (Hermans et al., 1992). In contrast to Tomkins and McAdams, rather than seeing the narrative as the product of a single author – a single I – Hermans believes that there is no single perspective for an author, but rather many different positions from which the story can be told. Valuations are a product of a conversation with the self among different voices. Therefore, the life story is the product of many different I positions.

4.3.2.3 McAdams' Life Story Model of Identity

Consistent with his predecessors, McAdams' theory of identity emphasises that stories are the accepted medium for conveying how human beings make sense of their sometimes fragmented lives (McAdams, 1988b). The central assumption of the Life Story Model of Identity is that a person self-defines by creating an autobiographical

story, complete with setting, scene, character, plot and theme (McAdams, 1988b). Life stories not only involve biographical facts but also selectively highlight certain past and present experiences to construct narratives that make sense and provide meaning to both the storyteller and audience. There are four components of McAdams' Life Story Model of Identity. The first component is the ideological setting, which refers to the context of beliefs and values that provides the backdrop of the life story. The second component is the nuclear episode, which refers to highlighted events which enlighten both the author and the audience about how the individual has come to be. The third component is the imago, which refers to the main characters in the story. The fourth and final component is the generativity script, which refers to the adult's concern for, and commitment to, the well being of the next generation. The two dimensions of thematic lines and narrative complexity are woven through the four components. Thematic lines convey content. Like many other researchers, McAdams states that the thematic lines of agency and communion run through life stories, and each is reflected in content analysis systems. Narrative complexity reveals organisation or structure, in terms of how the individual arranges the various characters, plots and themes of the story. Just as stories differ in content, they also differ in complexity; stories can range from structurally simple to the complex, and reflect an individual's level of understanding of self and the world. Another important concept within the model is the conceptualisation of redemption and contamination sequences. McAdams believes that these two distinct narrative strategies relate to how people make sense of major life changes. The above concepts are discussed in detail in Section 4.4 McAdams' Model of Identity: Development of the Life Story.

McAdams' model is based on Tomkins' Script Theory, but McAdams' focus is on identity (McAdams, 1988b). Tomkins' Script Theory addresses general personality structure and dynamics whereas the Life Story Model addresses identity per se, which is only one aspect of personality, albeit a key one (McAdams, 1988b). McAdams (1995b) explained that a person's identity fits into the wider context of "personality". Personality is best thought of as a number of constructs placed in three distinct levels or domains. Level 1 consists of dispositional traits, which are global and stable dimensions of personality, such as those included in the Big Five Framework (McCrae & Costa, 1990). Level II consists of personal concerns and refers to personal strivings, life tasks, defence mechanisms, coping strategies, domain specific skills and values and

a range of other motivational, developmental, or strategic concepts that are linked to a particular time, place or role. Traits provide the "framework" for human individuality, whereas personal concerns fill in the details (McAdams, 2001). Level III refers to the concept of identity as a life story, to how a person's psychosocial world is arranged to provide life with unity and purpose. Thus, personality is a complex pattern of traits, personal concerns and stories. To understand a person requires a consideration of each of the three levels. One should have a sense of where that person stands on a series of dispositional traits in order to understand general behavioural patterns across situations over time, how the person deals with and acclimatises to life tasks and concerns in a particular place, time or role, and what kind of stories the person creates about the self.

McAdams' (1988b) Life Story Model is also based on Erikson's (1963) developmental concept of ego identity. According to Erikson, identity issues arise in late adolescence and young adulthood (the fifth of eight stages in psychosocial development). Erikson (1959) employed the term "identity" to refer to an individual's attempt to answer the psychosocial question "Who am I?" McAdams agrees with Erikson's idea that adolescence is the first time that a person is motivated to evaluate personal history, explain new possibilities for the future by exploring and consolidating ideological and occupational options and social roles, and find their place in the world. Erikson (1959) maintains that the construction of an identity configuration is like a story, as it is comprised of plots, characters, settings, scenes and themes. It aims to integrate or order, into a meaningful and coherent whole, many different things, such as skills, values, beliefs, roles, and goals (Erikson, 1959).

McAdams' Life Story Model differs from Erikson's original stage model. Erikson confined identity formation to a single psychosocial stage (emerging adulthood) but McAdams' model highlights the continuation of identity work across the adult years (McAdams, 2001). McAdams built on Erikson's ideas when he proposed that the identity configuration *is* the life story. If identity itself is structured like a story, then the self is a story (McAdams, 1994, 2000). People create who they are; they script their lives like authors. McAdams argues that an adult has an identity in his/her life to the degree that he or she can successfully create and internalise an integrative life narrative, with settings, characters, plots and themes, arranging the reconstructed past, perceived present and anticipated future (McAdams, 1988b).

McAdams (1996) stated that a person's life story is a psychosocial construction: while the author or storyteller constructs the story, the story content is determined by culture. The person and culture co-author identity, so that different kinds of stories ring true in different cultures. That is, stories about witches might make sense in 17th century America, but would not fit expectations for life narrative accounts in contemporary Australia (Howard, 1991; McAdams, 1996). Life stories are understandable within a particular culture, and yet they are unique constructions, never to be repeated, differentiating one person from the next. A person's evolving and dynamic life story is a key part of what makes up their individuality, surrounded by particular family and friends, in a particular society, and in a particular historical moment.

There are many similarities and differences among Tomkins' Script Theory, Hermans' Valuation Theory and McAdams' Life Story Model of Identity. The theories identify basic principles and common themes for contemporary narrative psychology. However, the theoretical differences reveal controversies concerning the unity versus the multiplicity of selfhood, and the focus on personality as a whole versus one aspect of it, namely identity. In practical terms, there are theoretical and methodological differences regarding the degree of comprehensiveness and adaptability among the three theories. McAdams' Life Story Model of Identity was the theoretical framework of choice for the present study because it is (1) adaptable and flexible and (2) comprehensive. The adaptability and flexibility of McAdams' theoretical framework has been demonstrated by the variety of studies which employ his procedure. For example, Leonard and Burns (1999, 2003) have published two qualitative studies examining different aspects of women's lives, for which the interviews were based on the personal life story interview of McAdams. The authors used this approach as a way of asking participants to consider certain life events, such as major life turning-points (Leonard & Burns, 1999) and paid and unpaid work (Leonard & Burns, 2003). Therefore, McAdams' model can be used in a variety of ways, with researchers being able to utilise certain aspects of the model or the whole model. The model is also comprehensive; for example, McAdams' theory allows hospital experiences to be placed in the context of an entire life story. McAdams focuses on the importance of the content of stories and established a coding system to analyse the content, which provided a structured way to identify the main issues facing female inpatients. In

addition, analysing redemption and contamination sequences provided a structured way to examine how women made sense of their experience. The following sections discuss these components of the model in more detail and provide an explanation of how the model addresses the objectives of the present study.

4.4 McAdams' Model of Identity: Development of the Life Story

As previously noted, there are four components of McAdams' model. As the model provides a framework for conceptualising the development of the person from birth to death, the components are discussed in terms of human development in the following sections.

4.4.1 Infancy and Narrative Tone

Although human beings begin to construct self-defining life stories in adolescence and young adulthood, the process of gathering material for the story begins in infancy (McAdams, 1990, 1994). Essentially, the relationship between the first two years of life and personal myths of adulthood may be expressed in what McAdams calls "narrative tone" (McAdams, 1990, 1994). Narrative tone refers to the underlying essence of the story, whether it conveys an optimistic or pessimistic tone about human life. It tells the listener or the reader about the author's underlying faith in the possibilities of human intention and behaviour. The first formative influences on narrative tone include attachment relationships and understandings of intentions and outcomes. Recent research (Tomasello, 2000) suggests that by the end of the first year of life, infants come to understand and recognise other people's behaviour that appears intentional. For example, a 16-month-old infant will not just mimic any behaviour; rather, the child will attempt to reproduce behaviours which appear to be intended and goal orientated. By this stage, infants attain a global sense of whether their wishes and desires are possible. For example, infants who have a secure attachment bond to their caregivers are likely to have a positive foundation for subsequent identity formation. The foundation may help to provide the infant's life with an unconscious conviction of hope and trust in the world, a sense of optimism about human striving, and the attainability of dreams (McAdams, 1994). In the Life Story Model of Identity, early experiences provide the raw material or resources for the construction of identity in adolescence and adulthood.

4.4.2 Early Childhood and Images

From infancy to early childhood, the elements of the story move from general tone to specific imagery (McAdams, 1994, 2000). The imagery of the story is determined by the pictures, sounds, smells, tastes, metaphors, smiles etc. that the author creates. Images provide stories with a distinctive feel. People begin accumulating emotionally charged images for identity in their preschool years (McAdams, 1994, 2000). The main sources of these images are family, friends, schools, books, television, and imagination. During these years, children are cognitively predisposed to understand the world in terms of imagery; they show what Piaget calls preoperational thinking, where the child represents the world in symbols and imagery and is unrestrained by logical reasoning (Inhelder & Piaget, 1968). This does not mean that children of this age cannot understand a story's plot; rather children focus on the images that capture their imagination, for the whole story is too complex and systematic to be incorporated into their daily world of fun and imagination (McAdams, 1990). A great deal of these early images disappear, but some of the more significant images and representations may remain and become embellished to assume major positions in people's life stories (McAdams, 1994, 2001). Every life story has its own unique imagery.

4.4.3 Late Childhood and the Organisation of Motivations

From early to later childhood, the elements of the story move from imagery to themes. As children enter formal schooling and develop logical and systematic thought, they come to appreciate stories as thematically organised wholes (McAdams, 1990, 1994, 2000). A theme is a recurrent goal-orientated sequence in narrative, which represents a more complex level of story than does imagery (McAdams, 1994, 2000). An image exists in a moment, but a theme is a sequence of moments forming a particular pattern over time. Older children firmly understand that stories are about the "vicissitudes of human intention" organised in time (Bruner, 1986). Older children perceive stories as goal-orientated sequences, and they invest interest in the characters of the story as a function of the desirability of the goals towards which the characters strive.

Themes convey motivation: what characters want, desire, need, and are striving to attain (McAdams, 1989, 1994, 2000). McAdams (1989) postulates that much of

human behaviour reveals unconscious desires, and these desires consistently drive behaviour across different situations and over time. In many stories, what characters desire and are working to achieve is some form of power, love, or both. The idea that human lives are energised by two contrasting tendencies of power and love has long been an underlying theme for many writers (e.g., Adler, 1964; Freud, 1953; Sullivan, 1953). For example, Freud (1953) distinguished between the "death instinct" (which motivates people to behave aggressively, thus highlighting personal power) and the "life instinct" (which motivates people to seek out each other in loving unions). Angyal (1941) divided human motives into needs for autonomy and homonomy. Adler (1964) also distinguished between the aggression drive, which came to be understood as a general striving for superiority, and the striving for social interest. Erikson (1995) distinguished between autonomy and basic trust, and Sullivan (1953) discussed the need for power versus the need for interpersonal intimacy and tenderness.

McAdams draws on David Bakan's (1966) conceptualisations of power and love. Bakan employs the terms agency and communion to refer to themes of power and love respectively. Agency refers to the individual's efforts to expand, assert, perfect, and protect the self. It also refers to achieving independence, autonomy and self-definition through separating the self from others, and to striving to be masterful, powerful and competent within one's environment. Agency is depicted in personality traits such as dominance and extraversion, and also achievement motivation (Bakan, 1966; McAdams, 2000). Communion refers to the individual's attempts to unite with other individuals, in bonds of love, intimacy, friendship and community. It also involves embracing the human desire for involvement with others, for interdependence, nurturance, affection, comfort and sharing. Communion is captured in personality traits such as agreeableness and nurturance, and it is also reflected in intimacy and affiliation motivation (Bakan, 1966; McAdams, 1989, 2000). Communion evokes the image of surrendering to another person, a community, or an idea (McAdams, 1988b, 1989). The idea appears to be similar to concepts such as Maslow's (1968) experience of "Being-Love" (highlighting the welcoming of the other into a mutually enjoyed, reciprocal union), and Buber's (1971) "I-Thou" relation (emphasising dialogue between people).

Life stories can be analysed with respect to the degree to which thematic lines of agency and communion dominate the text. McAdams' research shows that people who have a strong need for power tend to compose life stories in which themes of agency

dominate, whereas those high in intimacy motivation emphasise themes of communion (McAdams, 1988b).

In more recent years, like McAdams, Hermans has also focused on narrative theories of personality and identity that construe people's life stories in terms of agency and communion (Hermans, 1987, 1988, 1992a; Hermans & Hermans-Jansen, 1995). Hermans suggests that two basic motives characterise life narratives. Adapting Bakan's (1966) concepts of agency and communion, Hermans distinguishes between agentic S-motives and communal O-motives. S-motives concern the striving for *self*-enhancement, *self*-maintenance, *self*-expansion, power and control, and O-motives involve the longing for contact, union and intimacy with *other* people and the surrounding environment (Hermans, 1987, 1988, 1992a; Hermans & Hermans-Jansen, 1995).

4.4.4 Adolescence and the Consolidation of an Ideological Setting for Identity

In adolescence, the narrative form, including settings, scenes and themes, begins to consolidate. During this time, the adolescent may also begin to consciously and unconsciously work through an ideological setting for the life story (McAdams, 1994, 2000). An ideological setting is the backdrop of beliefs and values that positions a story within a particular ethical and religious milieu. It is difficult to construct a meaningful life narrative before the setting of beliefs and values is firmly established. With the beginning of formal operational thinking, adolescents are able to think hypothetically; they turn their reflective powers upon themselves and search for answers to abstract philosophical, ethical and political questions such as "Why am I here?" "What is my purpose on earth?" (Inhelder & Piaget, 1968; McAdams, 1994, 2000). As they ponder these questions, they search for a value system, an ideology that can help to organise and guide their life story. For each individual, the ideology will incorporate some sort of balance between the two overarching themes of agency and communion (McAdams, 1988b).

Habermas and Bluck (2000) reviewed studies supporting Erikson's (1959) and McAdams' (1994, 2001) assertion that the development of the necessary cognitive tools for constructing a global coherence in a life story begins in early childhood and continues throughout late adolescence (Habermas & Bluck, 2000). The social motivational demands to construct a life story also begin during adolescence. The

studies show that temporal sequencing of past experiences begins to occur at about age eight and continues throughout mid-adolescence. This newly acquired ability is followed by the attainment of a cultural concept of biography by about age 10, which involves selecting and arranging life events into coherent life narratives. Many studies show that an integrated person-concept emerges in early adolescence that can be used to integrate different episodes, thereby giving adolescents an understanding of cause and effect, and coherence (Habermas & Bluck, 2000). Habermas and Bluck also summarise diverse evidence that a biographical interest develops in adolescence as the frequency of thinking about oneself and the use of diaries increases. Preliminary studies also suggest the development in mid to late adolescence of biographical conceptions of how individuals change due to life experiences while still remaining the same person. Also in mid- to late adolescence, individuals develop the ability to summarise and interpret complex text, and become aware of the necessity to interpret past events. This ability may continue to develop into adulthood. These cognitive tools are necessary for constructing a life story (Habermas & Bluck, 2000).

4.4.5 Reconstructuring the Past: Nuclear Episodes

While adolescents begin to formulate personalised beliefs and values, for the first time in the life cycle they are also likely to adopt an historical perspective of the self (McAdams, 1990, 1994, 2000). Young people seek to understand the meaning of what they were, in the context of what they are in the present and what they may become in the future. As a way of gaining perspective, they begin to sort through their memories, in order to highlight important turning points in their perceived autobiography. McAdams calls these highlighted points nuclear episodes (McAdams, 1988b). Nuclear episodes are the critical incidents or moments scattered throughout the life story which stand out and shape lives. People feel that these scenes belong uniquely to their own lives. McAdams (1988b) stated that nuclear episodes can be perceived as high, low, turning, ending and starting points in one's past. In these memories, it is not so much what actually happened, but what the memory of the key event symbolises in identity.

Erikson and Alder both maintained that human beings choose to remember the past in a particular way, a way that affirms a personal myth which one formulates about the meaning of life (McAdams, 1994, 2000). However, there is also an unconscious

element which draws people to certain events. Therefore, identity is a product of choice, but it is also selectively influenced by personality factors such as motives and attitudes (McAdams, 1982). Woike, Mcleod and Goggin (2003) have recently added to the empirical evidence, demonstrating that implicit motives, which are unconscious and not readily articulated, such as agency and communion, are linked to the accessibility of autobiographical memories associated with the implicit motive. Specifically, participants who wrote about an emotional experience with an achievement theme had significantly higher scores on implicit agency motivation. When an event occurs related to one's implicit motivation, it may trigger an emotional response that increases the possibility of encoding and subsequent accessibility. Thus, identity is created through conscious choice and unconscious influences.

McAdams believes there are two general types of nuclear episode: continuity and change (McAdams, 1994, 2000). Episodes of continuity are moments of truth that define who individuals are and what they stand for. They can be seen as stories from the past that either reveal an individual's true nature or help to explain how one came to be the person one is (McAdams also calls these episodes "origin myths"). For example, a woman who perceives herself as a loyal friend may remember incidents throughout her life in which she helped a friend. Therefore, a nuclear scene may present evidence for one's self-perception (McAdams, 1993). Nuclear episodes of change are turning points, critical moments in which life takes a new direction (Leonard & Burns, 1999; McAdams, 1990, 1994, 2000). For example, McAdams (1993) tells of many people describing vivid turning points in which they come to a new understanding of the self or experience a crucial change in their lives. Leonard and Burns (1999) explored turning points in the lives of midlife and older women based on McAdams' methodology. The authors commended McAdams' methodology for providing a valuable way to explore and understand how the women's lives were shaped, and for giving participants free range to choose experiences that counted for them. Research often focuses on researcher-chosen variables; however such variables may not necessarily be those that are subjectively important. For example, the authors mentioned extensive literature on the psychological effects of menopause, but the female participants scarcely referred to it. However, the death of a relative or close friend was the most commonly mentioned adverse turning point, but is largely ignored by the literature (Leonard & Burns, 1999).

McAdams' nuclear episodes are conceptually closely linked to a number of related concepts such as Tomkins' (1991) nuclear scenes, Brown and Kulik (1977) and Pillemer's (1998) personal event memory, and Singer and Salovey's (1993) self-defining memory. These concepts are discussed in detail in the following section.

4.4.5.1 Tomkins' Nuclear Script

One of the scripts which Tomkins has extensively discussed is the nuclear script (Tomkins, 1991). As previously described, a nuclear script develops out of a nuclear scene, which is a positive childhood scene that ultimately turns bad (Carlson & Carlson, 1984; Singer & Salovey, 1993; Tomkins, 1991). It is assumed that nuclear scenes also involve an unresolved wish or conflict, most often stemming from childhood and usually of a psychodynamic nature, such as the Oedipal conflict, dependency needs, or aggression. Although there may be a "quick fix" for the conflict, it is related to larger, recurrent themes that are unresolvable and continually arise throughout the individual's life. The recurrent nature of the conflict is a function of chance encounters and the individual's tendency, through magnification, to unconsciously recreate the conditions of previous nuclear scenes (Tomkins, 1991). For each individual, nuclear scenes and nuclear scripts develop as a result of the frequency of repetition of incidents that share one or more of these major life conflicts.

As the name suggests, nuclear episodes share conceptual overlaps with Tomkins' nuclear scenes. Even though Tomkins' nuclear scenes can be considered a subset of McAdams' nuclear episodes, the basic idea behind the two constructs is very similar: definitional past events describe who one is, and these events are continually linked to present experiences and shape interpretations of new events, placing them in the context of what has been (Singer & Salovey, 1993).

4.4.5.2 Autobiographical Memory

Over the past 15 years, cognitive psychologists have expressed growing interest in how people encode, store and retrieve information relating to memories of specific life events (McAdams, 2001). Much of this work falls under the conception of autobiographical memory. A prevailing theme in this literature is that autobiographical memory helps to locate and define the self within an ongoing life story. Brown and Kulik (1977) proposed that highly surprising and important events cause the automatic

encoding of personal circumstances. They labelled this phenomenon "flashbulb memory" and reported the results of a questionnaire study. They defined the memory as an especially vivid event in the life story, likening it to a photograph where the memory captures a concrete experience of what happened, and what the person was doing, feeling and thinking when the flash was activated (McAdams, 1993). As the encoding process is automatic, the memory trace frequently contains characteristic personal details that are unrelated to the significant event itself. The memories are then elaborated into narrative form through overt and covert rehearsal. Brown and Kulik's article prompted a number of follow-up studies (e.g., Bohannon, 1988; McCloskey, Wible, & Cohen, 1988; Pillemer, 1984; Pillemer, Koff, Rhinehart, & Rierdan, 1987; Rubin & Kozin, 1984; Winograd & Killinger, 1983) and commentaries (e.g., Cohen, McCloskey, & Wible, 1988; Neisser, 1982; Pillemer, 1990; Schmidt & Bohannon, 1988; Thompson & Cowan, 1986). One critic (Neisser, 1982) argued that the vivid memory is not analogous to a flashbulb picture but rather a benchmark: "They are places where we line up our own lives with the course of history itself and say, 'I was there' " (Neisser, 1982, p. 48). Investigations by memory researchers have revealed that remembering is predominantly vivid when the events have a high emotional impact or widespread consequences (Brown & Kulik, 1977; Usher & Neisser, 1993). Examples are memories of President Kennedy's assassination (Winograd & Killinger, 1983), memories of a space shuttle explosion (Bohannon, 1988), or memories of painful or embarrassing experiences such as childhood inoculations (Goodman, Rudy, Bottoms, & Aman, 1990).

Pillemer (2001) highlighted that in the various studies on flashbulb or vivid memories, in each instance the memories under study corresponded to the person's own personal circumstances when the news was received. For example, where they were, what they were doing, and how they felt, rather than to factual information about the event itself. He asserted that significant personal memories are structurally similar to conventional flashbulb memories of nationally important events. He believes that personal memories fit within broader conceptualisations of autobiographical memories.

According to Brewer (1986, 1988), autobiographical facts can be distinguished from personal memory. Autobiographical facts denote knowledge about an event that the person has participated, but they lack visual imagery of the event. Conversely, a personal memory possesses visual imagery of the experience and a belief that the

memory was personally experienced by the self (Brewer, 1986, 1988). Therefore, Pillemer (1992) asserted that personal memory of vivid events is more than just the result of receiving shocking news; it involves personal details about how the event was experienced by the rememberer (the flashbulb memory of the events). Recalling personal experiences is about mentally "reliving" the events, and relating them to others. It is precisely the reliving and the awareness of such events that distinguishes personal memories from learned autobiographical facts. Pillemer (1992) believed that a more general and inclusive term than flashbulb memory was needed, such as "memory of personal circumstances". He defined personal event memory as a memory which embodies a particular event that occurred at a certain time and place; it contains a detailed account of the person's own personal circumstances at the time and includes sensory imagery (visual, auditory, olfactory or tactile) (Pillemer, 1998).

There has been recent work extending Brown and Kulik's (1977) research to memorable incidents from people's own lives. For example, Rubin and Kozin (1984) found that memories of early romantic experiences possessed flashbulb-like qualities. Pillemer et al. (1987) examined female students' memories of menarche, and, consistent with memory theory, found that those who reported feeling less knowledgeable and therefore associating menarche with negative feelings provided more information about its onset. In a recent article, Pillemer discussed memories of momentous events. He believes that, when these memories are presented in autobiographies, such events are frequently described as important and even life-altering (Pillemer, 2001). Furthermore, he believes vivid memories can continue to impact upon a person's life long after the original occurrence of the event. Remembering specific episodes can influence feelings, behaviours and self-concept. People entering unchartered territory are especially attentive to their surroundings because they do not have general rules to guide their behaviour. These novel events carry important information about how things work in different environments, and they can be recalled often, thereby enhancing their place in memory (Pillemer, 2001). In other words, these memories can impart general life lessons by providing information which can guide subsequent behaviour (Pillemer, 1992, 1998).

There is also very little difference between McAdams' nuclear episodes and the constructs of flashbulb memory and personal event memory. A nuclear episode may be more flexible in its criteria, for example nuclear episodes are not necessarily

characterised by elements of surprise and emotional charge. However, all three memories are consequential to the rememberer and involve rehearsal because they are continually narrated both to the self and others as they are revisited throughout life.

Singer and Salovey (1993) presented a conceptual framework for personality as a way to organise autobiographical memories. Within this framework, Singer and Salovey label the memorable experience "self-defining memory", which they see as a memory that defines who a person is. The memory is vivid, affectively charged, repetitive, linked to other similar memories, and related to an important unresolved theme or enduring concern in the individual's life (Singer & Salovey, 1993). They argued that feelings that people continue to have about an experience after it has occurred is a function of how relevant it is to their long-term goals. Moffitt and Singer (1994) found that participants' memories were indeed self-defining, in that the majority of them were connected to at least one important striving in their lives. Their results also suggest that affective responses to memories are linked to personal strivings. Specifically, participants who recalled memories relevant to the realisation of their strivings rated their memories as positive. Also, participants who generated avoidance strivings recalled more memories related to the failure to achieve their strivings, and these memories tended to be less positive.

There is also very little conceptual difference between Singer and Salovey's (1993) self-defining memories and McAdams' nuclear episodes. Self-defining memories may be considered a broader category of remembered experience than nuclear episodes. Singer and Salovey have not yet classified all the different types of self-defining memories, so there may be categories other than those of continuity and change already identified in nuclear episodes.

4.4.5.3 Empirical Studies of Nuclear Episodes

McAdams (1993) states that nuclear episodes often reveal central thematic lines of agency and communion. Researchers have coded agency and communion in various ways. McAdams and colleagues (McAdams, 1982, 1984; McAdams & Powers, 1981; Woike, 1995) built on previous work to delineate and validate a standard set of thematic categories that captured the motivational essence of agency and communion as expressed in narratives of consequential autobiographical scenes.

McAdams performed research with student samples (McAdams, 1982, 1988b) and community adults (McAdams, Hoffman, Mansfield, & Day, 1996) which consistently demonstrated that nuclear episodes reflect dominant thematic lines in an individual's life. Participants typically created Thematic Apperception Test (TAT) stories that were scored for their intimacy and power motives. The TAT is a projective personality test that was designed in the 1930s by Morgan and Murray (Morgan, 1995). The original purpose of the TAT was to reveal the underlying dynamics of the participant's personality, such as motives of power and intimacy (Morgan, 1995). In McAdams' research, at a subsequent time, participants noted various memories of nuclear episodes such as peak and nadir (low point) experiences. Results showed that participants scoring high on TAT intimacy motivation tended to recall positive memories with strong themes of love, communication, and sharing embedded in them, and tended to list personal strivings concerning warm and close relationships. Alternatively, high power participants recalled memories that were more reflective of the desire for mastery, success, and autonomy, and listed personal strivings concerning success and feeling strong (McAdams, 1982, 1988b; McAdams et al., 1996). However, no relationship was found between motive scores and intimacy and power themes in recollections of unpleasant experiences. It was concluded that motives may not relate to memories of negative experiences in the same way as they relate to positive experiences (McAdams, 1982, 1988b). The research suggests a thematic coherence in personality across the areas of key autobiographical memories, social motives, and daily goals (McAdams et al., 1996).

Research involving American university students strongly supports that power and intimacy motives can readily predict certain kinds of behaviour and impressions formed by others (McAdams, 1980; McAdams & Powers, 1981). For example, students scoring high on TAT intimacy motivation were rated by friends and acquaintances as significantly more warm, loving, sincere, and appreciative, and significantly less dominant, outspoken and self-centred than students scoring low on the motive (McAdams, 1980; McAdams & Powers, 1981). In addition, participants who scored highly on TAT intimacy motivation produced psychodrama scenarios that were characterised by interpersonal interaction, which led to loving, liking, peacefulness, happiness, or tender behaviour for characters, reciprocal and noninstrumental

communication, and relinquishing of manipulative control when interacting with others (McAdams & Powers, 1981).

4.4.6 Young Adulthood and Characters in Narrative

From adolescence to young adulthood, the main task in identity formation becomes the creation and refinement of the main characters in the life story, which McAdams calls "imagoes" (McAdams, 1988b). All stories have characters, and in life stories the author of the story is not only the main character but can also play a number of roles. An imago is an idealised personification of the self that functions as a main character in the life story (McAdams, 1988b). A person's life story is likely to contain more then one imago; each imago represents the many aspects of the self, for example present, past, future, ideal and feared self (McAdams, 1990, 1994). McAdams (1993) emphasised four points regarding imagoes. First, imagoes are not people. Imagoes are archetypal patterns of human thought and behaviour that consist of idealised images in life stories. They exist as characters in life stories but not as real people in life. The author of the life story is not these imagoes. Instead, the author's identity is the *story* about his/her imagoes. Second, imagoes are not the whole story. There are many aspects of a story such as theme, setting, image, tone, and plot, and a character is only one aspect. Third, imagoes can be positive and negative. For example, some personified idealisations of the self contain good and desirable attributes, but some people also develop negative personifications. Finally, imagoes can be both common and unique. Like life stories, imagoes can come in a variety of forms (McAdams, 1993).

McAdams demonstrated that individuals who scored high in intimacy or power on the TAT tended to tell stories of their own lives that featured imagoes with corresponding levels of agency or communion (McAdams, 1988b, 1994). People with a considerable need to feel strong and to have impact (high power motivation) create self-defining life narratives with powerful and agentic central imagoes (e.g., a warrior, a traveller, a sage, a creator). People with a strong need to feel close to others (high intimacy motivation) construct life stories whose central characters are caregivers, lovers, and loyal friends (McAdams, 1994).

4.4.7 Endings and Midlife: The Generativity Script

The last component of the Life Story Model of Identity is the generativity script, which begins in adolescence and early adulthood with the barest outlines and becomes more detailed by middle adulthood (McAdams, 1988b). Psychological research suggests that throughout the middle years of adulthood there is a steady increase in concerns about death and ageing (McAdams, 1990, 1993). As a response to this increasing concern, McAdams proposes that individuals may create a generativity script. The term generativity, a concept borrowed from Erikson, refers to individuals' concerns with what the legacy of their life story will be: in the words of Erik Erikson, "I am what survives me" (Erikson, 1968, p. 141). Erikson proposes that once the adult has consolidated a sense of identity and created long-term intimate relationships, he or she is psychosocially ready to make a commitment to society, to its continuation, and perhaps improvement, through the next generation. The generative adult cares for, cultivates, teaches, leads and supports the next generation (Erikson, 1997). Generative adults have a strong belief and place hope and trust in the future of humankind, even in the face of human destructiveness (McAdams, 1990). Generativity seems to draw upon agency and communion. For example, a legacy high in communion may be loving offspring and grandchildren who have been raised to value family and mutual support. A legacy high in agency might be an artistic creation, a successful business, or a life lived with integrity and righteousness.

McAdams, Diamond, de St. Aubin, and Mansfield (1997) examined the life stories of highly generative adults (adults with a strong concern for and commitment to the next generation). There were two groups of participants: highly generative adults and less generative adults, all with similar demographic characteristics. The life stories of the two groups were compared to determine the manner in which they constructed their identities. The results revealed that highly generative adults were significantly more likely to tell their stories in ways that closely resembled the overall form of a commitment story. In the prototypical commitment story, the central character (a) enjoys an early family blessing or advantage, (b) is sensitive to the suffering of others at an early age, (c) is guided by clear and persuasive personal beliefs that remain relatively stable over time, (d) sets goals for the future to profit society, and (e) transforms or redeems bad scenes into good outcomes (which was labelled a redemption sequence). Highly generative adults appeared to be more optimistic and were significantly more

likely than less-generative adults to include redemption sequences in their life stories. Redemption sequences will be discussed in more detail in Section 4.4.9, Redemption and Contamination Sequences.

4.4.8 Narrative Complexity

McAdams proposes that two dimensions run through life stories that enable researchers to explore personality: thematic lines and narrative complexity. Thematic lines convey the content of the life story, which was discussed in Section 4.4.3, Late Childhood and the Organisation of Motivations. Narrative complexity reveals the structure of the life story. By arguing that thematic lines and narrative complexity are the two basic dimensions across the life story, McAdams gives meaning and structure a prominent role in the foundation of identity. The narrative structure refers to how individuals organise the various characters, plots, facts and themes of life stories. One dimension of structure is the degree to which the individual creates complexity. As life stories are about oneself, they reflect to a large extent the complexity of the person's identity. Complex stories involve many characteristics, plots, subplots, themes, and minor themes, and are more likely to contain ambiguity, contradictions, and unresolved tensions. Stories with simpler narratives proceed in a more straightforward manner, but they may be powerful and eloquent in their singularity of theme and purpose.

McAdams' (1988b) research showed that the individual's ego development influences the complexity of his or her narratives. McAdams (1988b) perceives the ego to be an integrative framework of meaning that provides a guide for identity. The ego establishes rules and guidelines for the construction of identity. McAdams uses Loevinger's paradigm of ego development (Kroger, 1989), and measures ego stage by Loevinger's Sentence Completion Test (SCT). The SCT correlates the answers of 34 open-ended sentences such as "Most men think that women..." or "Sometimes she wished that..." with seven stages of ego development (Loevinger, Wessler, & Redmore, 1970). Participants in low ego stages understand the self and the world in simple ways, whereas people in high ego stages manifest a more complex understanding. This difference is reflected in the narrative structure of their life story (McAdams, 1988b; McAdams, Ruetzel, & Foley, 1986).

4.4.9 Redemption and Contamination Sequences

McAdams and colleagues (McAdams et al., 1997) described two distinctive narrative forms or strategies that people use in constructing life stories: redemption and contamination sequences. The two strategies relate to how people tell their life story to make sense of personal experiences that involve major affective changes. In a redemption sequence, the narrator portrays a change from an emotionally negative life scene to one that is emotionally good. The bad scene is salvaged, recovered, offset or made better when taking into consideration the subsequent good (McAdams et al., 1997). In contrast, a contamination sequence involves the shift from an emotionally good life scene to an emotionally bad life scene. The good is ruined, spoiled or contaminated by what develops (McAdams et al., 1997).

McAdams' redemption and contamination sequences are similar to Tomkins' limitation-remediation and contamination scripts respectively. Limitation-remediation scripts link scenes in which negative affect turns into positive scenes (Tomkins, 1987). This type of script begins with a negative affect situation where the central character of the narrative must suffer in some way. Over time, the character tries to undo the suffering, improve the situation, and move forward to a positive affect state. In this type of story, the character may suffer a lot, but the hope for a good outcome motivates the character to persevere. In contrast, contamination scripts link together scenes in which positive affect turns into negative affect (Tomkins, 1987). The central character unsuccessfully aims to undo the damage and experience goodness.

Narrative researchers believe that constructing and narrating stories enables individuals to make meaning out of life transitions (McAdams, Josselson, & Lieblich, 2001). Such stories help individuals cope with life's trials, affect the perception of the future, and help to determine the nature of interpersonal relationships and one's place in the world. More specifically, McAdams perceives redemption and contamination sequences as narrative strategies for making sense of major life events (McAdams & Bowman, 2001).

Research on survivors of illness and trauma has suggested that people have fundamental assumptions about the world, such as believing they are worthy, that the world is a good place, and that life makes sense (Janoff-Bulman & Berg, 1998). In the aftermath of traumatic events, some victims discover that these assumptions are illusions; for example, the world is not always a good place and sometimes life events

do not make sense. It is important to note that not all trauma victims experience disillusionment; some may experience no change to their basic assumptions about the world. This process of disillusionment is extraordinarily painful; however survivors commonly confront the terror of a meaningless and seemingly malevolent world and move to create a meaningful life. Survivors do not perceive benefits in spite of their losses, but rather create value and meaning in their lives because of their losses. The co-existence of positive and negative elements creates a psychological climate for appreciation and meaning. Trauma forces victims' fundamental assumptions to change. Therefore, they do not return to the person they were before the trauma; rather, their views of self and the world allow for the possibility of misfortune. It is the very awareness that tragedy can in fact strike at any time that promotes a new realisation of value and appreciation in their lives, and survivors often feel that life cannot be taken for granted.

Tedeschi and Calhoun (1995) stated that good outcomes of traumatic events can manifest themselves as growth in one or more of three different areas: changes in self (increased independence and greater self-understanding), changes in relationships with others (benefits in interpersonal relationships such as enhanced self-disclosure and emotional expressiveness), and changes in life philosophy and spiritual-existential beliefs. Thus, sometimes, the experience of survivors has redemptive and instrumental worth (Janoff-Bulman, 1992; Janoff-Bulman & Berg, 1998; Tedeschi & Calhoun, 1995). Survivors' perceptions of benefits amid the adversity of illness or trauma appears to be a similar concept to McAdams' redemption sequences.

Research has also emphasised that positively reinterpreting negative events leads to better psychosocial adjustment (Taylor, Wood, & Lichtman, 1983; Tennen, Affleck, & Mandola, 1991; Thompson, 1991). Given that perceived benefits may lead to better psychosocial outcomes, McAdams and colleagues (Grossbaum & Bates, 2002; McAdams, Reynolds, Lewis, Patten, & Bowman, 2001) have explored this link. Research has recently revealed that people who construct life stories where bad events are redeemed by good outcomes tend to be more satisfied with their lives, report high self-esteem and life coherence, and show lower levels of depression compared with people with fewer redemption sequences (McAdams, Reynolds et al., 2001). By contrast, contamination sequences were highly and negatively associated with the three indices of well being and positively associated with depression (McAdams, Reynolds et

al., 2001). Contamination and redemption themes were also found to be predictors of psychological well being variables such as environmental mastery and personal growth, and the redemption theme was a predictor of self-acceptance and positive relationship with others (Grossbaum & Bates, 2002).

4.5 Applying a Narrative Approach: Analysing Hospital Experiences

The present section highlights the components of McAdams' model which are most relevant to the present study. The present research focused on participants' accounts of their hospital experience to discern issues facing female hospital inpatients. McAdams' procedure allows life events such as hospital experiences to be placed in the context of the entire life story. In this way, participants were able to discuss their hospital experiences in the context of who they were prior to the experience and who they became, which allowed an exploration of the changes to self and to attitudes towards the health care system.

McAdams' four first order constructs of narrative development include ideological settings or values, imagoes or character development, nuclear episodes, and generativity scripts. The concept of nuclear episodes, and the like, have been most extensively discussed. The present research focused on nuclear episodes within women's hospital experiences, and adopted McAdams' conceptualisation of nuclear episodes in preference to other related constructs. McAdams perceives nuclear episodes to be significant, influential or mundane life events, but, importantly, people must draw upon these life events to help explain who they are and who they will become (McAdams, 1988b). He does not set rigid criteria that need to be met to ensure a memory can be defined as a "nuclear episode". For example, nuclear episodes are not necessarily characterised as involving unresolved wishes or conflicts, or elements of surprise or emotional charge. Therefore, for the purposes of this research, McAdams provided an applicable definition of nuclear episodes, because his conceptualisation was both flexible and open to interpretation within the context of this research.

McAdams places importance on the "content" of the nuclear episode, rather than on unresolved conflicts or long-term goals. As the focus of the present research was primarily on the role of power/agency in scenes highlighted by women within their hospital stays, the importance that McAdams places on the content of life stories, namely themes of agency and communion, was particularly useful.

McAdams (1992a) developed a coding system to organise the content of nuclear episodes, and he has begun to validate this system. The present study utilised McAdams' coding system of communion and agency to identify the main issues facing female inpatients. In particular, his coding scheme provided a structured method of exploring agency themes to ascertain if agency and power were important concepts in women's hospital experiences.

McAdams stated that people use redemption and contamination strategies in constructing life stories and making sense of personal experiences that involve major life transitions. This was particularly useful, as one aspect of this study was to explore how women understood a change in identity after a life-altering hospital experience. The examination of redemption and contamination sequences within women's stories provided a useful and structured way of achieving this objective.

4.6 Summary of the Chapter

A life narrative approach is based on the belief that a sense of self is created through stories. Much research has been carried out using the narrative approach to understand personal experiences of a range of health problems and life disruptions. One such disruption, which has received little attention, is a life-changing hospital experience. The experience of hospitalisation can threaten life narratives and disrupt the life path, and thus impact the life story.

McAdams' Life Story Model of Identity was the theoretical framework of choice for the present study. McAdams believes that the life story *is* identity, and creating identity is an ongoing process. Although gathering material for the life story begins in infancy and early childhood, McAdams states that identity issues arise in adolescence. In adolescence, the story begins to come together and a setting of beliefs and values (ideological setting) is formed. Adolescents are also likely to begin organising past experiences, and highlighting events (nuclear episodes) that are considered most important for self-definition. In young adulthood, the main task in identity formation is the refinement of imagoes or main characters in the life story. The last component of the model is the generativity script, which becomes important in middle to late adulthood. The generativity script refers to legacy and to what people hope to leave behind when they die, such as children or a successful business. McAdams proposes that life stories can be analysed by content (thematic lines) and by

structure (narrative complexity). In addition, McAdams argues that people create life stories involving redemption and contamination sequences, which are used to make sense of major life transitions.

Applying McAdams' model to the present study allowed the examination of what women perceived as important issues to hospital inpatients. In addition, analysing the content of women's stories, and in particular exploring agentic thematic lines, allowed the exploration of the role of power in women's narratives. Coding redemption and contamination sequences addressed the general aim of how women made sense of their life-changing hospital experience, by specifically examining changes to self and the level of contentment with the health care system. McAdams' coding system allowed a structured examination of these issues.

The next chapter describes the methodology of the main study. It provides a description of the research aims, the sample characteristics, the procedure, and an examination of the manner in which McAdams' methodology was used to analyse women's experiences to primarily identify the issues they faced as hospital inpatients.

CHAPTER FIVE

MAIN STUDY: METHODOLOGY

5.1 Overview of the Chapter

The majority of the psychological literature indicates that most people value control over their lives (Gatchel, 1980; Shapiro & Austin, 1998; Syme, 1989; Thompson & Spacapan, 1991), and illness is one situation where the sense of control can be disrupted. Studies also show that the role of control appears particularly salient in women's hospital experiences. The pilot study revealed that the majority of the women expressed feeling in control of their hospital stay, but between 15% and 40% reported feelings of powerlessness associated with the manner in which they were personally treated by the medical staff. Higher levels of powerlessness tended to be associated with serious illnesses, lengthy stays and experiences assessed as significant, which suggested that such hospital experiences have the potential to affect the sense of self. The comprehensiveness of the qualitative data suggested that qualitative methodology would be a useful way to continue study in this area. The main study was a predominately qualitative study and was conducted to provide a more in-depth investigation of this area. McAdams' theoretical and methodological approaches were a suitable way to further explore the role of agency, power and control in women's hospital experiences, and the life-changing aspect of the event.

One assumption underlying McAdams' Life Story Model of Identity (1988b) is that beginning in late adolescence and young adulthood, men and women living in modern societies seek to construct integrative narratives of the self to provide their life with a sense of unity and purpose. In the main study, participants were required to tell the story of their life-changing hospital experiences, in order to understand how they redefined the meaning of their existence, sought new sources of purpose, and reassessed their priorities. McAdams' methodology, particularly with respect to themes of agency and communion and the role of redemption and contamination sequences within the hospital "episode" of the life story, provided the means to examine the ways in which women had come to encapsulate their hospital experience. This chapter outlines the research aims for the main study, participant details, the interview schedule and questionnaire, and the manner in which McAdams' methodology was used to analyse participants' interview transcripts.

5.1.1 Research Aims

The main study had six aims. The first aim was to reassess the power themes (disrespect/insensitivity, diminished patient rights, lack of acknowledgement and not listened to) generated by the qualitative data in the pilot study. These themes highlighted the non-medical aspects of hospitalisation, namely behaviours on the part of health professionals which can influence women's perceptions of personal power. The purpose of this analysis was to reassess the importance of personal treatment with a larger sample of women.

The following four aims were associated with McAdams' framework. The main study utilised the narrative approach to explore the stories women told about a life-changing hospital experience and to identify the main issues they were facing. McAdams' (1988b) methodology enabled the exploration of the role of hospital experiences in women's life stories. Although narrative psychology has been used to explore life narratives of people with an illness or suffering a traumatic event, such as women coping with infertility (Kirkman, 1999) or parents discovering that their child has Down syndrome (King et al., 2000), no previous studies have specifically used McAdams' methodology as a way of exploring the impact of a hospital experience. McAdams (1993) asserts that life stories reflect personality variables such as social motives of power and communion. He has established a coding scheme to analyse the content of life stories with respect to themes of agency and communion. A second aim therefore was to explore themes of power and communion within women's narratives of their hospital stays using the coding scheme. McAdams' coding scheme provided a structured method of exploring agency themes to ascertain the importance of this concept in women's hospital experiences.

A third aim was to explore whether memories of hospitalisation would emphasise agency (power and control) over communion (relationships with others). As hospital is generally considered a place where the patient has little control, participants' memories of their hospital stay might emphasise themes of agency over the expression of communion. In order to explore this objective, the interviewer asked women to describe nuclear episodes which occurred during the hospital experience as well as prior to the hospital experience. The number of agency and communion themes in memories recalled before and during hospital were compared. It was assumed that if there were

more agency themes in stories told about hospital experiences in comparison to stories told about life events prior to the experience, the hospital situation might emphasise themes of power and control.

A fourth aim of this study was to explore the relationship between McAdams' and Hermans' codings of agency and communion. No research has compared the coding schemes, and as they show strong similarities and some differences, the present research attempted to assess the degree of agreement between the two schemes, and to explore how information gained from Hermans' scheme could add to understandings of women's narratives. A high degree of agreement was expected.

A fifth aim of this study was to explore how women made sense of their hospital experience and found meaning in the experience in order to unify it with their life story. McAdams argues that people use redemption and contamination sequences to make sense of major life changes. This aim was achieved by examining McAdams' redemption and contamination sequences within women's stories about their hospital experience. Specifically, the outcomes of women's hospital experiences (negative or positive) were examined in terms of the impact the experiences had on participants' sense of self and their attitudes towards the health care system.

The main study also involved an examination of women's perception of good and poor service quality provided by health professionals during the hospital stay. Thus the sixth aim was to understand how women want to be treated by health professionals.

5.2 Method

The main study was a qualitative study, utilising a methodology based on McAdams' Life Story Model of Identity. A small sample of women who perceived that they had had life-changing hospital experiences was invited to participate in a semi-structured in-depth interview. During the interview, the women discussed peak experiences and low points both prior to and during their hospital experience. The focus of the interview was on participants' hospital stays, including interactions with medical staff, perceptions of good and poor service, and the outcome of their experiences. The interview transcripts were coded according to McAdams' themes of agency and communion. The information gained from the interviews was used to further explore the role of power and control in women's hospital stays, the impact of hospital experiences in terms of sense of self and attitude towards the health care

system, and the ways in which women want to be treated by health professionals. Following the interview, the participants were given a questionnaire, which was based on Hermans' Self-Confrontation Method, and in which they rated their peak experiences and low points in terms of a list of affects. The information gained from the questionnaire was used to explore the relationship between McAdams' and Hermans' codings of agency and communion. Data collection did not continue once content "saturation" was reached. That is, data collection finished once the transcripts were read and coded and the content became repetitive and no new insights were likely to be obtained (McLennan & Miller, 2000).

The following section explores the recruitment specifications and procedure, sample characteristics, the interview schedule and procedure, and the content of the questionnaire. This chapter also describes the manner in which the interview transcripts were coded and the inter-scorer reliability for McAdams' themes.

5.2.1 Participants

5.2.1.1 Recruitment Specifications

The specifications for this sample were somewhat different to the pilot study. Participants were recruited on the basis that they were: (a) women between 20 to 75 years of age, (b) had a hospital experience after the age of 16 years, (c) perceived the hospital stay as significant in terms of how they have developed as a person, and (d) were in good health at the time of the study. The hospital stay was (e) of three nights or more, (f) occurred at least one year prior to the interview, and (g) was due to a physical illness such as an accident or major surgery. Volunteers who had a hospital stay due to childbirth, a chronic illness, or a mental illness (such as drug overdose, psychiatric reasons, or attempted suicide) were excluded.

5.2.1.2 Justifications for the Section Criteria

This study included women only because, as mentioned previously, women are considered to be one of the largest groups of consumers of the health care system, and men seem to dominate the system as high status providers. Therefore, it is likely that women hold strong views about the health professionals with whom they come into contact, and thus may experience a hospital stay more intensely. The participants were required to be adults who could clearly discuss their hospital experience thus the age

range of 20 to 75 years was chosen. This criterion was introduced to assist in recruiting mature women, and in avoiding the recruitment of participants with memory loss, which may be characteristic of old age.

Participants were recruited on the basis that they had a hospital stay of at least three nights. This was to ensure that there were sufficient experiences to discuss in the interview, and that the hospital experience was perceived as significant in terms of the impact it had on their lives. The results of the pilot study showed that participants who had longer hospital stays tended to perceive the experience as more significant.

The hospital experience had to have occurred a year or more prior to the interview. Temporal distance from the experience ensured that participants had been able to form emotional and psychological distance from the event. It was also hoped that participants would more readily construct and articulate personal narratives and organise information about themselves and their experience. Similarly, participants who were in good health at the time of the study (rather than in recovery or chronically ill) were recruited. Ideally, the hospital experience should have been a conclusive event (with closure), and there was temporal, emotional and psychological distance from the event so that it could begin to be integrated into identity. McAdams (1993) and Calhoun and Tedeschi (1998) comment that the reshaping of identity might not be completely experienced until a person has been able to construct personal narratives and organise information about themselves and changes to their life narrative. After the reshaping of identity, a person has the ability to describe their life narrative to others. Temporal distance from a situation may promote this condition.

Participants were recruited on the basis that their hospital stay involved a physical illness rather than a mental illness because individuals were required to think and discuss their hospital experience clearly and in great detail. This criterion was applied in order to avoid the recruitment of participants with cognitive distortions and memory loss, which may be characteristic of some mental illnesses.

Using McAdams' (1988b) framework, participants were sought who perceived their hospital experience as a significant life event. McAdams' (1992a) coding system has been found to be suitable for the analysis of accounts of discrete life-history episodes that are considered by the participant to be meaningful with respect to their sense of development as a person.

Women who had been in hospital due to childbirth were excluded from the study as childbirth per se has distinct issues of control and power (see Lupton, 1994; Martin, 1992), and the experience is also considered a significant event in itself. Therefore, women may find it difficult to separate the experience of the control issues within childbirth from the experience of control issues within the hospital stay. The role of control and power within childbirth may be considered a study in itself.

5.2.1.3 Recruitment Procedure

Articles in university magazines, radio interviews, advertisements in psychology lectures, pamphlets distributed at psychology conferences, and word of mouth among friends and colleagues were used to publicise the research and recruit participants.

Interested participants contacted the researcher and phone interviews took place to ascertain if they met the selection requirements. An interview was then arranged at a convenient time and place. Participants were asked for their address so that the researcher could send an information pack in preparation for the interview. The packs contained the consent form, information sheet, and a comprehensive booklet preparing the participant for the interview. The objective of the booklet was to enable participants to understand the framework of the interview and to become familiar with McAdams' concepts such as life story, peak experiences and low points. As the booklet contained all the interview questions, the objective was to invite the participants to think about their answers so that they were prepared for the interview, and to encourage a smooth interview process (the booklet is included as Appendix G).

5.2.1.4 Sample Characteristics

Initially, the sample comprised 22 women; however three women were not included in the final data analysis. Of those three women, one had completed the interview and questionnaire, but withdrew from the study following the interview. Another woman also completed the interview and questionnaire, but as the taped interview was inaudible it was not included in the study. The third woman became ill at the time of the interview, and wished to withdraw. The final sample comprised 19 women. Two women did not return their questionnaire; therefore their demographic data were not included in this section. The age range of the remaining 17 women was 23 to 74 years (*Mean* = 42.42 years, *SD* = 14.45 years). The majority of the sample was

tertiary educated (88.3%). The women's occupations varied considerably: three worked in the psychology/counselling field, three were nurses, two worked in education, another two were students, and the remaining participants each had a different occupation ranging from journalist, medical laboratory technician to unemployed. The majority of the participants were of an Australian background (64.7%), with two women (11.8%) of an Italian-Australian background, one French-Australian woman, one Indian-Australian, one American-Croatian-Australian, and one woman of a Persian-Australian background. Few women stated their religious affiliation, and of the participants who answered the question, the majority stated they were Catholic (29.4%).

Most of the participants had been inpatients in public hospitals (64.7%) within Australia (88.2%), with only two women describing a hospital experience outside Australia. The length of the participants' hospital stays ranged from three to 90 nights, with a modal stay of four nights. The hospital stays occurred when they were aged 19 to 64 years. The majority of the women (56.3%) were regarded as having serious and life threatening illnesses such as various types of cancer, or a brain haemorrhage. The remaining participants were considered to have a serious but not life threatening condition (defined as quality of life being adversely affected but little chance of death; for example, knee surgery where there was the possibility of not having full use of the leg, or hysterectomy where there were ongoing health complications). Ratings of the personal significance of the hospital stay ranged from 1 (not at all significant) to 10 (extremely significant). The mode was 10, with five women rating their experience as extremely significant. Perceived seriousness of the condition for which the women were admitted to hospital ranged from 1 (minor) to 7 (life threatening), with the rating distribution being bi-modal. Five women reported a rating of five showing moderate seriousness, and another five women reported a rating of seven, indicating they perceived their condition to be life threatening.

5.3 Materials and Procedure
5.3.1 Interview

McAdams' (1995a) life story interview is a semi-structured procedure in which an interviewer asks the participant a series of questions designed to elicit the main features of their self-defining life story. First, the participant is invited to imagine his/her life as a book, and each of its major parts comprising a chapter of the book. The

participant is asked to provide names for each of the chapters and to briefly describe the content. He/she is then asked to describe certain critical events in detail, such as peak or high points, nadir or low points, turning points, earliest memory and so forth. Looking back over the life story the participant is asked to describe great challenges which he/she has faced, and positive and negative influences on the life story. Considering the future, he/she is asked to describe different futures, such as positive and negative futures. The interview also involves a set of questions designed to elicit information about values and beliefs. Finally, the participant is asked to describe the central theme or idea that runs through their story.

To adapt the life story interview to the present study, an interview was designed to elicit the main features of a portion of a person's self-defining life story: the hospital experience. The interview required 60 to 90 minutes to complete (the interview schedule is attached as Appendix H).

Prior to beginning the interview, participants were reminded that the questions could give rise to strong emotions and reawaken painful or unresolved issues, and that it was natural that some emotion would be experienced. They were also reminded that the interview would be taped, but they were free to withdraw participation at any time, and of their right to confidentiality and anonymity.

The interviewer began by asking the participant to put the hospital experience into context by briefly describing the reason for hospitalisation, the time frame, and the length of the stay. The interviewer asked the participant to think about her life as if it were a book and to divide the book into chapters. The participant was invited to concentrate on the part of her life story when she was in hospital, and was asked to describe that chapter, and the chapters prior and subsequent to the hospital stay. Following the life chapters, the participant was asked to focus on her life before the hospital experience and to describe in detail two specific scenes or nuclear episodes which occurred at that time.

The nuclear episodes consisted of a peak experience (high point) and nadir experience (low point). For each scene, the participant was asked to describe in detail what happened, how the event began, when it occurred, the people involved, what the participant was feeling and thinking during the event, the time frame of the scene, and how the memory ended. The participant was then asked to focus on her hospital

experience and to discuss two to four nuclear episodes which occurred during this time. The participant was again asked to describe each scene in detail.

To adapt the interview for the present study, topics of discussion also included the impact of the hospital experience and how it affected the sense of self, and its impact on future relationships with the health care system. Discussion also focused on experiences and/or interactions with hospital staff which were perceived as helpful or not helpful, and how the negative experiences could have been improved to facilitate a positive outcome. At this point the participants were given a warning that the interview was drawing to a close, as one might do in a counseling session, to assist the participant to emerge from the memories of the hospital experience. The interview concluded by inviting the participant to discuss their ideas regarding the underlying message or theme of their hospital experience, and if it had continued to affect them.

After the formal questions, the researcher asked each participant if she wanted to share important aspects of the experience that had not been discussed. As the interview may have evoked feelings of vulnerability, it was hoped that this aspect of the interview would help create a nurturing and caring environment for the participant, and to provide her with a sense of being heard so that her vulnerability was not sustained.

At the end of the taping of the interview, the researcher gave each participant a brief acknowledgment of and/or feedback on her story to provide a sense of being heard and/or empowerment. The participant was again assured of confidentiality. When the interview was finished, each participant was invited to debrief with the researcher. Debriefing involved discussing the participants' feelings, asking what she was doing after the interview, and discussing the possibility of doing something enjoyable, preferably in the company of close friends or family in case of subsequent distress. The participants were also provided with referral information in case they felt distressed after the interview.

After the interview, participants were asked to complete the questionnaire. They were given a choice of completing the questionnaire in the presence of the researcher or at their own convenience. Those who decided to take the questionnaire away were provided with a reply paid envelope and asked to post the completed questionnaire. Women were also asked if they wanted to read their transcripts, as this seemed an appropriate way to strengthen the validity of the data and to ensure that the participants were comfortable with their stories. Interviews were transcribed. Conversation that

was not relevant to the experience of the hospital stay, including hesitations, false starts, some repetitive fillers, obvious grammatical slips and any identifying information, were all omitted from the transcripts. Eleven women were sent two copies of the transcript (one to keep and one to return) along with a reply paid envelope. They were asked to correct any errors, particularly of meaning and emphasis. Of the 11 women who read their interview transcripts, two returned their transcripts making minor corrections, and the remaining nine women approved them without alterations. Of the remaining participants, one woman said she did not want to read her transcript, another stated that she would think about it but did not maintain contact with the researcher, and the remaining six women did not reply to the researcher's email, letter or phone call.

5.3.2 Questionnaire

After the interview each participant was provided with a questionnaire which consisted of a demographic section and Hermans' list of affects (the questionnaire, information sheet, consent form and referral information are all included as Appendix I). The list of affects is used as part of Hermans' Self-Confrontation Method, based on his Valuation Theory. It is an idiographic method of self-investigation which was designed to explore the relationship between valuations and specific types of affect (Hermans & Hermans-Jansen, 1995). Hermans has developed several varieties of computations from participants' ratings of affects, which are designed to elicit information about agency and communion motives. The reason Hermans' list of affects was used in this study was to explore the relationship between McAdams' and Hermans' coding schemes. As the schemes both measure the motivational themes of agency and communion, the aim was to compare the degree of agreement between the two schemes. Additionally, considering that there are some differences between the schemes, the aim was to explore how information gained from Hermans' scheme could add to understandings of women's narratives. The differences are discussed in Chapter Six.

Hermans' method contains three parts: (a) the construction of valuations in an interview, (b) the connection of each valuation with a standard set of affect-denoting terms for studying the affective meaning of the valuations, and (c) discussion with the person about the results. Hermans (1987) specifies that it is not necessary to adhere rigidly to the three-step procedure, as the method is not devised as a standardised test.

Hermans also states that his intention is to present the Self-Confrontation Method as an invitation to invent alternative versions in light of theoretical considerations. Hermans' Valuation Theory was discussed in Chapter Four.

For the purposes of the present study, participants were asked to rate their peak and nadir experiences, which they had described in the interview, against a set of affects based on Hermans' investigations. Table 3 shows the list of affects that were presented to the participants in the questionnaire. The researcher reminded the participants of their peak and nadir experiences by summarising them in the space provided on the questionnaire. Concentrating on a single nuclear episode, participants were asked to indicate on a 5-point scale (0 = not at all, 1 = a little bit, 2 = to some extent, 3 = rather much, 4 = much, and 5 = very much), to what extent they experienced each affect in connection with the particular nuclear episode. All nuclear episodes were described with the same list of affect terms.

In the Self-Confrontation Method, there is a variety of computations from which information about the affective organisation of the valuation is obtained (Hermans & Hermans-Jansen, 1995). The affect terms and indices relevant to the present study are summarised here. Index S is the sum score of four affect terms that express self-enhancement (that is, self-maintenance and self-expression), that is, items 3, 7, 17 and 26 in Table 3. Index O is the sum score of four affect terms that express contact and union with the other, that is, items 10, 11, 14 and 22. For each valuation, the S:O ratio can be determined. When the experience of self-enhancement is stronger than the experience of contact with other, the value of index S is significantly greater than the value of index O (S>O). A 4-point difference between the values of indices S and O is considered to be significant. When contact with the other prevails, the value of index O is significantly greater than the value of index S (O>S). A difference less than 4-points is not significant, and therefore when this occurs both are considered to exist to the same extent (S=O).

Index P is the sum score of four general positive (pleasant) affects, that is, items 1, 5, 9 and 20. Index N is the sum of four general negative (unpleasant) affects, that is, items 6, 13, 25 and 28. For each valuation, the P:N ratio can be studied. This ratio indicates the well being that the person experiences in relation to this valuation. Well being is positive when the value of index P is significantly greater than the value of index N (P>N), negative when index N is significantly greater than index P (N>P), and

ambivalent when the values of indices N and P are not significantly different (P=N). A 4-point difference between the values of indices P and N is considered to be significant. The scores for each of the four indices, S, O, P and N, can range from 0 to 20.

Table 3

Affect Terms used in the Self-Confrontation Method

1. Joy	11. Love	21. Inferiority
2. Powerlessness	12. Self-alienation	22. Intimacy
3. Self-esteem	13. Unhappiness	23. Security
4. Anxiety	14. Tenderness	24. Anger
5. Happiness	15. Guilt	25. Despondency
6. Worry	16. Solidarity	26. Pride
7. Strength	17. Self-confidence	27. Energy
8. Stress	18. Loneliness	28. Disappointment
9. Enjoyment	19. Inner warmth	29. Inner calm
10. Caring	20. Trust	30. Freedom

Hermans explains that the four indices can be combined in several ways to create different types of valuations (Hermans & Hermans-Jansen, 1995). These valuations include positive self-enhancement (+S), negative self-enhancement (–S), positive contact with others (+O), negative contact with others (–O), positive combination of high self-enhancement and high contact with others (+HH), and negative combination of low self-enhancement and low contact with others (–LL). Each valuation type will be discussed in turn. Table 4 presents a summary of the different types of valuations and how they were considered to match with McAdams' agency and communion themes.

The +S valuation represents a high degree of autonomy and productive coping with the environment (Hermans & Hermans-Jansen, 1995). This type of valuation is associated more with self-enhancement affect than with affect indicating contact and union with another (S>O). Simultaneously, this valuation is associated more with positive than with negative affect (P>N). There are many manifestations of this valuation: some are simple, such as "I hope to get a better job through my tertiary studies". Occasionally, people find a more complicated means to self-enhancement, such as "While on holidays with my partner, I took over the responsibilities because I

knew the language" (Hermans & Hermans-Jansen, 1995). Hermans notes that while these two valuations are different, the commonality is that the individuals perceive themselves as having the ability to influence the situation, produce positive outcomes, and enjoy a certain degree of self-esteem under the circumstances. However, experiencing self-enhancement is not simply about feeling good due to one's own efforts; it also relates to the idea that self-perception varies according to the way someone thinks others perceive them (Hermans & Hermans-Jansen, 1995). Therefore, even when people expect they are capable of something, they are still relatively dependent on how they perceive others to respond to their accomplishments.

Table 4

Hermans' Valuations and Predicted Matches with McAdams' Themes

Valuation type	Description	Predicted match with McAdams' themes
+S	S>O and P>N	agency>communion in peak experiences
–S	S>O and N>P	agency>communion in nadir experiences
+O	O>S and P>N	communion>agency in peak experiences
–O	O>S and N>P	communion>agency in nadir experiences
–LL	low levels of S and O and N>P	communion and/or agency in nadir experiences
+LL	low levels of S and O and N>P	communion and/or agency in peak experiences
+HH	high degree of S and O and P>N	communion and/or agency in peak experiences

Hermans states that experiences of self-enhancement may differ in the extent to which they become internalised. For example, a high degree of internalisation signifies an inner strength that enables a person to have a strong belief in their own capacities and to be less dependent on the opinion of others. In contrast, people with a low degree of internalisation are greatly dependent on feedback from others and need constant positive feedback, as any form of negative feedback is threatening to their self-esteem (Hermans

& Hermans-Jansen, 1995). In terms of comparing McAdams' themes and Hermans' valuations, peak experiences, which showed more of McAdams' themes of agency than of communion, and were given a +S, were considered a match. The reverse was considered a mismatch; that is, peak or low experiences, which showed more of McAdams' themes of communion than of agency, and were rated as +S.

Valuations of the –S type have more self-enhancement affect than affect related to contact and union with the other (S>O); concurrently, they are more negative than positive (N>P) (Hermans & Hermans-Jansen, 1995). In this situation, the S affect (such as self-esteem and strength) emerges in a negative context. For example, a person who is infuriated may feel great strength and clench his/her fists, but simultaneously there are negative feelings of anger, disappointment and perhaps even powerlessness. Primarily, this affective pattern indicates some kind of opposition in which individuals feel opposed to somebody or something that is threatening their self-esteem (Hermans & Hermans-Jansen, 1995). An example of a –S valuation is "I don't want my parents to interfere with my affairs" (Hermans & Hermans-Jansen, 1995). A –S valuation can also indicate an over reliance on the opinion of others to such an extent that a high degree of self-enhancement can become extremely negative, indicating anxiety and worrying about the expectations of others (Hermans & Hermans-Jansen, 1995), for example, "I have to get a good grade so I don't disappoint my family" (Hermans & Hermans-Jansen, 1995). Hermans has also found that the expression of anger and aggression is usually found in –S valuations. He suggests that anger and feeling aggressive can be understood as expressions (sometimes unconscious) of the attempt to restore a threatened self-enhancement (Hermans & Hermans-Jansen, 1995). Hate sometimes accompanies anger and aggression, and similarly represents a defensive form of self-maintenance. As hate is generally perceived as a culturally unacceptable emotion, even though it may be rated as high, it may not appear in a person's written or verbal account of a valuation. Such a discrepancy can be found in any type of valuation, but it frequently occurs in –S valuations. Hermans and Hermans-Jansen (1995) state that it is not uncommon to find a discrepancy between the text and affective pattern, for example, a particular affect pattern is not in agreement with the formulation of a valuation. In terms of comparing McAdams' themes and Hermans' valuations, it was considered that low points, which showed more of McAdams' agency than communion themes, and were rated as –S, were a match.

Valuations of the +O type have more affect indicating contact and union with another than affect referring to self-enhancement (O>S), and more positive than negative affect (P>N) (Hermans & Hermans-Jansen, 1995). These valuations generally show that there is increased contact and union with somebody or something else (a person, group, animal, object or the world in general). Therefore, there may be less focus on the self and individual performance and more on another being or object. Hermans and Hermans-Jansen (1995) maintain that +O valuations can reveal themselves in aesthetic experiences, such as enjoying an evening at the opera, intense contact with the environment, such as enjoying the experience of camping, or the experience of comfort and consolation. Often, valuations relating to religious or spiritual experiences or to a particular philosophical view of the world are related to the positive fulfilment of the need for contact and union with the other. Hermans and Hermans-Jansen (1995) note that the +O valuation has an element of receptivity, as a certain degree of openness is required to gain contact and union with another. It can also be interpreted as the acceptance of situations that are beyond one's control, or as the experience of being accepted by and accepting another person; for example, "I can better accept my daughter's disability and therefore I can accept her for who she is" (Hermans & Hermans-Jansen, 1995). Sexual experiences, especially those with a receptive nature, also belong to the +O category. A peak experience that showed more of McAdams' communion than agency themes and was given a +O would be considered a match.

Valuations of the –O type can be described as having a greater degree of affect indicating the need for contact and union with the other than of affect showing self-enhancement (O>S). There is also a greater degree of negative than of positive affect (N>P) (Hermans & Hermans-Jansen, 1995). These valuations have two components: a loving orientation towards another person or object and a hindrance or boundary that makes this person or object unattainable. Depending on the individual's life story, –O can be manifested in a variety of ways, such as an impossible or forbidden love affair, the death of a loved one, an anticipated farewell or a feeling of intimacy for another but the inability to express it. Hermans argues that this structure is the latent base of a variety of valuations, which means that subjects unconsciously reveal this affective pattern (Hermans & Hermans-Jansen, 1995). Therefore, it is somewhat common for this type of valuation to produce a discrepancy between text and affect, with the text not

reflecting the same affective pattern scored by the participant. A match occurred when a low point showed a higher degree of McAdams' communion than agency themes, and a rating of –O.

The valuation –LL has a high degree of negative affect and low levels of affect referring to self-enhancement and contact and union (Hermans & Hermans-Jansen, 1995). Hermans stated that this category relates to a situation where both motives are simultaneously unfulfilled, which he labelled powerlessness and isolation. Typical examples include "I was raped and felt humiliated and sad" and "I have often felt victimised, which has made me fearful of my environment" (Hermans & Hermans-Jansen, 1995). The usual affect associated with –LL is anxiety, and a typical feature of intense anxiety is the experience of being victimised, a reduced feeling of strength to take control of the situation as though there is no way out, and a feeling that the experience is not being shared with another (Hermans & Hermans-Jansen, 1995). The –LL valuation can emphasise –S or –O. In the –S type, people feel anxious about their own aggressive impulses. They may be afraid of losing control and doing harm, or they may fear the negative consequences of their actions to restore their self-enhancement (Hermans & Hermans-Jansen, 1995). In contrast, in the –O type, the person may feel anxious over the actual or anticipated loss of or separation from another. It can also involve the threat of becoming too close to or overly dependent on another person. This situation may involve feeling powerless and of losing one's autonomy (Hermans & Hermans-Jansen, 1995). It is also possible, although rare, to have low levels of both S and O and to experience more P than N, which Hermans labelled +LL (Hermans & Hermans-Jansen, 1995). This valuation indicates that the absence of self-enhancement and of contact and union can be experienced in a positive way. Hermans describes it as passive enjoyment or empty satisfaction; for example, "I can enjoy a movie such as a comedy that doesn't call for any thought". Hermans believes that such valuations may represent an escape from tensions or negative feelings (Hermans & Hermans-Jansen, 1995). Mystic experiences also belong to the +LL category. Such experiences can be considered a temporary state of emptiness or of transcending one's motives. A match occurred when a low point showed McAdams' communion and/or agency scores and a rating of –LL. A match was also considered if a peak experience showed McAdams' communion and/or agency themes and a rating of +LL. This was the case as the –/+LL valuation can emphasise S or O. It was also assumed, for example, that if a peak

experience showed more of McAdams' agency than communion themes and an affective rating of +LL, the agency motive would dominate the experience.

The final form of valuation is represented as +HH, where high levels of self-enhancement and contact and union affects coexist with a high degree of positive affect (Hermans & Hermans-Jansen, 1995). Examples are, "I made a necklace as a gift for my girlfriend" and "I want to maintain my self-confidence; I only want to have healthy relationships or no relationship at all" (Hermans & Hermans-Jansen, 1995). In +HH valuations, one emphasis refers explicitly to one motive, while the other refers implicitly to the other motive (Hermans & Hermans-Jansen, 1995). For example, the valuation "I really enjoy a good tennis match" may score +HH. The valuation explicitly mentions the self-esteem derived from the tennis match, but does not explicitly mention the human contact part of the game. Hermans and Hermans-Jansen (1995) note that some implicit elements in valuations may indicate that some parts of valuations are on a less conscious level. Valuations referring to friendships generally belong to this category and often have an implicit S element. When people feel close to a friend, they experience mutual support and respect and fulfil the contact motive, and in turn experience positive self-esteem (Hermans & Hermans-Jansen, 1995). Comparing McAdams' themes with Hermans' +HH valuation, a match was identified if a peak experience showed McAdams' communion and/or agency themes. This was because, in +HH valuations, one emphasis explicitly refers to one motive while the other refers only implicitly to the other motive. Therefore, it was assumed that a peak experience, which scored as +HH and which showed more of McAdams' communion than agency themes would explicitly refer to the communion motive but implicitly refer to the agency motive.

For the purpose of the present study, an S type and an O type affective pattern were also considered. Valuations of the S type have more self-enhancement affect than affect related to contact and union with the other (S>O), but do not significantly differ in terms of negative and positive affect (N=P). A match would be identified with a peak or low experience that showed more of McAdams' agency than communion themes. Similarly, O valuations have more affect indicating contact and union with the other (O>S), but do not significantly differ in terms of negative and positive affect (N=P). In the same way, a match would be identified with a peak or low experience that showed

more of McAdams' communion than agency themes. The comparisons between McAdams' and Hermans' coding schemes will be described in the next chapter.

5.3.3 Coding of the Interview Transcripts

Two copies of each transcript were printed. One copy was read and coded in relation to McAdams' sixteen themes of agency and communion, and examples of themes were highlighted and colour coded. For example, passages showing communion themes were highlighted in pink and agency themes were highlighted in blue. The name of the particular agency or communion theme was written next to each highlighted passage. The second copy of the transcript was read and coded in relation to the four power themes found in the pilot study (disrespect/insensitivity, diminished patient rights, lack of acknowledgement and not listened to) and examples of good practice. When the power themes were identified, they were also colour coded. For example, green designated disrespect/insensitivity, diminished patient rights was highlighted in pink, lack of acknowledgement was highlighted in yellow, and blue referred to the perception of not being listened to. A red asterisk was placed next to examples of good practice.

Two matrices were created to organise the coding of McAdams' themes: one matrix in relation to the nuclear episodes in the participant's life before the hospital experience and one in relation to the nuclear episodes during the hospital stay (part of a matrix is presented as Appendix J). The rows represented the 16 themes and the columns represented each participant. Along each row, a column was ticked if the corresponding theme appeared in the participant's transcript. The matrices proved to be useful in organising the data, as quotes for each theme were easily located. For example, to view an agency theme, the researcher perused a particular row, and when she encountered a tick she sought the column number (representing the participant's transcript number), selected the corresponding transcript, and located the theme.

5.3.3.1 Pilot Study Themes

The four broad power and control themes which emerged in the pilot study were also sought in the data of the main study. The four themes were disrespect/ insensitivity, diminished patient rights, lack of acknowledgment, and not listened to.

5.3.3.2 Agency and Communion Motivational Themes

The accounts of peak and nadir experiences were coded for the presence of the 16 themes of agency and communion. The four positive agency themes (McAdams, 1992a) were:

1. *Self Mastery* – Through forceful and effective experience, the person is able to strengthen the self and to become a more powerful agent in the world. A common expression of the theme involves the person attaining dramatic insight into the meaning of his or her life.

2. *Status/Victory* – The person attains heightened status among his or her peers, through receiving a special recognition or honour or winning a competition. Status or recognition are achieved in relation to others; thus there is always a competitive context.

3. *Achievement/Responsibility* – The person reports substantial success in the achievement of tasks or important jobs. The person feels proud about meeting significant challenges or overcoming important obstacles, or about taking on major responsibility and taking charge of things or people.

4. *Empowerment* – The person is empowered or made better through his or her association with something larger and more powerful than the self. The empowering force is usually either God or some manifestation of a larger power in the universe, or a highly influential authority figure that provides important assistance or guidance for the person, such as a teacher or mentor.

McAdams' (1988b) negative agency themes include:

1. *Failure/Weakness* – The person fails in a task. The person is unable to do something that he or she wants to do because of some factor(s) within him or herself, and as a result is unable to experience feeling strong or powerful.

2. *Losing Face* – The person experiences shame (though not necessarily guilt), embarrassment, or humiliation in the presence of others.

3. *Ignorance* – The person is unable to know something that he or she desires to know. The person is confused and "in the dark", and thus is unable to experience mental strength, and laments this inability.

4. *Conflict* – The negative experience is a direct result of a conflict or disagreement between the person and others, which can include arguments or fights.

McAdams' (1992a) four positive communion themes in nuclear episodes were defined as follows:

1. *Love/Friendship* – The person experiences an enhancement of erotic love or friendship toward another person.

2. *Dialogue* – The person experiences a reciprocal and non-instrumental form of communication or dialogue with another person or group of others, which usually takes the form of an emotionally positive conversation between two people. It is necessary that the conversation between the subject and the other is affectively positive, reciprocal and viewed as an end in itself rather than a means to an instrumental end.

3. *Caring/Helping* – The person provides care and assistance for the physical, material, social or emotional welfare or well being of another person. The expression of this theme primarily captures emotionally positive experiences between relative unequals, in that the subject providing the nurturance is comparatively stronger than the person requiring the care, at least as far as the particular experience is concerned. Most examples of being helped do not score for Caring/Helping, but there is an exception to this rule, for example when a subject reports special acts of kindness by friends, or family, which suggests that he or she tends to perceive the world as a caring place where even those who are not duty-bound to provide care may still act in very caring ways.

4. *Unity/Togetherness* – The person experiences a sense of belonging with a group of people, a community, or even humankind.

The four negative communion themes (McAdams, 1988b) were:

1. *Separation* – The person is separated from friends, family, or a lover. This separation can occur through a variety of ways and usually involves circumstances which cannot be controlled; for example, a break-up, moving, going off to school, death etc. The person must express negative affect about the separation, aloneness, or being apart from the other.

2. *Rejection* – Somebody who has been a friend or lover has rejected the narrator. The other person wants to terminate a previously intimate relationship. The person must express negative affect about the rejection per se.

3. *Disillusionment about People* – As a result of a negative experience, the person states that he or she has lost faith in others (either a particular group of people or

even all of humankind) or is feeling disillusioned about people and their worth or goodness. A sense of betrayal or a breaking of trust often accompanies the negative experience.

4. *Another's Misfortune* – The person experiences the predicament of another; the person is saddened by another's misfortune, pain or death. A common example is depression experienced over the death of a loved one.

In the scoring system, the scorer determines the presence (score +1) of each of the 16 themes in each memory account. For the purpose of this study, memories were not only scored according to McAdams' description of the theme, but also in terms of the negative or opposite of the theme. For instance, a particular memory may reveal the agentic theme of Empowerment, such as feeling strengthened when praying to God. This passage would be labelled "Empowerment", as the memory shows themes comparable to Empowerment. A memory could also show themes negative of or opposite to Empowerment, such as if a woman is criticised for her faith or feels belittled by someone she admires. This passage would be labelled "opposite to Empowerment", as the memory shows the reverse of Empowerment. Considering McAdams' themes in this way conceptualises them as bipolar, as each theme has a positive and negative side.

McAdams (1992a) states that the scoring system is very conservative, in that only explicit examples of particular themes can be scored +1. Therefore, most themes in most scenes receive the score of 0. However, for the purpose of this study, the scoring system was not used in such a conservative manner. The coding was undertaken in a more flexible manner than intended by McAdams, to ensure that a sufficient amount of information about agency and communion emerged from the data. Also, a particular memory could be scored for a variety of themes. For example, an account of a woman giving birth to her first child may not only reveal themes of Caring/Helping, but also themes of Self Mastery through Control, as the woman may report feeling in control of the pain and successfully mastering the self.

5.3.3.3 Redemption and Contamination Sequences

Coding for redemption and contamination focused on the participant's entire story (taking into account participants' descriptions of their life prior to and during hospital and outcomes of the experience). Usually, McAdams codes for redemption and contamination in specific peak and nadir experiences. However, it became clear that,

for the purposes of the present study, it was advantageous to examine the overall experience, as typically the entire story led to a particular outcome(s), which provided a more detailed description of the impact of the experience, in comparison to individual incidents prior to and during the hospital stay.

A redemption sequence was defined as a clear and explicit transformation in the story from a particularly negative state to a particularly positive state (McAdams et al., 2001). To score for a redemption sequence, the particularly negative situation needed to either change into a particularly positive situation or to produce a positive outcome of some kind. The coder read each participant's transcript to determine if the negative experience resulted in a positive situation or outcome. One point was assigned to an account containing a redemption sequence. As discussed in the previous chapter, Tedeschi and Calhoun (1995) stated that good outcomes of traumatic events can manifest themselves as growth in one or more of three different areas: changes in self, changes in relationships with others, and changes in life philosophy and spiritual-existential beliefs. Therefore, the redemption sequences were distinguished as representing one of the three types of positive outcome.

Contamination sequences were coded in a similar manner. Accounts of hospital experiences were coded to determine if the positive event resulted in a negative outcome, or if the negative event was immediately preceded by a positive event. Points were given only when there was explicit evidence of a direct move from a positive affect state to a negative affect state.

5.3.3.4 Good and Poor Quality Service

As in the pilot study, examples of good practice were also sought because of the importance of acknowledging positive inpatient interactions with health care professionals. In addition, examples of poor quality service were highlighted to explore how women want to be treated, and to enable the documentation of practical examples for health professionals.

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5.3.4 Interrater Reliability

The researcher read and coded all the transcripts according to the four pilot study power themes, McAdams' 16 agency and communion themes and redemption and contamination sequences, and examples of good practice. An independent rater read the

first five transcripts in relation to the four power themes and McAdams' redemption and contamination sequences, and showed 100% agreement with the categorisation of themes. In terms of determining interrater reliability for the coding of McAdams' 16 agency and communion themes, a second independent rater read the first five interviews to become familiar with the stories and showed 100% agreement with the categorisation of themes. Subsequently, from the remaining 14 interviews, the second independent rater randomly selected and read a further five interview transcripts and independently coded them for McAdams' 16 agency and communion themes. Interrater reliability for the categorisation of themes was calculated and Cohen's kappa was equal to .94, $p <$ .005, which indicated near perfect agreement.

The results are presented in Chapter Six. Specifically, the chapter provides an in-depth examination of women's stories about their hospital experience which they perceived as having irrevocably altered their lives.

CHAPTER SIX

MAIN STUDY: RESULTS

6.1 Overview of the Chapter

Chapter Five described the method of the main study, including the research aims, participants, materials, procedure, coding and inter-scorer reliability for the coding of McAdams' themes of agency and communion. This chapter continues the description of the main study by reporting the results. Throughout this chapter, quotes from participants' transcripts are included. Beside each quote there is a participant number, which refers to the transcript number, and a page number, which refers to the page number of the transcripts. Within each quote, key words relevant to each theme are highlighted. Interview transcripts are available to other researchers from the author on request.

The chapter begins with the power and control themes found in the pilot study, which included disrespect/insensitivity, diminished patient rights, lack of acknowledgment and the perception of not being listened to. This section reviews these themes in the data of the main study and provides examples of each theme.

The second section involves a description of McAdams' agency and communion themes found in nuclear episodes which occurred during hospital. This section also includes examples illustrating each of the agency and communion themes evident in the interview transcripts. It includes summaries highlighting the main findings, and paying particular attention to the agency theme, keeping in mind the potential importance of the role of power in women's hospital experiences.

The third section examines agency and communion themes found in nuclear episodes which occurred in the participants' lives before the hospital stay. This section compares the types of themes that were found in nuclear episodes which occurred during and prior to hospitalisation to determine if stories about hospital emphasised themes of agency.

In the fourth section, McAdams' and Hermans' coding schemes of agency and communion are explored. This section includes an assessment of the degree of agreement between the two schemes, and an exploration of how information gained from Hermans' scheme could add to understandings of women's narratives.

In the fifth section, McAdams' redemption and contamination sequences are explored, and the participants' stories examined to highlight how the women made sense of their experiences and unified them with their life stories. The chapter concludes with a summary of how women want to be treated in the health care system.

6.2 Power and Control Themes from the Pilot Study

The first aim was to reassess the power themes (disrespect/insensitivity, diminished patient rights, lack of acknowledgement and not listened to) found in the qualitative data in the pilot study. The purpose of this analysis was to reassess the role of power within women's hospital experiences, and the importance of personal treatment with a larger sample of women. Of the 19 women, 12 women's transcripts highlighted the power themes. Examples of each theme follow.

6.2.1 Disrespect and Insensitivity

Of the 19 women in the sample, 10 gave 15 accounts in which medical staff treated them in a disrespectful and insensitive manner. For example, Participant 20 had a hysterectomy and subsequently her bladder ruptured. She was discharged from hospital with a urinary catheter, and as she was discharged she asked a doctor to write her a sick leave certificate. Before the surgery she was told that she would have six weeks of sick leave, and she was also aware that she might need to wear the catheter for more than three weeks:

> (The doctor said) "Oh yeah, you probably only need three or four weeks (of sick leave)." And I said "But I'm wearing this!" and he said, "**That's alright, can't you do modified duties?**" I said, "Not in my job, it's all or nothing. **I'm not teaching with a wee bag hanging off my leg. No way**" (Participant 20, p. 163).

In this account the doctor appeared to lack the understanding that wearing a urinary catheter, even for a short period of time, could be embarrassing. Therefore, insensitivity and disrespect can be perceived when medical staff act in uncaring and unsympathetic ways.

Another example of insensitivity occurred in the hospital experience of Participant 1. She recalled that she disliked her doctor because he did not acknowledge her concerns:

> I didn't like this doctor, when I complained to him about stuff, he'd say, "**You have no idea I see hundreds of people everyday** … Well I do this to hundreds of people everyday" and **that didn't particularly make me feel better** … I didn't care about all the other people, I just cared about how I was feeling and he **didn't acknowledge** that, he just **brushed it off** with a comment that I'm sure he had fed hundreds of others (Participant 1, p. 5).

Although the doctor may have thought that his response was helpful, the patient perceived it as lacking sensitivity, and when this occurs the patient can feel alone and sad.

Participant 16, who had a lumpectomy after she was diagnosed with breast cancer, recounted the occasion on which she met with the oncologist to discuss treatment options. She described the oncologist as being insensitive to her feelings:

> (The oncologist said) "If it ever comes back **you're going to die**." … that was the worst point throughout it … I guess being told something like that … absolutely shocks me.… I still think about it now … it **makes me wary** of going to new doctors (Participant 16, p. 123).

The participant described the oncologist as trying to convince her that chemotherapy was the best option. The doctor may have thought that warning her would be an effective way to influence the patient's decision, but the patient perceived her scare tactics as insensitive, which had a lasting effect.

Participants also recalled situations where they were treated with discourtesy by medical staff. For example, Participant 15 recalled a nurse who treated her with discourtesy after her surgery:

> I remember an experience one night with a male nurse … I was still on a drip giving me fluids, I needed to go to the toilet at

night. I wasn't allowed out of bed, so I had to get a pan. It must have been the second time that night and he made some comment about "**God, do you wee like this at home?**" and I said "No! I've had four children, I've got this drip in…" it was like I was apologising to him. And afterwards when I started to think about it I got quite angry … **it shows to me lack of sensitivity or lack of empathy for what it's like to be confined to a bed and not be able to get around** (Participant 15, p. 117).

This woman emphasised the importance of hospital staff treating patients with sensitivity, because, typically, patients are dependent on the staff for their survival, which she did not consider a pleasant experience.

The nursing staff, I realise yes they're busy – rushed off their feet – but it's **really important I think at least stay in touch. If they haven't been a patient themselves they need to have the experience to get in the bed and experience what it's like to be helpless** and to wait for someone else to bring you a jug of water, or bring you some pain relief or whatever (Participant 15, p. 117).

6.2.2 Diminished Patient Rights

Five women recounted nine occasions on which they perceived the medical staff as treating them like children. For example, Participant 6 described the time she fell in the shower:

The nurse that was looking after me **told me off** and got me up in the commode chair and took me back in my bed and then sat me out of my bed, and because I put myself back into bed, **she came in and told the three other patients that shared my room that I was lazy** because I went back to bed instead of sitting up (Participant 6, p. 35).

Being "scolded" has connotations of parents or teachers reprimanding children, and when adult patients are treated in that manner it highlights the power imbalance that exists between patients and medical staff.

Other accounts of diminished patient rights portray medical staff as disbelieving patients' opinions and as distrusting their ability to make informed decisions about their own health care. For example, Participant 17 was sure of her diagnosis but the medical staff would not believe her: "**It was like my evidence didn't count, it was the tests that counted. I found that really disempowering**" (Participant 17, p. 129). Another woman recounted an experience in which she portrayed her oncologist as lacking faith in her ability to make a decision about her treatment: "(I) tracked down information on the Internet, made a decision, went back and told her and she (the oncologist) said, '**Well you should have taken the other option**'" (Participant 16, p. 122).

One woman commented that when you are a patient it can sometimes feel like you have no basic rights:

> (In terms of) the noise that the night nurses make. That just amazes me all the time. I know that it's day/night time for them, but you're desperate to get some sleep – it's as boring as hell and they talk as if it's daylight.… **And that's what I mean by (patients as) bit player, you don't really count; they're running their own system. They'll talk as if it's daytime because that's their daytime. But the fact that you're lying there half dead is quite irrelevant.** It's a bit of a shock (Participant 17, p. 139).

6.2.3 Lack of Acknowledgement

Seven women described nine very different accounts of lack of acknowledgment. For example, Participant 14 spoke about feeling ignored. She was admitted to hospital and brought to her room in preparation for surgery, "**Nobody came into the room**, I starved myself like most people do … nobody came in until 5pm, and I was there all day long" (Participant 14, p. 108).

Participant 1 recounted an episode in which she felt that her doctor did not acknowledge that her circumstances were a major concern for her. She was scheduled to have some particularly distressing medical tests, which she thought were not

necessary to diagnose her condition. She had attempted to discuss her views with the doctor but was unsuccessful. She was dreading the tests and had been crying the previous day in anticipation. The day of the test, the doctor came into her room:

> He stood at the end of the bed while reading my chart, **wasn't making that much eye contact** with me the whole visit. I wanted to punch him because he **wasn't paying attention to me** and I was supposedly his patient, he was **dismissive** … **if he looked at my face it might have told him that I'd been crying the whole time** (Participant 1, p. 6).

This woman's account conveys anger about the doctor's lack of acknowledgment of her distress and at his attitude in a situation that was of great concern to his patient.

Participant 11 described a different situation where she felt that her doctor did not appropriately acknowledge the importance of her test results. The woman went into hospital for a double mastectomy and after the surgery her doctor gave her the grim test results: "(The doctor said) 'Oh you've got this great big tumour, it's seven centimetres in size and you've got all these lymph nodes involved, and would you like a copy of the pathology?'" (Participant 11, p. 83). The woman explained that the doctor's behaviour was "surprising" and "disappointing" because of the manner in which he dealt with the information. Although she understood the implications of the test results, she preferred to have the chance to discuss them, and as she was not given the chance, she felt that he dealt inadequately with the situation. Subsequently, the woman cried for most of that day, not only in response to the distressing news, but also because of the doctor's apparent lack of empathy, which shows the adverse impact of the doctor's behaviour.

6.2.4 Not Listened To

Six women described situations in which they felt that medical staff failed to listen to their opinions or concerns. Some felt that they were not listened to when doctors were hasty in making medical decisions or diagnoses, and described doctors as not believing their symptoms or pain. One example is of a woman who was experiencing extreme abdominal pain and went to hospital a number of times, but was continually turned away because the medical staff said they could not help her. She described how she felt when she returned home:

> So I was at home **feeling absolutely defeated thinking that I should die,** it's best that way because **no one's listening, no one's believing the pain I'm in** … I'm all by myself, I didn't know what to do.… I was … bedridden, **there was no one that would believe me or take it further, that was the hardest thing** (Participant 10, p. 72).

This woman described the impact of not being listened to: "**Stripped of everything, I had no self-esteem … trodden on … sinking and drowning and I just wanted to die … unworthy … absolutely defeated**" (Participant 10, p. 72).

Other accounts portray doctors as ignoring patients' views. For example, Participant 6 broke her leg, and had surgery on the leg, and believed after the surgery that her knee was not positioned at the correct angle. She tried to tell the medical staff of this and reported that they would not listen to her or would not believe her. The patient had cerebral palsy; therefore the hospital staff believed that her knee had always been positioned at that angle:

> It was very frustrating because they **didn't want to listen**, and it was just so obvious, even someone who hadn't seen me very often prior to the break … it was obvious to them, **so I didn't bother saying any more because I knew that it was going to get me no where**.… (It took the surgeon) 18 months to realise and admit that they have stuffed up, but I guess that it doesn't affect her life, it only affects mine, she keeps carving people up so what does it matter.… **trying to get them to see that it wasn't right was impossible because they didn't want to know** (Participant 6, p. 37).

As this woman's story demonstrates, such attitudes can lead to helplessness and low self-esteem. It highlights the power imbalance between the medical professional and the patient, as it appears that the opinions of the medical professional have more importance and substance than those of the layperson. It also seems that patients would appreciate having their opinions heard and taken into account when doctors make medical decisions. As Participant 9 acknowledged:

It must be hard for (doctors) in the sense that they've done what they had to do. They've asked you what the symptoms are, they've given you tests to run and it's all come back clear … I just sometimes feel that they're a little bit quick to jump to conclusions, and **it is really important that people are told to be aware of things and to have that confidence in themselves … that (their opinions are) going to be taken seriously as it can be and it's not just going to be dismissed**.… it's your body, and no one – even though doctors have their way of diagnosing and assessing you – they can't experience what you're experiencing (Participant 9, p. 70).

Perhaps collaboration is the key: doctors need to begin including patients in the health care process and to perceive patients' thoughts as valid pieces of evidence that may help in making decisions; and patients need to be more educated about diagnoses and symptoms.

6.2.5 Summary

This section explored the first aim, which was to reassess the power themes (disrespect/insensitivity, diminished patient rights, lack of acknowledgement and not listened to) found in the qualitative data in the pilot study. The four themes were clearly and consistently reflected in the data of the pilot study, and continued to be evident in the data of the main study. The theme of disrespect and insensitivity included being treated in uncaring, unsympathetic and discourteous ways. Exploring this theme showed that negative treatment caused participants to feel alone, sad, wary of doctors and helpless. Some participants felt that, as patients, they had diminished rights and were sometimes treated in childlike ways. For example, some were reprimanded in a similar manner in which teachers and parents scold children, and others felt that the hospital staff disbelieved their opinions or distrusted their ability to make decisions. This treatment highlights the power imbalance between patients and hospital staff. Participants noted that they sometimes felt ignored during their hospital stays or that hospital staff failed to acknowledge their concerns or distress. This caused them to feel angry and disappointed with staff. Some participants' transcripts also showed that they felt their opinions or concerns were not listened to. Participants subsequently felt that

their opinions and concerns were not important, which resulted in feelings of helplessness and unworthiness.

The information captured by the four broad themes highlights the importance of the manner in which medical staff treat patients, as negative treatment can lead to patients' feeling helpless, experiencing low self-esteem, or avoiding future interactions with doctors. The themes also highlight that the concept of power is complex and can be manifested in very diverse and subtle ways.

6.3 Peak and Nadir Experiences during Hospital: Patterns of Agency and Communion

The second aim of this study was to explore themes of agency and communion within McAdams' model as they related to women's narratives of their hospital stays. To achieve this aim, nuclear episodes were coded for the eight positive themes of agency and communion using McAdams' (1992a) coding system, and for the eight negative themes of agency and communion using McAdams' (1988b) coding system. As stated in the previous chapter, peak and nadir experiences were scored not only according to McAdams' description of the theme, but also in terms of the negative of or opposite to the theme. For example, a peak experience of being surrounded by many friends and family members may qualify for the communion theme of Unity/Togetherness. This experience would be labelled "Unity/Togetherness", as the memory shows themes equivalent to Unity/Togetherness. On the other hand, a low point of feeling alienated from a social group may provide evidence for ideas contrary to Unity/Togetherness, and this memory would be labelled "opposite to Unity/Togetherness". Additionally, each particular memory could be scored for a variety of themes. For example, an account of a woman giving birth to her child may not only reveal themes of Caring/Helping, but can also demonstrate themes of Self Mastery though Control, as the woman may report feeling in control of the pain and successfully mastering the self. Therefore, throughout the reporting of the results, various memories are discussed more than once if they show evidence of more than one theme.

Of the 19 participants, 17 reported both peak and nadir experiences which occurred during hospital, and two reported only nadir experiences. Participants reported

between one and three nadir experiences, and between one and three peak experiences. In total, 49 memories were reported: 26 nadir narratives and 23 peak narratives.

Agency and communion themes appeared in 45 (92%) of the 49 memories. In four nuclear episodes, there were no particularly salient agency and/or communion themes; therefore these received a score of zero for "absence of motivational theme". Tables 5 and 6 show the number of agency and communion themes found in peak and nadir experiences in women's stories about their time in hospital. A total of 73 themes were coded. Table 5 shows that 50 (68%) themes were of agency, and Table 6 shows that 23 (32%) were of communion themes.

Table 5

The Number of Agency Themes Identified in Participants' Peak and Nadir Experiences during Hospitalisation

Agency Themes	Peak experiences		Nadir experiences		Total
	Equal[a]	Opposite[b]	Equal[a]	Opposite[b]	
Self Mastery (Insight)	5				5
Self Mastery (Control)	5			13	18
Empowerment	5		1	4	10
Achievement/Responsibility	3			1	4
Status/Victory					0
Failure/Weakness			2		2
Losing Face			3		3
Ignorance		2	5		7
Conflict			1		1
Subtotal of Positive Themes	18	2	1		21
Subtotal of Negative Themes			11	18	29
Total					50

[a]The columns labelled "Equal" indicate the number of themes *equal to* McAdams' original definition of the theme. [b]The columns labelled "Opposite" indicate the number of themes *opposite to* McAdams' original definition of the theme.

6.3.1 Agency Narratives

6.3.1.1 Self Mastery

Tables 5 and 6 show that the women expressed more agentic than communion theme content. In particular, the most common theme was the agency theme of Self Mastery. Accounts of Self Mastery involve successful mastery, control, enlargement and perfection of the self, where the subject is a more powerful agent in the world (McAdams, 1992a). McAdams (1992a) states that a common expression of this theme involves the attainment of dramatic insight into one's own life and identity that results in a transformation in self-awareness, and entails the realisation of new goals and life plans. Another common expression involves being in control of one's destiny and attainment of a sense of power. Other examples show up in stories of feeling strengthened by an important life event.

6.3.1.1.1 *Self Mastery (Insight).* As indicated in Table 5, five women's accounts of peak experiences during hospital showed Self Mastery through the participant attaining a dramatic insight into the meaning of her own life (Participants 7, 8, 9, 16 & 19). McAdams (1992a) asserts that Self Mastery through Insight is not a mere lesson in life; rather it is a fundamental transformation of self-awareness or a quantum leap forward in self-understanding, which entails the realisation of dramatically new goals, plans or missions in life, and is a profound insight into one's identity. Each of the five women's peak experiences, showing themes of Self Mastery through Insight, were unique, but shared the common theme that they entailed the realisation of a dramatically new life philosophy.

Participant 8 described a peak experience that occurred one morning during her hospital stay as she was lying in bed staring at the flowers that had been sent to her:

> I just became totally overwhelmed and I started to cry but it was a really positive happy feeling. Then I just thought "**I've woken up today and I'm alive**." … I thought "This is good! I'm okay, I can do this." So even though I had the uncertainty, I thought "Well, I'm still here and everything's all right" **and I remember that vividly.… And I believe from that moment … that has shaped the way … (I) do things now … things took on more purpose and meaning** (Participant 8, p. 54).

She believed the peak experience led her to change the way she viewed life: she was very determined to make the most of every day.

> **Every day is really precious** … **we take so much for granted and we're very lucky**. We live in a great country, we've got so much – we're very privileged and sometimes we don't take advantage of it. … **Gee, all those times I wasted doing really stupid pointless things**. You don't need to do that, you **just need to do things that really count** (Participant 8, p. 53).

Another participant had a dermoid tumour removed from her ovary and recalled how she came out of surgery and was told it was successful; while the ovary had to be removed, the tumour was benign, and it had not damaged other organs. She recalled that the experience changed her way of thinking:

> (I have a) sense of **how valuable and precious life is**, I still even now wanted so much to savour that feeling … **to have your health is so good and so valuable it's the most precious commodity** that you can ever have and it's just **not worth worrying or stressing about anything else – because ultimately, if you have your health, you've really got a lot** (Participant 9, p. 68).

Participant 19, who had a head injury, described a peak experience which occurred one night during her hospital stay while she was lying in darkness looking at the full moon through the hospital window:

> (Through the) ugly aluminium silver framed window … it just was this amazingly cheesy, beautiful full moon. And I thought the inside of the place seems so soulless in comparison, with the aluminium windows and the boring eight-bed room with the square walls. **I thought about the seasons and the moon and how everything just keeps going and I don't have to get stressed. It was just this really comforting sense … It's just a really nice reminder that life moves and it's okay and this'll pass.…** There's a lovely quote from a British saint …

"All shall be well, all manner of things shall be well." And there was a sense of that. **I didn't need to strive quite so hard, because I didn't need to be responsible for every moment, just that things move and seasons keep going and that it all shall be well**. And I did carry it with me (Participant 19, p. 157).

Since she had worked with head injury patients, she was aware that "they didn't always crisp up nicely" (Participant 19, p. 157), but her peak experience made her feel hopeful that she would recover and "I can have my life back at some point" (Participant 19, p. 157). That moment continued to affect her, because since that time, when she became anxious, she would repeat the phrase of "all shall be well" and was reassured.

All the participants explained that their peak experiences had a big impact on their lives and they continued to carry what they had learned from their respective experiences into their present day lives.

6.3.1.1.2 *Self Mastery (Control).* Table 5 shows that five accounts of peak experiences during hospital reflected ideas of Self Mastery through Control (Participants 1, 12, 15, 17 & 21). One woman described a peak experience in her hospital stay when she had her second magnetic resonance imaging (MRI). She recounted that she disliked the procedure and she tried to explain her anxieties to the hospital staff but did not feel they were adequately acknowledging her distress. She wanted advice on how to cope with the procedure, but realised that she was able to put her faith in her own coping abilities:

I remember thinking why don't you put all your energy and all your thoughts onto one thing, close your eyes and just concentrate on this thought the whole time … I just concentrated on one thing which was just happy thoughts and **I remember feeling so proud of myself when I got out. I couldn't believe that I had done it, it didn't take very long and I had gotten through it.** I remember saying to Dad, I can't believe it, I did it, I did it! I was really happy and smiling.… **I had relied on myself to get through it and I was able to** (Participant 1, p. 8).

The participant felt very positive because she was able to cope throughout the experience. Earlier in the interview the participant described herself as "independent", "my own person" and "self-sufficient". During the peak experience she was able to master the situation and control her reaction to the situation in accord with the image of herself as a powerful agent, an independent and self-sufficient person.

Another participant said she felt "disconnected" after an ear operation because her sense of balance and vision had been affected, and she was not able to read, watch television or have visitors. She described a peak experience that showed themes of Self Mastery through Control as she remembered a physiotherapist had suggested she buy a walkman and listen to the radio. She took up the physiotherapist's suggestion and it dramatically improved her situation:

> I didn't feel quite so alone, and I didn't feel quite so much a patient. **Because when you're in hospital you're very much governed by hospital routine and you have to have your meals at a certain time, and you have to have physio or rehab at a certain time, and shower at a certain time.… it was a way where I could choose for me when and how I wanted to listen to something**. And I felt I knew what was happening out there in the world. **So I suppose it was a point of moving forward from being a patient, to getting back to life** (Participant 15, p. 115).

This participant felt she had regained some control over her life through being able to choose how she used her time. Additionally, this freedom of choice represented progress from being a patient and being ill to regaining her independence and strength.

Participant 21 described the peak experience of successfully showering by herself:

> **I wanted to do it for myself**. And that was really the high point of my stay from then on – was **being able to have this shower by yourself, and obviously feel much better at the end of it** (Participant 21, p. 182).

This woman's account showed a strong sense of determination to regain her independence. This simple yet important experience enabled this woman to feel powerful and effective, as her own actions were able to result in positive outcomes. She was also strengthened by her achievement because she reported that she subsequently began to feel hopeful that she would recover and feel strong again.

6.3.1.1.3 *Opposite to Self Mastery (Control).* Table 5 shows that 13 accounts of nadir experiences (reported twice by Participant 17 and once by Participants 1, 3, 6, 7, 8, 11, 13, 15, 16, 20 & 21) illustrated themes negative of or opposite to Self Mastery and demonstrated disempowering experiences of physical debilitation, descriptions of lack of control over one's body, feelings of helplessness as a hospital inpatient in the face of medical staff, and anxiety associated with the uncertainty of their illness. Themes opposite to Self Mastery through Control were the most common theme. Four women commented on their feelings of helplessness and dependence on the medical staff for their survival because they had no control over their bodies. For example, Participant 3 recalled the negative experience of looking down and seeing tubes and wires coming out of her body:

> I was lying on a bed with the rails up on each side lying reasonably flat. **I had a complete lack of control. I was quite helpless really because I had tubes and wires everywhere, I had a urinary catheter, I had the drip and other bits and pieces, difficulty moving, shocking nausea … I was unable to be independent and it all just seemed too much** (Participant 3, p. 27).

Participant 15 also described a low point as she commented on her lack of independence when she awoke from an ear operation feeling extreme nausea and experiencing double vision:

> **I felt totally dependent. My survival was totally dependent on people around me.** (It makes) you more aware I guess of **the power imbalance of some one who's sick and helpless and the person they rely upon** (Participant 15, p. 118).

Such comments highlight that being physically helpless, immobile and confined to a hospital bed places the patient in a subordinate position to the "healthy" person.

Two women spoke about the helplessness they felt because they did not understand why they were experiencing their health problems, and the doctors could not provide them with answers, which appeared to intensify their frustration. For example, Participant 17 recounted the despair she felt after a long string of problems delayed her recovery. The medical staff were unable to determine the cause of the problems, and the final straw was when she lost control of her bladder in the middle of the night and two young nurses came to change her bed:

> I just sat in the chair and I just cried and cried and I think they thought I was just embarrassed, and they were trying to go "It's all right, it happens" but it wasn't just the embarrassment – it was the whole ordeal catching up with me and I just cried and cried and cried. **I didn't know why this was happening** and it was humiliating. **I realise that it would have been one thing after another now, about four things had gone wrong in the process … the humiliation, the despair of this is just really really awful, I don't know what to do. And no one else seems to know what to do either** (Participant 17, p. 137).

This experience not only highlights the embarrassment felt when patients are unable to control their bodily functions but also the powerlessness, vulnerability, and uncertainty experienced when patients cannot understand what is happening to their bodies.

Three women described the despair they felt when they were overwhelmed with pain after regaining consciousness after surgery, and the helplessness they felt due to their physical debilitation. Participant 21 was diagnosed with breast cancer and had her lymph nodes removed, and recalled the excruciating pain:

> **I just thought life is horrible. I just don't even want to be here**, the whole time there wasn't anything good that I could think of at all. It was like you're just **overcome with this feeling of pain and suffering** (Participant 21, p. 180).

This woman described pain as overpowering, so that there was a sense that patients were not only subordinate in terms of the hospital hierarchy, but their own pain also overpowered them. Another woman who had a total abdominal hysterectomy was experiencing severe wind pain:

> The middle of one night and I couldn't sleep and it just felt like I wanted to go to the toilet … that pain. It was about three in the morning, and I'd been awake for a while. I just could not believe that wind pain could be so bad.… I wanted to go home and I just wished I could get to sleep, it was just a **despair** feeling I think. That was a really awful low point. It was almost like I thought **surely they could do something for this** (Participant 20, p. 167).

This account conveys a feeling of helplessness and frustration from being unable to do anything for the pain.

Two women commented on the helplessness they felt when their doctors treated them insensitively. Participant 6 described that she fell and landed on her knee, and after undergoing an operative procedure to repair it realised that her knee had been positioned in the incorrect angle to her leg. She described the registrar as being dismissive of her concerns:

> (The registrar's) attitude to me was just to put the x-rays under my nose and of course it's right, here are the x-rays, and that was his solution. **He didn't care at all** … **To me, it was almost like, well you've got cerebral palsy, why would you be intelligent, why would you know what your leg was like** (Participant 6, p. 34).

The outcome of the operation caused the participant to lose her job because she was unable to walk properly; in turn her unemployment resulted in her loss of independence.

> **(I) felt incredibly frustrated and fairly helpless and feeling like that it didn't matter whatever I said or did, nothing was going to change, more or less my world as I knew it had gone**, and it had been taken away by this one surgeon, and I

didn't have my independence which is very important to me.

To me, (it felt like), we'll just sweep you under the carpet, you're a nobody, you're just a piece of meat (Participant 6, p. 39).

The woman's account conveys how she felt a complete lack of compassion from her doctor and the account is redolent with imageries of helplessness. The participant said that she considered complaining about the surgeon but felt that a complaint would be futile: "**So really you don't put a complaint in because you think there's no point, because it's not going to change anything**, it's not going to fix up my leg" (Participant 6, p. 39). The participant's helplessness extended beyond the outcome of the operation and was also highlighted in her attitude towards the health care system.

6.3.1.2 Empowerment

The second most common agentic theme after Self Mastery was Empowerment, which McAdams (1992a) describes as memories where the subject is enlarged, enhanced, built up, or made better through his or her association with something larger and more powerful than the self. In memories showing themes of Empowerment, the empowering force is usually either (1) God, nature, the cosmos or another manifestation of a larger power in the universe, or (2) a highly important teacher, mentor, minister, therapist or authority figure who provides significant assistance or guidance for the subject. In addition, certain religious experiences qualify, for example when the subject reports that God or another larger force was made manifest to him or her. Certain experiences of empowerment in nature may also qualify.

Table 5 shows five peak experiences (reported by Participants 2, 10 & 12 and two accounts reported by Participant 16) and one nadir experience (reported by Participant 12) in which themes of empowerment, reassurance, hopefulness and feeling "built up" through association with a powerful person, such as a doctor, are expressed. The women recounted memories of interactions with physiotherapists, doctors and nurses where they felt empowered because the health professionals gave them information explaining the surgery, the condition, or the particular medical procedure. Participants 2 and 12, who had knee surgery and a hip replacement respectively, recounted that they felt empowered by their interaction with physiotherapists as they were taught how to walk again, which symbolised the return of their independence:

> **She actually got me out of the bed and taught me to use one**
> **of those walking frames** … And that was good because **at least**
> **I could move**, I only got from the bed to the door, and then that
> was enough (Participant 2, p. 15).

Participant 12 recounted, "So I was only in bed for a day, **so that was very empowering too, learning to walk straight away**, and then we did the stairs, that was the peak experience I think" (Participant 12, p. 94). Both these women recounted that they felt empowered not only because the physiotherapists taught them how to walk, but were also assisted by the manner in which they were taught: "**The way she went about it and she was there for me … And it was just her reassuring manner all the time, supporting** and never pushing harder than I wanted to go" (Participant 12, p. 94). The participants commented that the empowering experience of learning more about their condition and the understanding and reassurance which they received from the health professionals gave them hope that they could learn to walk again and recover.

Participant 10 had a different type of empowering experience with her surgeon. She recounted that, after her operation, her surgeon came to see her and took off his hat and did a dance in the day surgery to make her smile. Similar to Participants 2 and 12, the surgeon's behaviour empowered the participant by filling her with hope.

> He had even taken a part of the day, even if it was five to 10
> seconds, to do something with humour … **So he turned a**
> **situation that was potentially sad and low into something**
> **positive, so even when I was in that much pain he offered**
> **hope**, that's all I wanted, and that in itself was beautiful.… (The
> experience was) **Positive, comfort to my soul, my well being,**
> **my way of thinking, positive that there is a way even when**
> **everything else seemed in the dark** … That memory will
> always stay in my heart forever because it is such a beautiful
> and positive thing in my heart (Participant 10, p. 79).

It is evident from the woman's memory that the simple act of the surgeon in making her smile "built her up"; she was "made better" through the interaction as it provided the critical support that she needed. Also, the participant emphasised that the experience lived on in her heart, which highlights the strengthening effect it had for her.

6.3.1.3 Opposite to Empowerment

Four narratives of nadir experiences (reported by Participants 1, 6, 11 & 18) showed themes contrary to Empowerment, such as feeling disempowered, weakened or reduced through association with something more powerful. The disempowering forces were described as nurses or doctors. For example, Participant 6 described a situation where she felt disempowered through her interaction with her surgeon. After her knee operation, her surgeon came to do the daily rounds:

> He lifted up the bottom of the sheet, looked at it and said, "Oh, I thought we did a better job than that", and left it at that. So that really filled me with confidence.… **I guess the only way I could describe it, which is really stupid, is like a balloon deflating, I just seemed to sink down more and more within myself, and just basically wanting to stay down in that little hole if you like** (Participant 6, p. 39).

The memory shows that the participant felt weakened and demoralised through her association with the more powerful doctor.

6.3.1.4 Achievement/Responsibility

McAdams (1992a) states that themes of Achievement/Responsibility are revealed in narratives where the subject reports substantial success in the achievement of tasks, jobs or instrumental goals, or in the assumption of important responsibilities. The subject feels proud, confident, masterful, accomplished or successful in (1) meeting important challenges or overcoming important obstacles concerning instrumental achievement in life, or (2) taking on major responsibilities for other people and assuming roles that require the person to be in charge of things and/or people. Rather than winning, the subject strives to do things or assume responsibility in such a way as to meet an internal or external level of excellence (McAdams, 1992a).

Table 5 shows that themes comparable to the agentic theme of Achievement were apparent in three narratives. Participant 7 described two peak experiences where she referred to the positive outcome from surgery and recovery from her illness as overcoming obstacles, describing the achievements as "**that was the big hurdle over**"

(Participant 7, p. 43) and "**I've got through**" (Participant 7, p. 44). Participant 21 described a peak experience where she first attempted to have a shower by herself after her surgery and was successful. She described the experience as an achievement, which made her feel confident in her recovery, "**That sense of achievement … gave me the feeling that if I can do this now, in all this pain … I can get well again, I can get strong again**" (Participant 21, p. 182).

6.3.1.5 Opposite to Achievement/Responsibility

Participant 2 described a very different memory which was a low point and showed themes contrary to Responsibility. She spoke about her career, in which she was accustomed to being the boss, assuming responsibility, and being in charge of others. However, contrary to her role as "leader" outside the hospital, she described the low point in hospital as quite the opposite, as she was unable to take charge of the nurses. For example, "**I was too easy going, I placed no demands on them at all, and then I found that I was a push over**" (Participant 2, p. 17).

6.3.1.6 Failure/Weakness

Agentic narratives, which illustrate themes of failure or weakness, are those where the person reports that they have failed in some task or venture. The person is unable to do something that he or she wants to do because of some factor(s) within him or her. Consequently, the person is unable to experience the goal state of feeling strong or powerful (McAdams, 1988b). Table 5 shows that there were two low experiences (described by Participants 1 & 2), which scored for Failure/Weakness, emphasising bodily failure. Participant 1 described the low point when it "hit home" that she was in hospital for a congenital condition of the spine. She reported, "**My body had failed me**" (Participant 1, p. 3). She became sick and was unable to feel control over her body and therefore she did not feel strong or powerful. Participant 2 did not have control over her bodily function as she was unable to urinate after surgery, and consequently, she was unable to feel strong or powerful: "Well they gave me a bedpan about three times and said to try to pee, and **I really concentrated … and in the end I said I can't do this**" (Participant 2, p. 16).

6.3.1.7 Losing Face

Agentic narratives showing themes of Losing Face describe situations where the person experiences shame (though not necessarily guilt), embarrassment, or humiliation in the presence of others (McAdams, 1988b). There were three low experiences recounted which were scored as themes of Losing Face. The narratives highlighted situations where the participants experienced embarrassment and humiliation in the presence of nurses and doctors. Participant 2 recounted two low experiences. One experience occurred a few minutes before surgery, when she was told that she would have an epidural, whereas the participant was under the impression that she was having a general anaesthetic. She cried because she was scared and unfamiliar with epidurals:

> So by the time I got down there (theatre) **I was so embarrassed**
> **I could not stop the tears from flowing down my cheeks**, and
> I was saying to the nurses who were taking me down, "I'm not
> usually like this, I have had heaps of surgery it's really no big
> deal" but just the thought of the epidural (Participant 2, p. 11).

Participant 17 recounted a low point where she felt "humiliation" when she lost control of her bladder in the middle of the night and wet her bed.

6.3.1.8 Ignorance

Agentic memories, which illustrate themes of Ignorance, are evident when the person is unable to know something that he or she desires to know. The person is confused, disorientated, in the dark. Consequently, he or she is unable to experience mental strength, and he or she regrets this inability. There were five nadir experiences (reported by Participants 2, 8, 10, 12 & 20) which showed themes of Ignorance, where the participants did not know what was involved in a particular medical procedure or operation, or the reasons they were experiencing pain or feeling sick. Consequently these participants were unable to experience mental strength and felt helpless and lost due to their lack of knowledge.

The low point reported by Participant 2, who was unexpectedly told that she would be having an epidural, also showed themes of Ignorance. The woman panicked because she did not have knowledge or experience with an epidural:

> I thought that I was having a general anaesthetic and then **I thought oh oh a needle in the spine, oh my god, people get paralysed, all this fear and panic** … and I felt like my bottom part of my body was in a bucket of ice, it didn't feel numb it just felt like it was freezing cold, and all I wanted to do was warm it up and **I couldn't move anything and it was like a really scary yuck experience.… prior to that I was not afraid of medical procedures** (Participant 2, p. 13).

Due to this woman's lack of knowledge she felt vulnerable and scared and consequently could not experience mental strength, which has led to a fear of epidurals and medical procedures in general.

Participant 12 had a similar nadir experience in that she went into hospital for a hip replacement but she was not told that the procedure involved the severance of nerves, which meant that she would have to learn to walk again:

> **I didn't realise that, I got a big shock … I didn't know that was part of it**, and I was a bit apprehensive if I would be able to do it.… I guess I was pretty fearful too, I thought, what if I can't, I've just got this new life going (Participant 12, p. 92).

Her story showed that she was unable to feel strong because she was unprepared for the result of the surgery.

6.3.1.9 Opposite to Ignorance

There were two peak experiences in which themes opposite to Ignorance, representing the attainment of knowledge (reported by Participants 2 & 12) were revealed. In both narratives the participants felt confident and assured because they were able to either understand what was happening to them, or felt involved in their health care. This emphasised an element of control, rather than "going along for the ride". For example, Participant 2 reported a peak experience in which she felt strength due to her attainment of knowledge. She recounted an experience after her surgery where the physiotherapist explained the surgery, the reasons she was experiencing so much pain, the recovery process, when she should expect the pain to subside, and the

types of exercises she should be doing to aid her recovery. The participant said that knowing what to expect was very important:

> **And I think communication, when you are in pain, and you have gone through something very traumatic, it's really important to tell you what to expect**, so you don't think oh my god, this is going to last forever, this is so much worse than I expected, because it was, it was quite a shock, because I didn't know how invasive the procedure was, and why it was that I couldn't recover as quickly as the girl next to me (Participant 2, p. 15).

Such knowledge made the participant feel "relaxed", "confident" and "reassured".

6.3.1.10 Conflict

Agentic stories, which demonstrate themes of Conflict, are evident when the person describes a negative experience that is the direct result of a conflict or disagreement between the person and others, including arguments or fights. One narrative showed themes of Conflict. It appeared that participants wanted to disagree when they were unhappy with a certain situation but seemed either afraid to argue with the medical staff, thought that they should be polite, or were too sick to disagree. The experience described by Participant 2, of being unable to urinate, not only showed themes of Failure/Weakness, but as she disagreed with the nurses, there was also an element of Conflict. She was uncomfortable because her bladder was full, so she asked the nurses for a catheter:

> They said "At least you don't have to do this" … **I said something sarcastic to them "Well I'm not paid as a nurse, I didn't choose that as a career path, that's your problem**, put it in … you chose to be a nurse, not me" (Participant 2, p. 17).

6.3.2 Summary

The second aim of this study was to explore themes of power and communion within women's narratives of their hospital stays using McAdams' coding scheme.

Analysing participants' interview transcripts using the coding scheme provided a structured method of exploring power, and allowed an examination of the role it plays within hospital experiences.

Exploring agency and communion themes revealed that the stories women told about their hospital experiences showed more themes of agency than of communion, with the agency themes of Self Mastery, Empowerment and Ignorance being very common. The data also showed that negative themes were more prevalent than positive themes, and themes opposite to Self Mastery through Control were the most common. Several participants recalled experiences in which they felt powerless, either because of their dependence on hospital staff for their survival, being unable to understand reasons for being sick, overwhelming and debilitating pain, or due to being treated insensitively by hospital staff. Other participants recalled experiences which showed themes of Self Mastery through Control, such as feeling in control of certain elements of their hospital stay, being able to cope with medical procedures, and showing independence or having freedom of choice. Participants also recalled experiences which showed themes of Self Mastery through Insight. As a result of having survived illness and surgery, these participants described the realisation of entirely different life philosophies.

The reports also contained experiences of feeling empowered or built up due to interactions with doctors. The doctor may have either provided the participant with information or treated them in a particularly positive manner, thereby encouraging the participant to feel strengthened and confident. In contrast, some participants reported occasions where a negative interaction with a staff member caused them to feel disempowered or demeaned.

The results also highlight that knowledge is an important source of power. Participants reported that lack of knowledge or information about medical conditions or medical procedures led to feelings of confusion, disorientation and weakness. In contrast, the attainment of knowledge was reported to lead to feelings of confidence, strength and power.

6.3.3 Communion Narratives

The following section involves the analysis of communion themes in women's narratives about hospital. Communion is manifested in the sense of being at one with others, which emphasises contact and union. Table 6 shows the number of communion

themes evident in women's peak and low memories of hospitalisation, and is referred to throughout this section.

Table 6

The Number of Communion Themes Identified in Participants' Peak and Nadir Experiences during Hospitalisation

Communion Themes	Peak experiences		Nadir experiences		Total
	Equal[a]	Opposite[b]	Equal[a]	Opposite[b]	
Caring/Helping	3		3	3	9
Unity/Togetherness	3			1	4
Love/Friendship					0
Dialogue					0
Disillusionment about People		2	8		10
Separation					0
Rejection					0
Another's Misfortune					0
Subtotal of Positive Themes	6	2	3		11
Subtotal of Negative Themes			8	4	12
Total					23

[a]The columns labelled "Equal" indicate the number of themes *equal to* McAdams' original definition of the theme. [b]The columns labelled "Opposite" indicate the number of themes *opposite to* McAdams' original definition of the theme.

6.3.3.1 Caring/Helping

McAdams (1992a) states that in narratives that show themes of Caring/Helping, the subject provides care, assistance, nurturance, help, aid, support, or therapy for another, providing for the physical, material, social or emotional welfare or well being of another person. Such narratives capture emotionally positive experiences between relative unequals in that the nurturer is relatively stronger than the person requiring assistance or care. Although most examples of being helped or cared for do not score for Caring/Helping, there is an exception to this rule. Narratives can score for Caring/Helping when a subject reports special acts of kindness done by others, even though the subject is receiving rather then giving kindness. Such narratives suggest that the subject tends to perceive the world as a caring place, where even those who are not

duty-bound to provide care may still act in very caring ways. An emotional quality of caring must accompany the assistance, which is usually associated with providing counselling or therapy concerning major life traumas or interpersonal difficulties. Developing empathy for other people, even if it is not acted upon in a given event, scores as Caring/Helping.

As Table 6 shows, six narratives showed themes of Caring/Helping, with participants describing the world as a caring place and being cared for by the health professionals in ways that were unexpected. Of the six narratives, three (Participants 3, 7 & 21) reported a nadir experience and another three (Participants 3, 12 & 14) reported a peak experience. Although the health professionals were duty-bound to provide care, the participants perceived them to be providing care beyond their duty, for which they were particularly grateful. The narratives also showed that the participants perceived the world as a caring place. For example, Participant 3, who had a laparotomy and removal of a tumour from the right ovary, reported a peak experience on her fifth day in hospital where her pain was decreasing, she was more mobile, she had commenced a light diet, was tolerating food, and she was feeling blessed that the tumour had been benign. She was feeling particularly lucky to have her supportive friends, family and hospital staff surrounding her:

> On that day **I just felt so grateful and really blessed**, and **I think part of that was that I had so much support, the support came from all sides … I felt secure, the nursing staff were really good … they were absolutely terrific, and even the domestic staff, they were just so nice, really good, nothing was a bother, you didn't feel uncomfortable about ringing the bell, they were just terrific, you couldn't fault them**, and I'm a fairly critical person, I have fairly high standards and expectations of others and myself. **So I felt very supported and secure, very grateful, very blessed** (Participant 3, p. 25).

This participant also showed empathy for other people that did not have support:

> **And then you think of other people who haven't got that support** particularly immigrants, you look at the poor

Vietnamese people that come and they haven't got that family support around them, and **you just think that you admire them so much for coping as well as they do** (Participant 3, p. 26).

Participant 3 also reported a nadir memory the day after her surgery, when she was experiencing extreme nausea:

I can remember that I must have been sitting upright at this time and I was sick and this poor middle aged nurse that came in and had been caring for me all that shift, she was due to knock off and I just threw up absolutely everywhere, it went everywhere. **And I'll never forget just how fantastic she was, she would have been tired, it was the end of her shift and she never made me feel that I was a nuisance or that I had done something dreadful** (Participant 3, p. 27).

This excerpt shows that the participant perceived the nurse to act above and beyond her call of duty, which caused her to think very highly of the nurse. As a result of this experience she was able to empathise with others in similar situations:

I think I am probably able to empathise with others better now who have been through a surgical procedure, who have been through something traumatic like that … but probably having these experiences makes you better, you realise the importance or the impact that you have as a nurse is much greater than perhaps you realised and the subtleties come through to patients in a big way **… but I think that you grow and you learn from all these experiences so that perhaps you can understand and better help someone that's facing some sort of trauma** (Participant 3, p. 29).

Two more women reported nadir experiences in which they were grateful for the care they received from nurses. For example, Participant 7 described an experience the night before surgery when medical staff needed to insert a central venous catheter, also referred to as a central line, in which a small, flexible plastic tube is inserted into the large vein above the heart, and through which drugs and blood products can be given

and blood samples withdrawn in preparation for surgery. The woman described that, at one point in the procedure, the nurse needed to leave the room and she was left alone. She looked down at her chest and began to panic and rang the bell:

> **The nurse heard the button ring and came and sat with me and let me bawl and said it's ok to cry … it was like being with an angel** in that particular context, **that kind of reassurance** (Participant 7, p. 43).

It is clear that the participant was particularly grateful to the nurse for holding her hand and allowing her to cry, and the nurse's behaviour appeared to have exceeded the woman's expectations. Another woman who had been diagnosed with breast cancer also described a low point in hospital: the first evening after having her lymph nodes removed. The woman needed to go to the toilet but she was anxious about walking because she was in a lot of pain. She was also concerned that she was not going to be cared for because an agency nurse was on duty, and she appeared "stressed" and "hassled". She was worried that they would not be able to communicate properly because the nurse had a strong accent. The nurse helped her to the toilet and washed the participant: "(I) was in agony the whole time, **but she (the nurse) was actually fantastic.… (The nurse) ended up being very kind, very gentle and really understanding**" (Participant 21, p. 180). In this narrative, although it was a particularly low point because the woman was in an extraordinary amount of pain, she reported that the care she received from the nurse went beyond the nurse's normal role. Although the nurse was very busy, she not only gently helped her to the toilet, but she washed her and her manner was gentle and understanding. As the woman was overcome with pain and was in a very vulnerable position, she greatly appreciated the nurse's demeanour.

6.3.3.2 Opposite to Caring/Helping

Three women (Participants 1, 11 & 18) each reported nadir experiences that showed themes opposite to Caring/Helping, such as medical staff acting in an uncaring and insensitive manner. Specifically, reports included doctors with poor bedside manner, failure to make eye contact, and dismissing of patient concerns, and nurses neglecting patient requests. One woman reflected:

> **A lot of people that I encountered during my hospital stay
> had no respect for me and they didn't have any time for me,
> they didn't care to. When I had concerns it wasn't a big
> deal for them … I wanted them to listen to me and pay
> attention to me** about what I was asking for and what I was
> concerned about … I don't feel that they had any respect for me
> (Participant 1, p. 8).

These narratives convey sadness on the part of the women because they were treated with disregard.

One woman who had been diagnosed with breast cancer reported a different low point, where shortly after the delivery of her results she began to think about her husband and three children. Due to this woman's illness she was afraid that she was not going to be alive to care for her family, to take care of her children, to meet their needs and to look after them during difficult times: "All I could think about was that I **wasn't going to be around**" (Participant 11, p. 82).

6.3.3.3 Unity/Togetherness

McAdams (1992a) states that the theme of Unity/Togetherness captures the idea of being part of a larger community. In narratives which show this theme, the subject experiences a sense of oneness, unity, belongingness, solidarity or harmony with the group of people, a community, or even all of humankind. A common expression of this theme involves the subject being surrounded by friends and family at an important event, such as a wedding, and experiencing strong positive emotions because a group of important people has joined him or her at this time. There were three peak experiences (reported by Participants 11, 13 & 14) which captured the theme of Unity/Togetherness. Two experiences were very similar, as the women described visiting times during their hospital stay when they were surrounded by friends and family. These narratives included descriptions of a sense of harmony, strong feelings of happiness, and being lucky to have such loving and supporting family and friends. One woman reported, "It just really made me realise how important my family were to me … it just reinforced who were the **important people in my life and who really cared for me**" (Participant 11, p. 85). Another woman expressed similar sentiments: "Having my friends come and

visit and realising **how lucky I was to have such good friends**" (Participant 13, p. 102).

One woman recalled another type of peak experience. She described the hospital atmosphere, with everyone helping each other, and she felt a sense of solidarity and allegiance that she had not experienced prior to the hospital stay:

> I saw what a lovely atmosphere there was in the hospital, **everybody helping each other and everybody being honest**, because I didn't have a very happy home and I thought I didn't know such a place and people existed.… **I didn't have much of a family, so that was my family, my friends and patients** (Participant 14, p. 107).

As a result of this positive hospital experience, this woman changed her career path from studying art and decided to become a nurse.

6.3.3.4 Opposite to Unity/Togetherness

Participant 2 described a nadir experience in which themes contrary to Unity/Togetherness such as exclusion, loneliness, separation and alienation from a group of people were identified. The participant shared a room with a young girl who had a large number of family and friends visiting her throughout the day regardless of visiting hours. She reported that every time the young girl had visitors, they would draw her curtains around her bed:

> **They would come in … and see me and they wouldn't even say hello, they would just come in and … then they would close the curtain.… so her friends kept locking me in.**… for five days all I saw was white curtains, **I was trapped**, and all I could do was listen to her and her … friends bringing her flowers and giggling and laughing … Every time I tried to pull the curtain back there would be a half an hour break before another group of her friends would come in and pull the curtain again.… **I felt like I was in the way, an unwelcomed guest in her party, and that's why they kept shutting the curtains on me, to block me out, they had no right to shut the curtains,**

> **and shut me out from the world**, but they did, they just kept
> shutting the curtains, and all I could see was white sheets
> (Participant 2, p. 16).

In this narrative, it was clear that the participant experienced strong negative emotions because she felt isolated from the group of people in her room, while the white curtain may be interpreted as a metaphor for alienation.

6.3.3.5 Disillusionment about People

The most common communion theme was Disillusionment about People. As a result of an adverse experience, the person remarks that he or she has lost faith in others (either a particular other or a group or even humankind), or is feeling disillusioned about people and about their worth or goodness. A sense of betrayal or a breaking of trust often accompanies this adverse experience (McAdams, 1988b).

Table 6 shows that there were eight nadir narratives (reported by Participants 1, 2, 6, 9, 10, 14, 16 & 19) in which themes consistent with feelings of disillusionment, such as interactions with health professionals which resulted in a loss of faith in the health care system were recalled. For example, Participant 10 was diagnosed with an ovarian cyst that had twisted around her gallbladder. Prior to her diagnosis she was experiencing excruciating pelvic pain which she explained as constant second degree labour pains. She went to the emergency ward of a public hospital and was admitted for four days, during which she was diagnosed with a cyst on her left ovary. She said that staff did not seem to understand or believe that she was experiencing an extraordinary amount of pain and was told to go home. Over the next three weeks, which she primarily spent in bed, she called the hospital and visited the emergency department several times but was repeatedly told to go home, to take panadol, that she may have a virus, that it was stress related, and the hospital could not help her. On one of her hospital visits, she was told that she had been put on a waiting list to have a laparoscopy. The participant was in so much pain that she was unable to wait that length of time. Her frustration ended when she found a private surgeon who diagnosed her condition, and realised the urgency of surgery. However, the way she was treated by the doctors in the hospital had caused her to lose faith in the health system and to distrust doctors:

> (The experience has) changed my way of thinking tremendously, I'll never be the same again. I'm highly gullible by nature … In my life now … I think hang on, I'm going to question that … and learn from my past … (Currently) **I'm very sceptical and not so trusting** … **to this day I still hold so much hurt and resentment to the fact that no one wanted to listen** … **I felt that I was stripped of everything, I had no self-esteem … I have to learn to … question things and have a bit of guard around me.** And that's what I am learning because I have found that **I have given my all and I have been trodden on** (Participant 10, p. 75).

Participant 1 spoke about a doctor who had a poor bedside manner, as he did not acknowledge her concerns or her distress, and dismissed her worries. When asked about the impact of that particularly distressing interaction, she replied, "**Unfortunately it has led me to hate all doctors**. I think the health care system is a joke, I avoid going to the doctor until it's absolutely necessary" (Participant 1, p. 7). As can be seen in this example, such adversive interactions can have disastrous effects on patients' attitudes towards the health care system. Similarly, Participant 2 was unhappy with the way she was treated by the anaesthetist because he did not acknowledge her obvious distress about having an epidural, made no attempt to alleviate her concerns, and simply walked out of the room.

> **Prior to that I was not afraid of medical procedures, I trusted the doctors and I trusted the nurses**, I'm not saying that I don't, but I've got to tell you **there're some rat bags out there** and not that they are not capable, but that their bed side manner leaves a lot to be desired, **and in future I will pick and choose my GP very carefully … you do have to shop around**, you can't just assume that just because he has 10 bits of paper on the wall therefore he must know, because it is not an indicator at all (Participant 2, p. 14).

The impact of this interaction led the participant to experience a loss of faith in the credibility of health professionals.

Two women had different nadir experiences: one woman was incorrectly diagnosed and the other was dissatisfied with the outcome of surgery. They felt disillusioned about doctors, not only because of the way they were personally treated but also because of the medical treatment. Participant 9 had been diagnosed with a dermoid tumour on her right ovary, and after it was removed she was told that it was benign. When the participant went for her check up six weeks after the surgery she was told that the results were incorrect and they had found stage three cells in the tumour, which indicated borderline malignancy. This experience caused the woman to lose faith in the medical system:

> So I think after having that experience, overall you come out feeling like you want to take more control over your own health. Because **you feel you can't completely leave it all to the medical system, that you have to trust your own instincts** and do your own homework and keep going to doctors until you get an answer … **I think I've probably lost a little bit of confidence in the health system and in doctors … should I really trust my health into somebody else's hands so completely?** … Not that I'm overly sceptical, but just keep that **little bit of reserve** that it might not always be as you expect it to be (Participant 9, p. 67).

Another woman had broken her leg, and after surgery on her knee she believed that her knee was not positioned at the correct angle to her leg. She lost faith in the medical profession because of a combination of the disrespectful way she was treated by the doctor, and the distressing outcome of the operation:

> I guess in a way you are in a position where you have to trust them … in terms of the medical profession, **no I don't trust them** and even for me to go to my GP, I have to be nearly dying to go and see him … **I don't trust them and I don't like them because I think they think they are so much better than every one else**, they don't like to admit they have made mistakes and they just choose to ignore their patients because they're so much better (Participant 6, p. 38).

6.3.3.6 Opposite to Disillusionment about People

Participant 16 described two peak experiences in which themes opposite to Disillusionment about People, such as a sense of renewed confidence in another person were shown. One peak experience concerned the occasion on which she saw a different doctor because her regular doctor was unavailable, and she was pleasantly surprised by his behaviour, "**Wow there is someone nice out here**.… that was a high point to realise that there are some doctors out there that are nicer" (Participant 16, p. 124). The other peak experience described by Participant 16 involved a positive interaction with a nurse. This participant was diagnosed with breast cancer and during chemotherapy she encountered a nurse who discussed the side effects of chemotherapy, and asked her how she was feeling. She said the peak experience changed her attitude towards health professionals: "There are people who are understanding and not willing to look at you as just being a patient" (Participant 16, p. 124). As a result of this woman's positive experiences she has shown a renewed satisfaction and hopefulness in her interactions with health professionals.

6.3.4 Summary

The second aim of this study was to explore McAdams' themes of power and communion within women's narratives of their hospital stays. Of the total number of themes coded, 32% were of communion. Reports of Caring/Helping showed experiences where participants believed that the hospital staff went above and beyond their duties, and these recollections clearly demonstrated feelings of gratefulness and appreciation. Some participants also described memories of being treated coldly and heartlessly, even though health professionals were bound to provide care.

Memories that showed themes of Disillusionment about People clearly illustrated the power of health professionals. For example, when health professionals treated patients insensitively, misdiagnosed or made mistakes, patients felt betrayed and disappointed. Such experiences had adverse repercussions for future interactions with health professionals, and implications for participants' own health, as some of the women subsequently avoided the doctor.

Participant reports of Unity/Togetherness highlighted the importance of visiting times and being surrounded by family and friends, and these experiences provided positive emotions.

6.4 Peak and Nadir Experiences before Hospital: Patterns of Agency and Communion

In previous chapters, it has been suggested that patients may have little control in hospital, and thus stories about hospital may emphasise themes of powerlessness. The following section addresses the third aim of examining whether the content of memories recalled during hospital, compared to before hospital, emphasise agency (power and control) over communion (relationships with others). To achieve this objective, from interview four onwards, the interview included a question in which women were asked to describe nuclear episodes that had occurred in their life prior to the hospital experience, as well as during the hospital stay. The addition of this question enabled the number of agency and communion themes in memories recalled before and during hospital to be compared. It was assumed that if the number of agency themes was greater in stories told about hospital experiences, compared to stories told about life events prior to the experience, the hospital situation may be one which emphasises themes of powerlessness and control.

A total of 15 participants were asked to describe nuclear episodes which occurred in their life prior to their hospital stay. Of the 15 participants, 10 reported both peak and nadir experiences before hospital. Three participants reported only nadir narratives, and two participants could not think of peak or nadir narratives in their lives before their hospital experience. In comparing these two participants with the 13 (who were able to think of peaks and/or lows prior to hospital), the one characteristic which appeared to distinguish them was that the latter two might have lacked life experience. The participants were aged 27 and 23, and had had their hospital experiences at ages 22 and 20 respectively. They spoke about their life prior to hospital in terms of completing high school, being accepted into university, and completing degrees. There was one other participant in the sample who was of a similar age (23) when she experienced her hospital stay, but she was able to think of life highlights such as travelling and work experience. Such experiences provide opportunities for the self to be challenged; for

example travelling provides the opportunity to compare one's way of life with other cultures.

For those participants who recalled nadir and/or peak experiences, one nadir, and between one and two peak experiences, were reported. Agency and communion themes appeared in 23 (96%) of the 24 memories. For one participant there was no particularly salient agency and/or communion theme in the nadir experience, and this narrative was treated as a memory without thematic content. Tables 7 and 8 show the number of agency and communion themes found in peak and nadir experiences in participants' lives before hospital. In total, 32 themes were reported. Table 7 shows that of those themes, 22 (69%) were agentic and Table 8 shows that 10 (31%) were communion themes. The next sections briefly describe the main agency and communion themes which were found in women's stories before their hospital stay. A more detailed presentation is included as Appendix K.

6.4.1 Agency Narratives

Narratives which had agency themes of Self Mastery were the most common type of narrative recounted in the participants' lives before the hospital experience. In particular, stories showing themes contrary to Self Mastery though Control, such as helplessness, powerlessness, and limitations, were the most common. For example, Participant 6 reported the nadir experience of her twin brother being in a coma: "**Just being there and not knowing, and not being able to do anything**" (Participant 6, p. 36).

Table 7 shows that the second most common theme was Empowerment. These experiences showed participants' feeling empowered and made better through their association with loved ones, nature and God. Participant 21 reported a religious experience which occurred when she was working as a nurse on evening shift at a nursing home. She was washing an elderly man with an intellectual disability, who had previously fallen and broken his hip and subsequently developed pneumonia. The patient was in extreme pain:

> **I was just in the room holding his hand and I just said a prayer. I just said "Please God, take (patient's name) out of his pain." And before the other nurse came back he died**. It was totally amazing. And she came back in and I said, "He's

dead! He's dead." And I couldn't believe it, I was just in shock. It was just an amazing thing, **it was like God had listened immediately**.… I just felt "Thank God!" literally someone's listening, someone cares about him and also that he wouldn't have to suffer any more – that he could be taken out of that place (Participant 21, p. 179).

Table 7

The Number of Agency Themes Identified in Participants' Peak and Nadir Experiences before Hospitalisation

Agency Themes	Peak experiences		Nadir experiences		Total
	Equal[a]	Opposite[b]	Equal[a]	Opposite[b]	
Self Mastery (Insight)	3		1		4
Self Mastery (Control)	3			5	8
Status/Victory					0
Achievement/Responsibility	2			1	3
Empowerment	4				4
Failure/Weakness			2		2
Losing Face					0
Ignorance			1		1
Conflict					0
Subtotal of Positive Themes	12		1		13
Subtotal of Negative Themes			3	6	9
Total					22

[a]The columns labelled "Equal" indicate the number of themes *equal to* McAdams' original definition of the theme. [b]The columns labelled "Opposite" indicate the number of themes *opposite to* McAdams' original definition of the theme.

6.4.2 Communion Narratives

Table 8 shows that Caring/Helping was the most common type of communion theme. For example, Participant 15 described a common manifestation of Caring/Helping as she recalled the care and love she felt while giving birth to her third child.

Table 8

The Number of Communion Themes Identified in Participants' Peak and Nadir Experiences before Hospitalisation

Communion Themes	Peak experiences		Nadir experiences		Total
	Equal[a]	Opposite[b]	Equal[a]	Opposite[b]	
Love/Friendship					0
Dialogue					0
Caring/Helping	3		1		4
Unity/Togetherness					0
Separation			1		1
Rejection			2		2
Disillusionment about People			2		2
Another's Misfortune			1		1
Subtotal of Positive Themes	3		1		4
Subtotal of Negative Themes			6		6
Total					10

[a]The columns labelled "Equal" indicate the number of themes *equal to* McAdams' original definition of the theme. [b]The columns labelled "Opposite" indicate the number of themes *opposite to* McAdams' original definition of the theme.

Rejection and Disillusionment about People were the second most common communion themes. McAdams (1988b) states that narratives which show themes of Rejection describe experiences in which somebody who has been a friend or lover has rejected the subject, and wishes to terminate a previously loving and caring relationship. The person must express negative affect about the rejection. For example, Participant 12 described a low point when her three children all moved out of the family home at the same time without discussing it with her. She felt she had been "left out of the plan" (Participant 12, p. 90). She expressed sadness, surprise, and shock about being excluded from the plan: "I guess I was shocked in that they only told me they were going to do it after they planned it, **I felt that there was a big line drawn between us**" (Participant 12, p. 90).

Participant 21 described a low point in her life which showed themes of Disillusionment about People. She recalled working in the aged care system and feeling

disillusioned with her work colleagues. She described them as "**lost causes … defeated people** … took no pride in what they were doing, and a lot of them mistreated the elderly" (Participant 21, p. 178).

6.4.3 Comparison of Agency and Communion Themes in Women's Narratives

Thirteen participants recalled memories of peak and/or nadir experiences both during their life before their hospital stay and during their hospital stay. Table 9 shows a comparison of agency and communion themes in women's narratives prior to and during hospitalisation. As shown in Table 9, regarding the memories recalled before the hospital experience, it was found that of the 13 participants, nine (69.2%) women recalled memories that showed more agency than communion themes, while four women (30.8%) recalled memories which showed either more communion than agency themes or an equal number of agency and communion themes. In relation to the memories recalled during the hospital experience, seven (53.8%) women recalled memories that showed more agency than communion themes, and six (46.2%) recalled memories which showed either more communion than agency themes or an equal number of the two themes. Pearson's Chi-Square showed that the difference between the number of participants who recalled agency compared to communion narratives prior to and during the hospital experience was not significant: $\chi^2 (1, N = 13) = 1.94, p > .05$.

Table 9

Comparison of the Number of Participants Recalling Nuclear Episodes by Thematic Content

Thematic content	Numbers and percentages of participants	
	Nuclear episodes prior to hospitalisation	Nuclear episodes during hospitalisation
Agency > Communion	9 (69.2%)	7 (53.8%)
Communion >= Agency	4 (30.8%)	6 (46.2%)
Total	13	13

6.4.4 Summary

A third objective was to explore whether the content of memories recalled during hospital would emphasise agency (power and control) over communion

(relationships with others). In order to explore this objective, the number of participants who recalled agency in comparison to communion narratives before and during hospital was compared. Contrary to prediction, the content of stories which were set in hospital, in comparison to stories of life prior to hospital, did not significantly emphasise aspects of power over communion. Similar to the stories told about hospital stays, memories of experiences prior to hospitalisation emphasised themes of agency, and in particular themes negative of or opposite to Self Mastery through Control. Such themes involved ideas of helplessness, powerlessness, weakness, and the inability to make a difference or have an impact.

6.5 Exploration of Hermans' and McAdams' Coding Schemes

The fourth aim of this study was to explore the relationship between McAdams' and Hermans' coding schemes. This was achieved by assessing the degree of agreement and overlap between McAdams' and Hermans' codings of agency and communion, and also by examining how information gained from Hermans' scheme could add to understandings of women's narratives. Following the coding of the interview transcripts, participants' ratings of each nuclear episode with the set of affect-denoting terms were examined, the four indices (S, O, P and N indices) were calculated, and the type of affective pattern (+S, S, –S, +O, O, –O, +HH, –LL, +LL) was determined.

Notable differences between Hermans' and McAdams' agency and communion codings must be acknowledged before comparisons can be made. First, Hermans' affective meaning of important experiences may reveal a more unconscious level of the self, in that the affects do not need to be explicitly stated or even conscious for them to be revealed. This is not the case for McAdams' agency and communion themes, as a theme can only be coded if it is explicitly referred to. Hermans' indices therefore have the potential to add to the understanding of nuclear episodes as they may reveal implicit elements. Second, McAdams and Hermans categorise certain experiences in slightly different ways. For example, Hermans considers experiences involving religious, spiritual or philosophical experiences as related to the positive fulfilment of the need for contact and union with the other (+O). In contrast, McAdams typically categorises religious experiences, such as feeling empowered by God or that God is made manifest, as the agentic theme of Empowerment. Taking these differences into account,

McAdams' themes and Hermans' indices were expected to show high levels of agreement, but a perfect match was not anticipated.

Tables 10 and 11 show the degree of agreement between Hermans' affective patterns and McAdams' agency and communion motives within all the peak and nadir experiences recounted by the sample of women. For example, in reference to Table 10, participants described five peak experiences which predominately showed more of McAdams' agency themes than communion themes, and from participants' affective ratings were considered a positive self-enhancement (+S) experience. The shaded areas show mismatches between Hermans' affective patterns and McAdams' agency and communion themes. For example, in Table 11, one participant described a low point which showed more agency than communion; however, the participant rated the experience as negative contact with others (–O). Table 10 shows that participants described 26 peak experiences and 19 of those were considered a match between Hermans' S- and O-motive scores and McAdams' agency and communion themes. Therefore, there was a 73% match. Table 11 shows that participants described 31 low points, and 26 of those memories were considered a match; therefore there was an 84% match between Hermans' scores and McAdams' themes.

Table 10

The Number of Peak Experiences Sorted by Affective Pattern and McAdams' Agency and Communion Themes

No. of McAdams' themes	The affective pattern of the nuclear episode									Total
	+HH	+O	O	–O	–LL	+LL	–S	S	+S	
More agency	5	3	1	1				1	5	16
Agency and Communion	2					1		1	1	5
More communion	1	3				1				5
Total										26

Note. The shaded areas indicate mismatches between the affective pattern and McAdams' agency and communion themes.

6.5.1 Matches between McAdams' Themes and Hermans' Indices

In the following section, descriptions of peak experiences and low points are presented which demonstrate a match between McAdams' themes and Hermans' indices. The matches are illustrated by examples from interview transcripts. As only a selection of matches is presented here, a more detailed presentation is included in Appendix L.

Table 11

The Number of Nadir Experiences Sorted by Affective Pattern and McAdams' Agency and Communion Themes

No. of McAdams' themes	The affective pattern of the nuclear episode									Total
	+HH	+O	O	–O	–LL	+LL	–S	S	+S	
More agency				1	13		1	1		16
Agency and Communion				2	3					5
More communion					8		2			10
Total										31

Note. The shaded areas indicate mismatches between the affective pattern and McAdams' agency and communion themes.

Table 10 shows that eight participants (Participants 7, 8, 9, 11, 12, 15, 17 & 19) described peak experiences, which were calculated as +HH (positive combination of high self-enhancement and high contact with others). These experiences were varied, as some participants explicitly expressed references to both agency and communion, while others explicitly expressed one motive and only implicitly referred to the other motive through their rating of affects. For example, one participant described a special time with her daughter in a park. She made two explicit references which indicated satisfying the need for contact and union with another by contact with the environment and spending time with her daughter, whom she was particularly close to. For example, "One of my favourite places … picking up **autumn leaves** and we were **lying under this tree** and we were **watching the sun through the leaves**" (Participant 11, p. 81). As this participant made no explicit reference to the S (self-enhancement) element in the

experience, Hermans' information added to the analysis of the memory, as the implicit S element may be that the participant experienced positive self-esteem from her relationship with her daughter.

Three participants (Participants 11, 13 & 14) recalled peak experiences which were assessed as +O (positive contact with others) and showed more communion themes than agency. The experiences were all very similar and described instances during hospital where family and friends surrounded them and they felt loved and cared for, thereby satisfying their need for contact and union with another. For example, "**Having my friends come and visit and realising how lucky I was to have such good friends**" (Participant 13, p. 102).

Two participants recalled peak experiences that were rated as +LL (positive combination of low self-enhancement and low contact with others), which Hermans and Hermans-Jansen (1995) identified as rare occurrences. Participant 3 recounted her fifth day after surgery, when she felt considerably better and had been told that her tumour was benign. The rating indicated that there was an absence of self-enhancement and contact and union, but this was experienced in a positive way. She repeated several times while describing the experience that she felt "blessed", "inner peace", and she realised that, "I was not what I was before but it's going to be ok" (Participant 3, p. 25). This suggests that it may be a type of spiritual experience. Hermans explains that spiritual experiences belong to the +LL type of affective pattern. The moment of the experience may be understood as a state of being empty but content, rising above motives.

Five participants (Participants 2, 12, 14, 16 & 17) had peak experiences which showed more agency than communion themes, and were categorised as a +S (positive self-enhancement) affective pattern. The experiences were very different, but the shared theme was that each participant perceived herself to be in control of her circumstances, which made her feel strong, proud and confident. For example, one woman described a peak experience that occurred when she was a teenager. She was talented at art and had received a scholarship to continue studying art. This event made her feel in control of her destiny, strong and proud of herself. The teachers continued to give her positive feedback: "After the first or second year the professor asked me if I would be a student teacher" (Participant 14, p. 108). This was another valued achievement which again increased her self-esteem.

Regarding nadir experiences, Table 11 shows that the sample recalled 24 low points, which showed a –LL (negative combination of low self-enhancement and low contact with others) affect pattern. Six of the low points were experiences before hospital, while 18 were experiences during hospital, which suggests that the hospital environment and sickness may give way to disempowering and isolating experiences. The –LL type of valuation shows high levels of negative affect and low levels of both self-enhancement and contact and union with another. Some of the experiences explicitly verbalised a lack of fulfilment in one motive and implicitly referred to a lack of fulfilment in the other, while other experiences explicitly referred to a lack of both motives. Although low levels of self-enhancement and contact and union with another were presented in different ways, the prevalent theme was that the women felt there was no way out of their predicament, with one woman clearly stating, "**I could not see the way out of it … I just had no way out, I felt I had no way out**" (Participant 19, p. 153). The experiences clearly illustrated powerlessness, because the women's actions had no bearing on their circumstances. Also, isolation was experienced as the participants were alone or with another person who did not show sensitivity or empathy, and hence they felt alone.

Participant 10 recounted a low point in her life before the hospital experience which showed more agency than communion themes, and which she rated as a –S (negative self-enhancement) experience. She suffered from alopecia, which is severe hair loss, and her recollections showed that she felt disempowered by the illness and that it greatly affected her self-esteem: "To see it all come off is awful and I think that I **never want to go outside again and deal with people**" (Participant 10, p. 76).

6.5.2 Mismatches between McAdams' Themes and Hermans' Indices

In the following section, descriptions of peak experiences and low points are presented which demonstrate a mismatch between McAdams' themes and Hermans' indices. As only a selection of mismatches is presented here, a more detailed presentation is included in Appendix L. Table 10 shows that three participants (Participants 7, 10 & 19) described a peak experience during hospital which showed more agency than communion themes but scored as a +O. For example, Participant 19 described a time when she was in hospital and she was looking at the full moon through the window. An agentic theme was evident as the experience helped her gain insight

into the meaning of life, which made her feel strong and in control. However, she rated the experience as +O. Hermans notes that valuations pertaining to a particular philosophical view of the world are related to the need for contact and union with the other. Participant 19 described her thoughts while looking at the moon:

> I thought about the seasons and the moon and how everything just keeps going and I don't have to get stressed. It was just this really comforting sense, I still get that sometimes when I go to the beach and my life has wound me up incredibly. And I go down to the beach and I think, "The waves are still coming in … You know, it's okay. **These things will pass and the waves will still be coming in**." It's just a really nice reminder that life moves and it's okay and this'll pass (Participant 19, p. 157).

Therefore it may have been a philosophical or religious experience.

Participant 15 described a low point when she woke from surgery to find herself powerless because she was so sick with dizziness and nausea, and she realised that she was extremely dependent on those around her. When she woke she realised that her friends were at her bedside. This account scored as an agency theme, as she had lost her autonomy and self-control; however, the woman rated the experience as –O (negative contact with others). As she rated anxiety as high, this may have been a case of –O anxiety, as the woman had to surrender herself to the care of the hospital staff and became overly dependent. Therefore, closeness was at the expense of her autonomy and self-control. Alternatively, as her friends were unable to stay very long, feelings of –O may have been manifested in the anticipated farewell. Additionally, she may have had the feeling that despite others being available, she was in a sense "on her own" in terms of having to deal with the experience of illness.

Participant 14 recounted a low point before her hospital experience when her mother left her and her father and took the two youngest children. She remembered that she returned home from school to find the house empty. The account was scored as a communion theme as she was separated and felt apart from her mother. However, the woman gave it a –S rating. Although her account did not explicitly express feelings of opposition toward her mother, her ratings indicated that the experience adversely affected her self-esteem because her mother's departure blocked her attempts at self-

enhancement. She did not mention anger in her account, perhaps because anger is often perceived as culturally unacceptable for women. However, she rated it very highly among the list of affects. Hermans states that feelings of anger in a –S valuation may be indicative of some implicit need for self-maintenance.

6.5.3 Summary

The fourth aim was to explore the relationship between McAdams' and Hermans' codings of agency and communion. Comparing the level of agreement between Hermans' indices and McAdams' themes revealed that there was a strong match, with a 73% match for peak experiences and an 84% match for nadir experiences. The ratings of Hermans' affects added to understandings of women's narratives by showing that although agency was the focus, there was also an implicit element of communion. Communion was manifested in memories of isolation and closeness at the expense of participants' autonomy and self-control. This finding was revealed in the differences between McAdams' and Hermans' methods. For example, participants' verbalisations of peak or nadir experiences were sometimes inconsistent with their ratings of self-enhancement and contact and union with others. This showed that Hermans' method of "participant-rated" affects has the ability to tap into implicit feelings and thoughts, whereas McAdams' method of "researcher-rated" coded themes shows that agency and communion themes can only be coded if such information is explicitly expressed. Often, communion was an implicit element of a memory such as the loneliness and isolation caused by hospitalisation and illness.

In addition, McAdams and Hermans have different classifications of events representing agency and communion. For example, the experience of becoming to close to or overly dependent on someone may involve feeling powerless and losing one's autonomy. Hermans would categorise this experience as negative contact with other (–O), and in contrast, as the experience involves a loss of control, McAdams would categorise it as an agency theme.

Hermans' indices also revealed that the sample recalled a high number of nadir experiences showing a –LL affect pattern. Further exploration showed that of the 24 memories which showed an affective pattern of –LL, six were memories prior to hospitalisation and 18 were memories of hospitalisation. In particular, examples of –LL memories during hospital highlighted insensitive treatment of patients, of staff failing to

acknowledge patient distress, and perceptions of lacking control over the future. The experiences were varied but the prevalent theme was that of powerlessness, isolation, and of feeling that there was no way out of the predicament.

6.6 Redemption and Contamination Sequences

The following section addresses the fifth aim of this study, which was to explore how women make sense of their hospital experience and find meaning in the experience to unify it with their life story. McAdams states that people use redemption and contamination sequences to make sense of major life changes. This aim was achieved by examining McAdams' redemption and contamination scenes within women's stories. Redemption scenes involve the move in storyline from a bad, affectively negative life scene, to a subsequently good, affectively positive life scene. According to Tedeschi and Calhoun (1995), good outcomes of traumatic experiences can manifest themselves as growth in one or more of the following areas: changes in self, changes in relationships, and changes in life philosophy and spiritual/existential beliefs. In contrast, in a contamination sequence, the storyteller depicts a change from a good, affectively positive life scene, to a subsequently bad, affectively negative life scene. The good is undermined by the proceeding events.

All of the participants revealed either positive or negative changes following their hospital experience, which were expressed as either perceptions of themselves, attitudes to the health care system, attitudes to life, or attitudes toward others. Eight interviewees (Participants 1, 2, 6, 9, 10, 15, 17 & 20) described negative changes to self and/or attitudes toward the health care system following their hospital stay. Six participants (Participants 3, 7, 12, 14, 18 & 19) described positive outcomes expressed as changes to self. One participant (Participant 13) described positive outcomes manifested in changes in relationships. Four participants (Participants 8, 11, 16 & 21) described positive outcomes which were evident in changes in life philosophy.

6.6.1 Contamination Sequences

Eight women described themselves in positive terms before the hospital experience, but subsequently described negative outcomes in terms of the change to self and/or their attitude towards the health care system. All of these women described at least one occasion on which they were treated in a negative manner by hospital staff,

such as with insensitivity or disrespect, and were particularly disturbed by their lack of control during their stay. Some stated that their negative attitude towards the health care system was due to negligence involving misdiagnoses and unsuccessful surgery. Others yet described negative outcomes in terms of complications that resulted in the deterioration of their state of health, and which they felt could have been dealt with differently by doctors. In general, this group of participants had something to lose; they enjoyed their life and described positive self-perceptions before hospital, and in some way each of them experienced a loss after hospital.

Participant 1 described both negative changes to her self-perception and attitude toward the health care system following her hospital stay. She was diagnosed with a congenital disorder of the spine. There was a tumour at the end of her spinal column which needed to be removed. As a result of the delicate position of the tumour, she developed bacterial meningitis, and due to the type of condition and the complications, there were many possible outcomes including death, brain damage, and nerve damage. She described her life and self-perceptions prior to the hospital stay as very positive. She lived in the country and had finished secondary school, was accepted into university and moved to the city. This woman felt on the verge of a new life chapter. She described what it meant to be admitted to hospital:

> **One of the major turning points in my life was when I got accepted into university to do the course that I always wanted to do. It also involved having to move to the city and so that in itself was a huge move for me and it also meant that I was becoming independent and my own person.** Not only was I going to be studying the career that I always wanted to have, but also I'd have to be quite self-sufficient. **So then after being at university for one year, making a few new friends and experiencing a new city and experiencing the life of a university student, that's when I got sick and that's when I had to go into hospital.… before hospital I was really excited, energised**, it was going to be a new chapter, and was going to be meeting a whole heap of new people … when I got sick and **after I was out of hospital, freed from hospital I was about to say, I had to go back home to live, and I had to rely**

on everyone in my family again, and so it was like my world was literally turned upside down because it was going from all these high expectations of what my life was going to be, to suddenly not only having to have this traumatic experience, having to be in hospital, and having had all these terrible experiences in hospital, but then I always refer to that year as the year I deferred uni, it was like **the year I stopped my life for a year, and I became quite reliant on every one, I wasn't independent … I had to put all the excitement I had about my new uni life on hold** (Participant 1, p. 1).

Becoming sick meant more to this woman than simply feeling unwell and being inconvenienced by going to hospital; it represented a loss of her new life, with hospital being synonymous to a "prison".

Participant 1 also described the hospital stay as changing her self-perceptions of an independent and energised young woman to a "weakened" person with low self-confidence:

Before my hospital experience I was far more confident. I felt really good about myself, and I liked where everything was going.… Even when I was fully recovered I felt weaker, and I felt vulnerable while I was recovering … And I even remember … my voice wasn't as strong … my friends would say to me "Your voice is strange". And I honestly feel that it weakened along with the rest of me … **I just felt not as confident … that whole thing of having all these great friends had faded and they had moved up** … they had completed their second year of uni and **I had been left behind** (Participant 1, p. 2).

This woman's hospital experience appeared to not only disrupt the planned course of her life; she also perceived it as taking a part of her life that she was never going to regain, and this was demonstrated in the feeling of being "left behind". She felt less confident, and mentally and physically weaker, and this was represented in her voice, as it appeared a metaphor for her lack of power.

This woman also experienced a negative outcome in terms of her attitude towards the health care system. She reported that she was treated with disrespect and insensitivity, and she felt that the doctors and nurses did not listen to and acknowledge her feelings and concerns. This treatment resulted in her negative attitude:

> A lot of people that I encountered during my hospital stay had no respect for me and **they didn't have any time for me, they didn't care to.** When I had concerns it wasn't a big deal for them … **the health care system is a joke**, I avoid going to the doctor until it's absolutely necessary (Participant 1, p. 7).

She also believed that this treatment played a part in her lack of confidence after the hospital stay. At the time of the interview, this was four years after the experience, and she said that it had taken her a long time to regain her self-confidence. She recalled that she had overcome the illness, but that she was still dealing with the effects of the manner in which she was treated, as this was having a lasting impact on her:

> **I'm still trying to overcome the hospital experience.** I don't know how I'll overcome it, but **I really didn't like the way I was treated. I felt a burden** because of what was wrong with me and **I had no control** of what was wrong with me.… I was constantly miserable and so worried about myself and in the end the nurses lost patience with me (Participant 1, p. 10).

6.6.2 Redemption Sequences

6.6.2.1 Changes in Self

Six women described themselves and/or their life in negative terms before the hospital stay, in terms of feeling confused, troubled and lacking control. Following the hospital experience, they perceived positive changes to self because they felt a sense of growth and perceived gains from their experience. All participants who described positive outcomes in terms of changes to self said that they were treated with respect, care, sensitivity and dignity, and there were some aspects of hospitalisation where they were able to exercise control and had freedom of choice.

Participant 7 suffered a brain haemorrhage and continued suffering multiple haemorrhages throughout her hospital stay. The surgeons decided to operate, which involved risks such as death or a major stroke. Fortunately the operation was a success. She described negative self-perceptions prior to hospitalisation, including lack of confidence, and of being confused and disillusioned about her life and the future:

> At that point in my life I was fretting about what I was doing and where I should be and who I should be … **feeling a bit inconsequential** … I was not confident about sharing my feelings, **I was terrified about being rejected … very unsure about myself** (Participant 7, p. 40).

As she was unsure of her future, the hospital stay helped her to put her life into perspective, and subsequently she developed a more positive outlook:

> **I think the experience was pivotal**, of nearly dying and coming to an appreciation of how close we all are to biting the big one, and **it was the ultimate kick up the backside** … **And the operation brought it back that I am important regardless of where I fit into the world and life's to be enjoyed for what it is and not what you perceive it should be.… the brain haemorrhage came and lifted me out of the way I was living and thinking and feeling** about most things and put me in a place where I … asked myself how I wanted to live and feel about things … **having all options removed I realised that I could go anywhere and do whatever I want** and not being able to define it right now is not necessarily a bad thing, it's actually quite liberating to realise that**.… life is something that you've got to really relish here and now, you've got to really let go of who you think you should be and enjoy being everyday** (Participant 7, p. 40).

The experience appeared to resolve her mixed feelings about herself and her place in the world. At the time she became ill, it seemed that she was in a negative mindset; thus

the hospital stay was less a disappointment or setback, in terms of something bad happening to her, but was more a means of drawing her out of her negativity.

6.6.2.2 Changes in Relationships

Participant 13 was living in America at the time of her hospital experience and was attacked by two assailants who tried to steal her bag and bit and stabbed her hand. She was admitted to hospital, as she needed intravenous penicillin to prevent infection. The experience increased her understanding of the importance of friends, especially when in hospital, because her friends provided her with support and care:

> It's made me very aware that when somebody I know goes into hospital I go and visit them to make sure they're being looked after. Because there's always something they need which isn't being taken care of. **It just made me really aware that you do need, when you're in hospital, for your friends to come and visit you** because they're the only people that are really going to look after you (Participant 13, p. 99).

6.6.2.3 Changes in Life Philosophy

Four women (Participants 8, 11, 16 & 21) had had breast cancer, and their hospital experience led them to change their life philosophies in similar ways. For example, they described themselves as busy, always on the go, and as stressed, rushed, perfectionist and goal-orientated people before the hospital experience. They described very similar changes in their perspectives on life after the hospital experience, such as "valuing life" and "every day is precious". They had very similar messages which they were able to take from their experiences:

> **Not bother with things that cause you stress and you can't change** – just **go with your heart** and **enjoy life** to the full really. How much we take it for granted (Participant 11, p. 87).

> Pain and hardship can be overcome when they come into your life and that life does contain suffering and pain. I've always thought that it doesn't, but it does.... I definitely don't get so

depressed about things that happen that are bad. **I don't feel like it's the end of the world when things aren't going as planned** (Participant 21, p. 184).

Participants describing positive outcomes manifested in changes to life philosophy mentioned occasions during their hospital stay when hospital staff treated them insensitively; and yet, unlike participants who described contamination scenes, such treatment did not appear to affect their attitude toward the health care system and they described positive outcomes. They appeared to describe an outcome that optimised their ability to feel better about their circumstances, and which essentially produced coherence within their life story. They appeared to understand that life contains hardship, but they had reconstructed a way to live their life with this knowledge, thereby changing their life philosophy.

6.6.3 Summary

This section presented data on the fifth aim of this study, which was to examine how women made sense of their hospital experience, and found meaning in the experience to unify it with their life story. This was achieved by exploring McAdams' redemption and contamination sequences within women's stories about their hospital experience. Coding women's transcripts for redemption and contamination scenes identified the outcomes of hospital experiences in terms of the impact the experience had on the sense of self and on attitudes towards the health care system. Regardless of the type of outcome, most participants showed they had learned from the experience. Some participants learned that they needed to be educated about health issues, to be assertive with health professionals, while others developed a greater understanding of themselves or an enhanced appreciation of their relationships with others. A highlighted difference between participants who had predominately negative outcomes and those who had predominately positive outcomes reflected in changes to self was their perception of control and the way they were personally treated in hospital.

6.7 What Women Want: Examples of Good and Bad Practice Displayed by Health Professionals

The following section examines the sixth aim of the study, which was to understand how women want to be treated by health professionals. This aim was

achieved by asking participants to describe examples of good and bad practices displayed by medical staff during their hospital stay and the manner in which they wish to be treated. Women's stories reflected that they appreciated behaviour such as showing care, concern and compassion (highlighting McAdams' communion theme of Caring/Helping), as well as practical behaviour, such as giving explanations and information (highlighting the opposite of McAdams' agency theme of Ignorance).

The participants emphasised that they appreciated it when the medical staff treated them like people rather than patients. This desire seemed to reflect the reverse of the power theme of diminished patient rights. Participant 6 emphasised that she wanted to be treated like a person:

> **To be treated as a person rather than "You're my job lot that I have to do**", and to have someone explain things to you rather than to shove things in front of your nose … **I just felt like I was a no body, I wasn't even a living thing** (Participant 6, p. 38).

This powerful statement demonstrates that when health professionals treat patients with discourtesy and insensitivity, it can leave an undeniably harmful impression on the patient. Examples of "personalised" treatment included nurses and doctors using humour, acting in a causal manner such as chatting about everyday affairs, and respecting patients' basic rights:

> **The staff treated me like a human, we told jokes, my surgeon would come in and throw his jacket on the chair and lie down on the bottom end of the bed and say, "I'm tired, can you move over please". We had a really good relationship, there was humour, we had a very good rapport,** and he wasn't the type of surgeon to stand at the foot of the bed, **he would come in and hold my hands and asked me what I wanted to do**. And a lot of the nurses would come in, and my Mum came in every day so there were always plenty of magazines, so all the nurses would be gossiping about who was sleeping with who, so during those times you could almost

forget the context and I think that helped a lot (Participant 7, p. 43).

Another example of being treated like a person was demonstrated when nurses and doctors acted in ways which showed that they cared. For example, Participant 7 also commented on the behaviour of the nurses. She had a brain haemorrhage and needed surgery, and was in a lot of pain. When she was unable to take more pain medication, the nurses helped her through the difficult times:

> The nurses they would come back and quietly run around and sit and **hold my hand, and bathe my forehead with lavender oil and a cool flannel and just talk to me**, they gave me such a belief in the human capacity to love and care and compassion (Participant 7, p. 42).

Such a simple but considerate act continued to remain in the memory of the participant. Similarly, Participant 10 commented on the kind act of her doctor holding her hand before she went into surgery: "For the first time someone showed some type of **compassion**" (Participant 10, p. 73).

Participant 3 commented on the behaviour of a nurse, which remained with her:

> I can remember that I must have been sitting upright at this time and I was sick and this poor middle aged nurse that came in and had been caring for me all that shift, she was due to knock off and I just threw up absolutely everywhere … I'll never forget just how fantastic she was, she would have been tired, it was the end of her shift and she never made me feel that I was a nuisance or that I had done something dreadful.… she was of the old school, she had trained in the old system and **she was just a very dedicated and a lovely person who didn't make heavy weather of a bad situation.… I was just so grateful that she was helping me, just really really glad that she was willing to help me** (Participant 3, p. 27).

This woman was obviously particularly grateful that during a difficult time she was made to feel comfortable and was well cared for.

The participants also emphasised that they appreciated and wanted to be treated with respect and sensitivity. This need also reflected the positive side of the power theme of disrespect and insensitivity. Most of the participants commented that to ensure such treatment, doctors needed to visualise themselves in the shoes of the patient, to develop empathy, especially in situations where the patient's dignity was at risk. For example, when Participant 2 described the occasion when nurses laughed at her because she asked for a catheter, she said she wanted to be treated "**More respectful** and a little bit **more empathic of what I was going through**" (Participant 2, p. 17). As described in the previous section, Participant 15 emphasised that hospital staff need to understand the role of the patient and the great significance of being dependent on staff for one's survival.

Many of the women also commented that they appreciated and needed to be listened to by hospital staff. Upholding this basic right not only ensures women's continued faith in the health care system, but is also empowering. Discounting patient opinions can be damaging to self-esteem and can cause helplessness. Once again, this desire reflected the contrary of the power theme of not being listened to.

Participants commented that they appreciated doctors and nurses who treated them with common courtesy. This treatment included nurses' and doctors' taking the time to ask patients how they are coping, acknowledging concerns, coming into their room to see them or check on them, and introducing themselves when they approach the hospital bed. For example, Participant 11 described the behaviour of her surgeon after she had had a bad day: "**He said 'I believe you've had a really low day.' So he knew … and acknowledged it**" (Participant 11, p. 84). Participant 2 commented on the behaviour of the night nurse: "**She just kept coming in to check if everything was OK … she was really caring**" (Participant 2, p. 12). She also said that she appreciated it when the physiotherapist "introduced herself by her first name and her surname … **she was quite down to earth**" (Participant 2, p. 15). The importance of common courtesy was also emphasised by Participant 1. She wanted to be acknowledged and addressed when doctors approached her bed, and she wanted doctors to explain the procedure involved in medical tests:

> When the specialists came in and they sort of walked in and
> (boyfriend) just walked out, they didn't walk in and say "We're
> about to do some tests with (patient)", or "We're about to talk to

(patient) now so if you're visitors, if you wouldn't mind leaving, we'll be about five minutes, and then you can come back in, you can go and grab a coffee", they walked in and they stood at the foot of my bed and they talked to each other and (boyfriend) just got up and left. We assumed they were there to see me and then they shut the curtains, so whoever else was there just left.… I would have liked them (to say) "Hello (patient)" and then "We are here to speak to her", or "We're (patient's) doctors, I'm doctor blah blah and I'm doctor blah" and not necessarily introducing their titles, and "If you wouldn't mind leaving" (Participant 1, p. 4).

Participants reported that they found it helpful when medical staff answered questions or explained diagnoses and options in language they could understand. This appeared to reflect the opposite of McAdams' theme of Ignorance, as they were able to experience mental strength. Participants commented that they felt empowered when they were able to discuss aspects of their care, as they felt they were treated like a partner rather than "just there for the ride" (Participant 8, p. 57). For example, Participant 2 thought that communication was important: "**Communication, when you are in pain, and you have gone through something very traumatic, it's really important to tell you what to expect**" (Participant 2, p. 15). Participant 20 had had an abdominal operation and was very distressed when she experienced wind after the operation. She commented that no one would explain what was happening and she became distraught as she thought of the possible explanations for her wind pain:

And then I was worried they'd done something to my bowels, that was the other thing. I was absolutely paranoid.… So that was my other fear, what if something was blocked there? **And nobody cared** and I was just going to blow up.… I just remember thinking, I'm in a hospital and here I am, I can't go to the toilet and I was really worried that everything was blocked off (Participant 20, p. 167).

This woman's account demonstrates the importance of doctors' communicating with patients, including information that doctors would normally take for granted.

6.7.1 Summary

This section explored the sixth aim, which was to understand how women want to be treated by health professionals. Apparently simple and small acts of kindness such as a smile, acknowledgment, or common courtesy, which may be taken for granted in daily life, appear very important during a hospital stay. Throughout participants' transcripts, it appeared that doctors may not be aware of the power of their behaviour. However, such behaviours play an important role in empowering patients and in determining the outcome of the hospital stay.

6.8 Summary of the Main Study

The four power themes found in the pilot study included disrespect/insensitivity, diminished patient rights, lack of acknowledgement and not being listened to. These four themes continued to be evident in the data of the main study and highlighted that power and agency played subtle but important roles in women's hospital experiences.

Identifying McAdams' agency and communion themes in women's stories about their hospital experiences revealed that agency themes were most prevalent. Participants' reports of feeling powerful or powerless were due to a variety of factors. For example, feeling powerful involved participants acquiring information and knowledge, being treated in positive ways by medical staff, changing their life philosophies, acquiring wisdom, and participating and feeling involved in the health care process. Reports of feeling powerless involved having to continually depend on staff, feeling pain and bodily weakness, not being able to understand the illness or its causes, lacking information, and receiving insensitive, disrespectful and unempathic treatment.

Comparing McAdams' themes in memories recalled before and during hospital revealed that there was no significant difference in the number of agency and communion themes. Stories about hospital did not emphasise power. Instead, power themes were prevalent in stories told about lives both before and during hospital. Specifically, themes opposite to Self Mastery through Control, such as helplessness and powerlessness, prevailed.

The women's stories also revealed McAdams' redemption and contamination scenes. McAdams states that people use redemption and contamination sequences to

make meaning from traumatic and life-changing experiences. The women reported changes to perceptions of self following their hospital experience. For example, some women viewed themselves as capable of dealing with life's challenges, while others viewed themselves as "weaker" due to the difficulties encountered during hospital. Some women reported relationship changes after the hospital experience in the sense of closeness or the deeper appreciation of peer support. Other women showed changes to their life philosophies, which incorporated a sense of wisdom, of shifting priorities, or of a greater degree of spirituality following their experience. The women also reported changes to attitudes toward the health care system. For example, the interview transcripts revealed feelings of being disillusioned by health professionals, of losing faith in the health care, and of wanting to avoid doctors. However, there were also positive outcomes, such as wanting to join the health profession, viewing nurses in a positive light, and feeling inspired by the care and sensitivity exhibited by health professionals. A commonality among the women was the importance of sensitive and courteous treatment during hospital. These participants believed that personal treatment plays a part in the outcomes of hospital stays, as the powerlessness and helplessness experienced as a hospital inpatient may be intensified if patients are treated in a negative manner.

The underlying message was that patients should be treated as autonomous and independent individuals, with respect, sensitivity, and acknowledgment of their concerns and distress. Also, feeling validated and listened to is empowering and plays a key role in ensuring satisfactory hospital experiences. This finding revealed that narratives involving good outcomes showed ideas opposite to the power themes, ideas consistent with McAdams' themes of Self Mastery through Control, Empowerment and Caring/Helping, and ideas opposite to Ignorance and Disillusionment about People.

The next chapter summarises, discusses, and integrates the results from both the pilot study and the main study. Limitations are addressed and some suggestions are made for future research in the area of control and of women's hospital experiences.

CHAPTER SEVEN

INTEGRATION AND SUMMARY OF THE RESEARCH

7.1 Overview of the Chapter

The preceding chapters presented the theoretical and empirical underpinnings of the current study, and the findings of the research undertaken. In this chapter the findings of the empirical studies are summarised and integrated. The process begins with a brief examination of the need for and importance of this research, then reiterates the adopted framework and the findings. The implications raised by the findings are then discussed, limitations of the current research and future directions considered, and conclusions that may be drawn from the thesis presented.

7.2 Rationale of the Study

The medical view of women, as both professionals and patients, has at times been reported as negative. Professional medicine was primarily defined as a masculine field, and women experienced many difficulties in studying medicine and entering the medical register. Currently in Australia, men continue to dominate the health care system as medical practitioners and women constitute the majority of health consumers. In addition, traditional gender role stereotypes have been shown to play a part in doctors' perceptions of their patients. Gender and gender inequality are likely to be just as important in a hierarchical social structure such as a hospital, as they are in wider society. Therefore, female inpatients may be particularly vulnerable in the low power position of a hospital inpatient, and may find it difficult to act as autonomous, confident and capable adults.

7.3 Power Themes

The pilot study conducted as the first part of this research project highlighted that, while the majority of the women were satisfied with their hospital stays, the experience of powerlessness was a feature of hospital inpatient life. Feelings of powerlessness were more likely to be associated with significant and lengthy hospital stays involving serious medical conditions. In the pilot study, the quantitative data reflected the themes which emerged in the qualitative data. The data showed that some women were distressed by the non-medical aspects of their treatment, such as

behaviours on the part of health professionals that influenced participants' sense of control while they were hospital inpatients. These included the women's recognition of examples, during their hospital stays, of disrespect, insensitivity, diminished patient rights, lack of acknowledgment, and not being listened to by hospital staff. In addition, the aforementioned power themes were also consistently revealed in the data of the main study, which demonstrated their importance.

Disrespect and insensitivity involved incidents such as uncaring and unsympathetic behaviour on the part of medical staff. For example, having symptoms discounted or treated with sarcasm. This sort of behaviour caused participants to feel sad and alone. Some of the women in both the pilot and main study samples expressed the importance of being treated with respect and sensitivity, because sickness is a time of vulnerability and dependency. As patients were at least partly dependent on staff for their well being, such vulnerability was intensified when they were treated with disrespect. This type of behaviour revealed the power imbalance between the sick and the healthy person. Consistent with the research conducted in the 1970s (e.g., Tagliacozzo & Mauksch, 1972), women who were treated in an unsympathetic, rude or otherwise negative manner felt powerless to take action, assert themselves and express their dissatisfaction, for fear of compromising their treatment.

Some women in the pilot and main studies described situations where they experienced diminished rights or loss of status. These involved, for example, being treated in a childlike manner such as being scolded or being reprimanded by nurses during their hospital stay for failing to abide by orders. Other manifestations of this theme involved participants' feeling that the medical staff distrusted their opinions or their ability to make decisions. Participants interpreted this treatment as doctors' being overly controlling and as discounting the patient role in the health care process. Other participants described incidents related to hospital routines in which they felt they had no basic rights, such as nurses on night shift being noisy while patients were trying to sleep. This treatment was described as disempowering because patients felt insignificant in the hospital environment.

There were also instances where the women felt that they were invisible or ignored. Such instances included both physical and emotional lack of acknowledgment. For example, patients complained that medical staff did not greet them, or introduce themselves prior to an examination. Patients described experiences where they felt

doctors or nurses did not take their concerns or anxieties into account. More often than not, the ignoring of patients resulted in negative repercussions, such as patients' avoiding subsequent consultations with the doctor and reports of feeling angry, lonely and sad.

The participants described occasions where they felt that health professionals were not listening to their accounts of symptoms or their concerns. In addition, participants interpreted hasty decisions by doctors or scepticism about their pain or symptoms as instances in which they were not listened to. The women interpreted this as the medical staff's distrust of patients' ability to care for themselves and as wanting to take full control of the health care process. This sort of treatment highlighted the power asymmetry that exists between the doctor and the layperson, in which the doctor perceives that he/she "knows best". This negative treatment led to a range of adverse outcomes such as low self-esteem, feelings of unworthiness, defeat and helplessness. The strong negative effects of this sort of behaviour may be explained in the close relationship women have with their bodies (see Gergen, 1992, 1994). Women may feel very strongly about their knowledge and intuition concerning their bodies, and if this is not listened to, their sense of self may also be compromised, which may be manifested in the range of harmful ramifications described by women.

The results broadened the idea of the role of power in hospital and highlighted the complex nature of power within the health professional–patient relationship. The comprehensiveness of the data suggests that hospital experiences are a salient aspect in the lives of women, which in turn supports the importance of such a study. The results of the pilot study provided a starting point, a glimpse of the importance of power issues, and a basis from which to move forward. It raised questions such as: Given that critical illness throws people into emotional turmoil, and powerlessness is likely to be manifested during hospital stays, what is the effect of such powerlessness, not only in terms of women's attitude to the health care system but also of the impact on their sense of self?

7.4 The Main Study

The main study developed from these questions and utilised the narrative theoretical framework of McAdams' Life Story Model of Identity. McAdams (1993) argues that people tell stories to make meaning and to provide a sense of order to

everyday life, and that through stories people establish a sense of who they are. Some narrative theorists (e.g., Kirkman, 1999) say that narrative structures life; therefore, if the very structure of life is shaken, then the use of narrative is necessary in understanding life disruptions. The experience of hospitalisation has the potential to threaten life narratives and disrupt the life path, and thus affect the life story. For example, certain elements of narrative are disrupted during hospitalisation. First, personal use of time is disrupted when one enters hospital as a patient, and time usage is in the control of hospital staff. Second, hospital can threaten a person's sense of self because a patient lacks normal social interactions. In addition, disempowering treatment and invasive medical procedures can threaten identity. On the other hand, hospitalisation may be perceived as a time of self-discovery and reflection, which may positively impact on identity. Third, people who have had a traumatic hospital experience may question basic assumptions about themselves and the world, and their perceived ability to control and understand the world may be shaken. Finally, hospitalisation can threaten the flow and unity of the life narrative, acting as a disruption to one's plans and ambitions for the future, and one's links with the past. The large quantity of published accounts of illness would seem to provide evidence of people's desire to tell stories about their illnesses. This desire may stem from the need to explain the experience to themselves and others, to unify it with the life story, and to make it meaningful.

7.4.1 Patterns of Agency and Communion

Transcripts of 19 women's structured interview-based narratives about their hospital experiences were coded according to McAdams' coding system of agency and communion. This revealed that the interviews contained more agentic than communion theme content. Agency is manifested in stories of self-protection and self-assertion, or powerlessness and weakness, and such stories highlight separation from others. As the literature indicates that the hospital environment can take control away from hospital inpatients, particularly female patients, it was expected that the women's narratives about their time in hospital would emphasise ideas of control and powerlessness, and this was the case. Additionally, as was expected, negative content was more prevalent than positive. This finding was likely, because stories about serious illness and lengthy hospital stays are, more often than not, unpleasant. The most common theme was one

that expressed the negative or opposite of McAdams' agentic theme, Self Mastery through Control. Women expressing this theme revealed stories of powerlessness due to physical debilitation, loss of control over bodily functions, dependence on medical staff and lack of autonomy, and anxiety associated with the uncertainty of illness. These stories highlighted the powerlessness associated with illness, and revealed the power imbalance between the sick person and the healthy person. These findings also built on the pilot study as they showed that powerlessness is not only associated with the way medical staff treat patients but can be experienced in a variety of situations. In particular, the pilot study showed that the way in which hospital staff treat patients can be a source of powerlessness. In addition, the main study showed that feelings of powerlessness can also arise from loss of bodily functions, pain or dependency on hospital staff.

Consistent with the findings of the pilot study, another expression of the theme revealing the negative of Self Mastery through Control was found in stories describing helplessness associated with medical staff treating patients inappropriately, such as insensitively, disrespectfully and in a dehumanising manner. This aspect of the theme highlighted the power imbalance between the medical staff and the patient, where the medical staff were in a position of authority, and the patient was in a vulnerable state and often did not feel comfortable asserting herself for fear of poor treatment in the future. Stories involving the negative or opposite of Empowerment highlighted the effects of unsatisfactory interactions with medical staff. For example, medical staff treating patients in discourteous and disrespectful ways caused participants to feel demoralised, disempowered, or weakened.

Another common agency theme was Ignorance, where participants were unable to claim mental strength due to a lack of knowledge about medical procedures or causes of pain and illness. Lack of mental strength resulted in feelings of helplessness, increased vulnerability, fear or weakness. These findings highlighted that "knowledge" places health professionals above patients, which contributes to the power imbalance.

On a more positive note, themes of Self Mastery through Control were evident in stories where participants felt in control of the situation, of their feelings or reactions, and where they experienced freedom of choice. These stories represented progress from being ill to regaining strength and confidence, which strengthened women and reflected their hopes of recovery. Stories of control appeared important for the majority of

women, who described themselves as independent individuals. Therefore, describing situations that they were able to master was in accord with images of themselves as autonomous women. Such stories are also important because they have implications for clinical practice. For example, empowering patients by offering treatment options and involving them in their treatment can inform good practice guidelines.

Having experienced serious illnesses and undergone major surgery, some women also described stories with themes of Self Mastery through Insight. Upon reflecting on their experiences, the women described changes in their perspectives on life or health. Some had subsequently acquired different life philosophies, experienced dramatic insights into their personalities, or the meaning of their own lives. These insights were reported as still important to the women in their current life situations.

The agentic theme of Empowerment was also relatively common, and was manifested in stories of positive interactions with medical staff, which enhanced or built up confidence in the female patients. Such interactions also emphasised that, when staff treated patients in a supportive and compassionate manner, patients felt empowered. Similar to stories of Self Mastery through Control, stories of Empowerment gave participants hope of recovery and the anticipation of the return of their independence. The interactions included occasions in which medical staff gave participants information or skills regarding rehabilitation or how to adapt to different lifestyles post-hospital. Accounts involving themes opposite to Ignorance emphasised that the attainment of knowledge, which led participants to feel strengthened, assured, confident, in control and involved in their health care, was very important. This finding stressed the benefits of health professionals' sharing their professional knowledge. These findings can also inform clinical practice; they show that compassionate treatment and information can empower patients.

Women's stories revealed a paucity of communion theme content. Communion is manifested in the sense of being at one with others or feeling isolated, which emphasises contact and union. The communion theme of Caring/Helping indicated that participants felt cared for and supported by medical staff through special and unexpected acts of kindness, such as being cared for physically and emotionally (holding the patient's hand, exhibiting understanding and gentleness). Although health professionals are expected to provide care, the participants recalled incidents of kindness which they perceived as beyond the call of duty. Such interactions made them

feel grateful, lucky and blessed. Stories showing themes opposite to Disillusionment about People revealed the benefits of positive interactions with health professionals. Examples were being treated sensitively and with respect, which resulted in renewed confidence in health professionals and optimism about future interactions.

Participants also described medical staff acting in uncaring ways, which was characterised as opposite to Caring/Helping. Examples include medical staff exhibiting poor bedside manner, dismissing patient concerns, and neglecting patient requests. Such treatment led participants to feel sad and alone. Stories of negative interactions with medical staff, incorrect diagnoses, or unsuccessful operations resulted in a loss of faith in doctors or in the medical system as a whole, and such stories were characterised as the communion theme of Disillusionment about People. Some participants described feeling let down or betrayed, which had led them to question the worth or goodness of health professionals.

7.4.2 The Prevalence of Agency Themes

The number of agency and communion themes found in nuclear episodes prior to and during hospitalisation were compared to determine if the hospital setting emphasised ideas of power. Contrary to expectation, it was found that there was no significant difference between the number of participants' recalling memories of agency compared to communion about life prior to and during hospital. Women's stories set in hospital did not emphasise ideas of power and agency any more than did stories about their lives in general. Rather, it was found that similar to the patterns of agency and communion within stories about hospital, narratives about life before hospital showed that agency themes were more common than communion themes. Similarly, the opposite of Self Mastery through Control was the most prevalent theme; this also emphasised the pervasiveness of negativity within the lives of this sample. Analysing women's stories according to Hermans' list of affects supported these findings, as –LL (a code representing negative combination of low self-enhancement and low contact with others) was the most common type of affective pattern. This pattern indicated a prevalence of powerlessness and isolation in the women's stories of their lives before and during their hospital stay.

Gergen's (1994) research on men's and women's autobiographies is consistent with the present findings, as she found that women's stories often express emotional

experiences, traumas, self-depreciation, self-doubt and self-destructiveness. One explanation for this finding is that people generally tell stories which conform to conventional and acceptable cultural forms (Gergen & Gergen, 1988; Gergen, 1992, 1994; Gergen & Gergen, 1993; McAdams, 2001). Generally, the high status man plays the hero and is the central figure of narratives. Women rarely play the central role, and have traditionally been denied narratives of power (Gergen & Gergen, 1988; Gergen, 1992, 1994; Gergen & Gergen, 1993). Feminists such as Heilbrun (1988) argue that in Western societies, many women "have been deprived of the narratives, or the texts, plots, or examples, by which they might assume power over – take control over – their lives" (Heilbrun, 1988, p. 17). Women tend to be cast in roles that are defined as stereotypically feminine, such as passive and service-orientated positions. Women typically play the helpless female, dependent on the male lead, to be wooed and won (Gergen & Gergen, 1988; Gergen, 1992, 1994; Gergen & Gergen, 1993). McAdams states, "It is painfully clear that life stories echo gender and class constructions in society and reflect, in one way or another, prevailing patterns of hegemony in the economic, political and cultural contexts wherein human lives are situated" (McAdams, 1992b, p. 112). McAdams (2001) and Gergen (1992, 1994) argue that analysing the content of life stories reflects the culture in which the story is told, at least as the author understands the self through biographical means. The prevalence of themes reflecting powerlessness may reflect this sample's perceived position in society. If this is the case, women who are already vulnerable due to their position in society may be even more vulnerable in hospital due to its patriarchal structure.

Another explanation for this finding is that the context in which the stories were told might have influenced their content. The participants were aware that the research was about hospital experiences; therefore they might have been "primed" to discuss hospital experiences rather than life in general. Stories may thus have emphasised themes of negativity and powerlessness. Alternatively, the pervasiveness of accounts about powerlessness and negativity may have been due to a selection bias. The selection criteria of having had a hospital experience of three nights or more that was perceived as significant in terms of the development of the self may have attracted a group of women who were particularly vulnerable in comparison to women in general.

7.4.3 How do Women Understand a Change in their Identity after a Life-Altering Hospital Experience?

Coding McAdams' redemption and contamination sequences within women's stories provided a means of exploring the outcomes of hospital stays and how participants made sense of their experiences. Redemption sequences involve the storyline moving from a bad, affectively negative life scene, to a good, affectively positive life scene. Eleven interviewees (58%) described redemption sequences and expressed positive outcomes from their hospital experiences. Of the 11 interviewees who described positive outcomes, six described positive changes to self, one described changes in relationships, and four recounted changes in life philosophy. Specifically, the women who described positive changes to self showed a distinct change from a negative self-concept to a positive self-concept in the aftermath of the hospital stay. These women described their pre-hospital life and their sense of self in negative ways, and the hospital experience appeared to be a means of lifting the women out of their negativity. For example, Participant 7 stated:

> **The brain haemorrhage came and lifted me out of the way I was living and thinking and feeling** about most things and put me in a place where **I could look at it and think well that's not productive**, and I asked myself how I wanted to live and feel about things, **it sort of gave me that perspective** (Participant 7, p. 40).

The present findings of positive outcomes in the aftermath of serious illness are consistent with the work of Charmaz (1983), who conducted interviews with 57 chronically ill people with varied diagnoses. She found that some people experience episodes of illness as tools of self-discovery and as an important source of self-development. In addition, the women who described redemption scenes emphasised that they were treated with care and compassion, and they noted that some aspects of the hospital experience were within their control. These findings show that McAdams' themes of Self Mastery through Control, Empowerment and Caring/Helping were often described in redemption narratives.

Of the remaining participants who described redemption narratives, four women had had breast cancer, and their hospital experience led them to change their life

philosophies. For example, they described themselves as busy, stressed, and as goal-orientated people before the hospital experience. After the hospital experience, they described very similar changes in their life philosophies, such as learning to enjoy life, "not bother with things that cause you stress and you can't change" (Participant 11, p. 87), and "I don't feel like it's the end of the world when things aren't going as planned" (Participant 21, p. 184). As these four women were the only participants with breast cancer in the sample, and were the only participants who showed changes in life philosophy, it would be interesting for future research to examine the role of type of illness in impressions of hospital experiences. Specifically future research could examine the relationship between illness type, perceptions of power and outcomes.

In contrast, in a contamination sequence, the narrator described a change from a good, affectively positive life scene, to a subsequently bad, affectively negative life scene. The good was undermined by the proceeding events. Eight participants (42%) described their life prior to their hospital experience as positive, but the positive life scene was undermined by the subsequent hospital experience, causing participants to describe non-adaptive changes to self and/or attitudes toward doctors and the health care system. In terms of negative changes to self, these findings were also consistent with the findings of Charmaz (1983) and Cartwright (1964). Their research showed that poor quality interactions, such as disrespectful treatment, lack of courtesy, the feeling of being infantalised or ignored can cause patients to feel depersonalised and can also result in the loss of self. These findings show that the power themes generated by the pilot data and themes opposite to McAdams' Self Mastery through Control, Empowerment and Caring/Helping were often described in contamination narratives. In terms of undermining women's attitudes to the health care system, the finding of this thesis is also consistent with past research reviewed in Chapter Two (Gridley et al., 1998; Taylor & Dower, 1997), as negative interactions with health professionals have been shown to have a detrimental effect on future relationships with the health system. This has important implications for women's health, as some women reported wanting to avoid subsequent consultations.

The hospital experiences described in the contamination sequences were unsatisfactory due to a variety of reasons, such as the manner in which participants were personally treated, negligence on behalf of the medical staff, or continued health complications which participants believed could have been dealt with differently.

Importantly, personal treatment (such as insensitivity and discourtesy) and control issues were again the main features of their stories. The group of women who described contamination scenes appeared to have much to lose; they had enjoyed life and reminisced about how they "used to be", and gave the impression that they could never "return" to the person they were pre-hospitalisation. This finding was consistent with research reviewed in Chapter Four (e.g., Doolittle, 1992; Wyller & Kirkevold, 1999) that emphasised the importance of returning to the life led prior to the onset of the illness or traumatic event. It appeared that the hospital experience took something away from the participants, whether it was their faith, self-esteem or health, and they perceived it as unrecoverable.

Coding redemption and contamination scenes once again emphasised the importance of perceived control during hospitalisation. McAdams draws on Tedeschi and Calhoun's (1995) research on redemption, and they state that a factor that can affect recovery from a traumatic event is a perceived lack of control over the event and/or its effects. The present findings were consistent with this notion, as participants who felt that they lacked control during their hospital stay, regardless of the reason for the lack of control, described negative outcomes in comparison to participants who reported some control.

As mentioned, the findings also emphasised the importance of the way women were treated by health professionals, as personal treatment played a part in determining the outcome of the hospital stay. However, the finding raises the question of why personal treatment was so significant in the hospital experiences of this sample. In daily life, people are often treated with discourtesy and insensitivity. For example, the bank teller, the shop assistant, or friends and family may show discourteous or unsympathetic behaviour, without much damage ensuing. However, such behaviour appeared to have a considerable impact on the women when they are sick. When participants spoke about experiences in their lives prior to their hospital stay, there were no recollections of instances of disrespect and insensitivity. However, when the participants described experiences during their hospital stay, many occasions involved insensitive or rude behaviour. It is upsetting to be treated negatively, but when one is sick, due to the vulnerability attached to the sick role, the distressing effects may be intensified. Participant 15, who described negative outcomes, echoed these sentiments:

> **It can be the way you're spoken to or the way you're treated**
> **that can have a big impact … You're quite powerless when**
> **you're really unwell** … If they (hospital staff) haven't been a
> patient themselves they need to have the experience to get in the
> bed and **experience what it's like to be helpless** and to wait for
> someone else to bring you a jug of water, or bring you some
> pain relief … **But I'm certainly aware when I'm unwell I'm**
> **much less empowered and much less able to assert myself**
> (Participant 15, p. 118).

In addition, the vulnerability of the sick role and the distressing effects of insensitivity may be intensified in a female inpatient. Gergen (1992, 1994) and Gergen and Gergen (1993) found that women refer to their bodies as an integral aspect of their identity. Thus, violations of the body represent invasive negations of identity. Considering women's close identification with their body, their vulnerability as hospital inpatients may be intensified and they may be particularly sensitive to negative treatment in environments where their body is potentially at risk.

7.5 Good Quality Service

In the pilot study, the women used stereotypical masculine characteristics to describe their treatment or interaction with health professionals, such as "controlled", "hard", and "standoffish". In both the pilot and main study samples, the women appeared to prefer interactions to reflect stereotypically feminine values and beliefs, in other words, the "softer" side of human interactions such as kindness, care, empathy and sympathy, which emphasise process rather than outcome, connection rather than detachment, and care rather than cure. As the female participants described their "perceived" medical treatment in masculine ways and described their "preferred" treatment in feminine ways, there may be a mismatch between this sample's expectations and the type of care they are receiving. Suggestions by participants of how women wanted to be treated by health professionals were related to both personal treatment (such as being treated with care) and practical treatment (such as the giving of information). The transcripts of the pilot and main studies emphasised practices that empowered patients and allowed them to feel involved in their health care and cared for. The examples of good practice also consistently corresponded to the power themes,

McAdams' agency and communion themes and narratives of redemption and contamination.

In terms of personal treatment, participants said that they disliked being treated in a dehumanised or detached manner. Practical examples of personalised behaviour on the part of health professionals involved expressions of caring, holding the patient's hand, acting in a friendly casual manner, and telling jokes. It may be difficult for some doctors to show their feelings and act in overtly caring ways, as doctors are taught, both implicitly and explicitly, to emotionally detach themselves from patients. In order to move from one traumatic situation to the next and to make rational decisions regarding diagnosis and treatment, they may attempt to distance themselves from the situation (Crossley, 2000). However, interactions involving both objectivity and caring may be possible.

Personalised and humanised treatment reflects ideas consistent with McAdams' communion theme of Caring/Helping, which resulted in positive outcomes and were frequently described in narratives of redemption. In addition, such memories caused patients to feel grateful and appreciative of their care and resulted in a renewal of patients' faith in health professionals and the health care system.

In the interviews women expressed the importance of health professionals' developing empathy for the patient and understanding what it feels like to be dependent and vulnerable. They felt that developing empathy would allow health professionals to more clearly understand the effects of insensitivity and disrespect. Good practices such as respect and sensitivity show the reverse of the power theme of disrespect and insensitivity, and are also consistent with the idea behind Self Mastery through Control, as they empower patients and make them feel confident and optimistic.

The women said that they wanted to be listened to by their doctors. This represented the women's desires to be involved in their health care. The participants perceived participation as having their interpretation of symptoms or conditions heard, acknowledged, and taken into account. Although the significance of symptoms may differ for patients and doctors, patients' opinions and feelings may, nevertheless, be important sources of diagnostic information. Yet again, wanting to be listened to by health professionals shows the opposite of the power theme not being listened to.

Being treated with courtesy was also important. The women said that they appreciated it when medical staff introduced themselves when they approached the

patient's bed, explained intended plans, and described tests or examinations before they were performed. Descriptions of good practice also involved health professionals who did not speak loudly and sat down beside patients rather than standing over the bed. Being treated with consideration and kindness is similar to the idea behind the communion theme of Caring/Helping and the agentic themes of Self Mastery through Control and Empowerment as such treatment empowers patients.

The sample also emphasised practical treatment, such as wanting medical staff to give information or answer questions about procedures, offer treatment options, and include patients in the decision-making process. This desire also represented patients' need for involvement and affected patients' sense of control while in hospital. This finding is consistent with the benefits of memories showing the theme opposite to Ignorance, as such empowering practical treatment resulted in positive outcomes.

7.6 McAdams' Life Story Model of Identity: Theoretical and Methodological Issues

One study objective was to explore the relationship between McAdams' and Hermans' codings of agency and communion. This objective involved exploring the degree of agreement and overlap, and examining how information gained from Hermans' scheme could add to understandings of women's narratives. As expected, a high degree of agreement was evident, with a 73% match between Hermans' and McAdams' coding of agency and communion within peak experiences, and an 84% match for nadir experiences. Like many researchers, McAdams and Hermans consider agency and communion to be two basic underlying motives driving behaviour. Hermans' list of affects allows a rating of motives in terms of their emotional content, whereas McAdams' Life Story Model allows thematic coding of a motivation typology in written and verbal accounts. Although each researcher measures the motives in different ways, comparing the two methods proved to be a useful and innovative way of achieving convergence and confirmation of results. Hermans' affect ratings also added to an understanding of women's narratives as they showed that although communion themes were rarely explicitly stated in the interviews, they did exist and were manifested in affects denoting isolation, a lack of contact and union, and feelings of closeness at the expense of participants' autonomy and self-control.

The manner in which Hermans' affect ratings added to understandings of women's stories highlighted two main differences between McAdams' and Hermans' coding systems. The first arose from the difference in the way power and communion were assessed. For a power or communion theme to be scored according to McAdams' method, there needs to be an explicit statement. In contrast, as Hermans' method is participant-rated, there does not need to be an explicit expression: the affect simply needs to be recognised from a list. Therefore, Hermans' method has the ability to capture feelings that may not be socially acceptable to recall in narrations (such as anger, aggression or hate) and affects associated with unspoken elements (such as taken for granted aspects or the backdrop of a memory). Participants' affective patterns showed that a lack of contact and union and feelings of isolation were rarely articulated but often evident in the settings of memories such as being physically alone in a hospital room or metaphorically alone when treated insensitively.

The second difference relates to differences in the categorisation of some experiences. For example, women's stories of over-dependency on hospital staff and powerlessness as a sick person were often scored for the negative of McAdams' agentic theme of Self Mastery through Control. However, Hermans considers memories of extreme dependency rated as distressing as related to the negative fulfilment of the need for contact with others. Therefore, communion was manifested in women's accounts of over-dependency and extreme closeness to hospital staff at the expense of their autonomy and self-control. It would be beneficial to clarify the nature of communion in stories of hospitalisation.

McAdams' life story technique was very useful in examining the issues women face as hospital patients. It was simple, showed evidence of validity, and produced a wealth of information. Together with Leonard and Burns (1999), the present author commends McAdams' methodology, as it provided a valuable way of exploring and understanding the women's hospital experiences, and of giving them free range to choose experiences that counted for them. As stated by Leonard and Burns (1999), research often focuses on researcher-chosen variables, but these variables may not necessarily be subjectively important for the participant. For example, as previously mentioned, there is extensive literature on patient adherence to and compliance with medical advice, but it appears that women are not particularly concerned about such issues as they were not mentioned in this study. Health psychology may be tackling

issues of compliance from the wrong angle. Research shows patients who perceive their doctor as less controlling are more satisfied with their relationship (Cecil, 1998; Flocke et al., 2002; Roter et al., 1997) and are more likely to adhere to medical advice (Sarafino, 1994). Therefore, if patients' perspectives of their interaction with the health care system were more carefully understood (especially in relation to issues of power), issues of compliance and adherence may subsequently improve.

McAdams' coding scheme was very suitable to code the stories women told about their hospital experiences. McAdams (1982, 1988b) stated that the positively phrased agency and communion themes designed to code peak experiences are not as useful in coding memories of nadir experiences. He subsequently designed negatively phrased agency and communion themes (McAdams, 1988b) specifically for coding nadir experiences. However, in the current study, the positively phrased agency and communion themes were very useful and applicable for both peak experiences and – when interpreted in the reverse – for nadir experiences, particularly in relation to hospital stays. For example, the theme coded as negative of or opposite to Self Mastery through Control produced much information about the range of control issues facing female inpatients. The negatively worded themes were also useful for describing nadir experiences, and when interpreted in the reverse, some of them were applicable to peak experiences.

Mishler (1986) states that one hallmark of a good qualitative study is the quality of its coding manual. He states that the coding manual must be sufficiently detailed for coders to differentiate between categories in terms of their intended core definitions and their respective ranges of reference. At the same time it must be sufficiently abstract for codes to be applied to new responses that vary in specific features from the manual's examples. There were changes to, and innovative uses of, McAdams' coding system which could have compromised its quality. They included (1) using the themes relating to negative nuclear episodes, which are relatively newly developed (McAdams, 1988b) and although there are basic definitions of each category, no accompanying examples exist; (2) using the reverse of the themes for both peak and nadir experiences, which had not been attempted before; and (3) contrary to McAdams (1992a) suggestion, the scoring system was not used in a conservative manner (see Chapter Five). These uses did not appear to interfere with the quality of the results. As was evident in the high interrater reliability and the high degree of agreement with Hermans' method, the

coding scheme proved to be replicable. It may be useful for future studies to reconsider the coding system, and to incorporate both currently coded themes and their reverse, and in particular to expand ideas of agency to incorporate powerlessness, as this theme was pervasive in women's experiences.

7.7 Limitations

As in most qualitative research, the samples in the pilot study and the main study consisted of volunteers, and thus may have differed from the general population of female hospital patients in two main ways. First, the samples may have had a particularly strong drive to make meaning of their hospital experience, to search for happiness, and to define their identity. Personal mythmaking is a major mechanism for making life meaningful, which may have drawn the women to participate in this study. Therefore, the sample may not be representative of women who have had a major hospital experience but who do not wish to reflect on it. Second, the participants may have been more extroverted or verbal in comparison to individuals who may be too shy to be interviewed by a stranger about a sensitive topic.

Mishler (1986) states that in telling a story in an interview situation, the participant may adjust the story, clarify some aspects, and add emphasis to others, depending upon the situation. The emphasis of the interview was on hospital experiences. Therefore, participants might have been primed to discuss negative issues such as powerlessness. Ideally, to minimise priming effects, research could utilise McAdams' Life Story procedure by inviting a large sample of women to tell their whole life story. The focus of analysis would be on the women who nominate a hospital experience as a turning point in their lives. Coding of agency and communion within these stories could determine the proportion of power issues within women's lives in general in comparison to their stories of hospital stays. Ideally, such research would need to involve multiple aims to ensure that the data generated from the women who did not have a hospital experience was used effectively, and that their participation in the study was useful. It would also be interesting to observe the number of women nominating a hospital stay as a turning point as an indication of the importance of hospital stays.

7.8 Future Research and Implications for the Medical Encounter

The importance of hospital experiences in women's lives has not been adequately emphasised in the psychology literature. The current research is a first step in examining women's perceptions of hospital patient life and the role of power in hospital. Consistent with the literature in Chapter One (e.g., Cross, 1986; Ross, 2001; Sack, 1984), the present research revealed that feelings of power/powerlessness can arise from the two distinct but related aspects of hospitalisation, namely the medical condition and the manner in which medical staff treat patients. This finding has theoretical implications for the construct of power within medical encounters, which in turn has implications for hospital administrators and quality assurance personnel assessing the patient experience. First, further qualitative research replicating this study and exploring the replicability of the power issues which emerged is needed. Problems such as limited generalisability, selection biases and priming effects need to be overcome. Ideally, it would be beneficial to develop this study by building on the data that was collected to generate hypotheses about power and agency. To test these hypotheses would require drawing on a random sample of women from hospital records, and controlling for demographic variables such as age, culture and illness by adopting a stratified sampling procedure; that is, breaking the female population into subgroups and recruiting participants from each. Such research could work towards clarifying the role and sources of power/powerlessness within women's hospital experiences, and constructing a measure of power as a hospital inpatient.

This research has also been a first step in looking at outcomes of hospital experiences and the factors that work towards positive and negative outcomes. For example, participants who felt in control of some aspects of their hospital stay (evident in narratives of Self Mastery though Control and Empowerment) and encountered compassionate and caring hospital staff (evident in narratives of Caring/Helping), which also impacted upon their sense of control, reported positive hospital experiences and redemption scenes. Systematic research regarding the relationship between the different sources of power and healthy outcomes needs to be conducted. It would also be interesting to conduct a longitudinal study exploring the role of agency, communion, redemption and contamination in women's stories about hospital and determining changes in the degree of narrative themes in the stories over time.

The significance of hospital experiences and their outcomes in the lives of women has implications for the important role of health psychologists within hospitals. Patients are dealing with a range of issues ranging from physical aspects to emotional issues (which may not be acknowledged in hospital), and psychosocial issues (such as potential changes to self). In addition, health psychologists have specialised knowledge about treatment and rehabilitation, including lifestyle changes which may accompany an illness. Patients may find it helpful to discuss concerns with a health psychologist, particularly those patients who perceive negative outcomes and contamination scenes.

The findings showed that personal treatment by hospital staff played an important role in women's hospital experiences. The findings suggested that, due to the vulnerability attached to the sick role, distressing effects of disrespectful or offhand treatment by health professionals were intensified. These findings have practical implications for the way health professionals treat patients. The research is important because it demonstrates that doctors, nurses and other health professionals need to allow time to attend to the affective as well as the medical aspects of the encounter. Participant 3, who described positive outcomes, emphasised the importance of the affective dimension of health care:

> **The treatment is the lingering thing**, not so much the surgery, but the treatment, **how I was treated as a person** is the overriding concern because I think that **most people can cope with most things that are done to them if they are treated with respect and dignity and fairness** … I think the **emotional side is equally or more important as the physical** (Participant 3, p. 30).

Specifically, health professionals need knowledge and technical skills, as well as a good bedside manner, compassion and communication skills. Future research could undertake patient needs assessments to clarify how patients want to be treated. Hopefully, many, if not all of these suggestions may be useful for patients of both sexes. Future researchers could also explore how male patients want to be treated by health professionals.

It also appeared that female inpatients might be particularly offended by negative personal treatment because of the close relationship between their bodies and

identities. Gergen and Gergen's (1993) research suggests that a woman's sense of identity is closely tied to her body. Thus it is not surprising that violations of the body are so unsettling for women and signify invasive negations of one's identity. It may be particularly distressing for women when they are treated negatively in situations such as hospital, where their bodies are potentially at threat. Although this research explored the change to sense of self as an outcome of hospital experiences, the relationship between women's bodies and identities was not part of this research agenda. Future research could explore women's perceptions of their bodies and identities while in hospital, and the perceived effects of personal treatment in such an environment. It would also be interesting to explore male patients' perspectives of personal treatment by health professionals to determine if they are also strongly affected by it or if it is an experience more common among female patients.

This research highlighted the different dimensions of the power imbalance as a female hospital patient, such as the imbalance between the sick and the healthy person, the high status doctor and the patient, and the gender-based inequality between male doctor and female patient. However, to comprehensively explore the affect of gender inequality within hospital, it would be useful to compare male and female inpatients' experiences and perspectives of power to determine if they differ. It would also be beneficial to explore the similarities and differences in today's Australian health professionals' interactions with female and male patients to determine if they are treated differently.

Future research would benefit from inviting health professionals to reflect on their everyday practice and on ways of thinking as a means of exploring perspectives of the health care system. Such research could help to determine if Australian health professionals are troubled by similar issues to those that trouble female patients, such as the emphasis on cure rather than care, and their lack of training in dealing with emotions. The present findings show that the way women want to be treated by health professionals reflects traditionally stereotypical feminine values, such as an emphasis on empathy and listening. Exploring health professionals' values and beliefs that underlie their relationship with patients might also help to determine the way in which the interaction patterns that characterise the doctor–patient relationship differ from male and female patients' values. Such research may help to determine if female patients' values and beliefs about treatment are consistent with the normative beliefs about

treatment characteristic of the medical profession. Such research would complement the exploration of the patient perspective and could be used as a way of formulating a health care system which meets the needs of both patient and professional.

7.9 Summary and Conclusions

The central aim of this thesis was to add to the body of knowledge regarding women's hospital experiences. Specifically, the thesis explored the power issues which female inpatients face, and examined the impact of hospital experiences on the lives and identities of women. These aims were addressed primarily through qualitative means by examining women's stories of hospital stays, and their experiences of power and agency within hospital.

Coding women's narratives of their hospital stays according to McAdams' themes of agency and communion showed that the negative of Self Mastery through Control was the most common one. The wealth of information gained from McAdams' coding scheme revealed that powerlessness as a hospital inpatient was experienced in a variety of situations. For example, feelings of control or powerlessness resulted from being ill, such as the empowering feeling of mastering pain or the disempowerment associated with losing control over a bodily function. Feelings of control or powerlessness also arise from the psychosocial issues of being a patient, such as positive and compassionate interactions with health professionals that lead to increased knowledge or negative interactions that result in decreased self-esteem.

The results highlight the importance of the manner in which health professionals treat patients personally, and that personal treatment can affect patients' sense of control. The power themes which emerged in the pilot, together with the information revealed through coding for themes consistent with and opposite to Self Mastery through Control, can be seen to support the proposition that behaviours on the part of medical professionals that influence patients' sense of their own control are manifested in multiple and subtle ways. Future research could replicate this study with varied samples to determine the importance of power issues and personal treatment in other patient samples. Further study is needed to clarify the role and sources of power within the hospital setting.

Powerlessness as a female hospital inpatient can also be intensified if it is experienced in various dimensions. Powerlessness can be experienced while sick, as

sickness is associated with vulnerability and dependency. Powerlessness can also be exacerbated in patients due to the hospital hierarchy, and to patients' dependency on health professionals in positions of authority. Feelings of powerlessness and vulnerability as a female inpatient can again be intensified by women's position in a low power group. Coding women's stories of their lives prior to and during hospital revealed the prevalence of themes of powerlessness and isolation. Narrative researchers assert that stories reflect cultural norms and validate the status quo. If these stories indeed reflect this sample's perceived position in society (namely that of inferiority), women who perceive themselves as vulnerable may be more vulnerable within hospital due to its patriarchal structure, and thus may find it more difficult to act as autonomous, and powerful adults. It is important to be mindful that the emphasis of the interview was on hospital experiences. Therefore, a selection bias may have come into play in attracting particularly negative women to the study. Alternatively, participants may have been primed to discuss negative issues such as powerlessness, and the extent of powerlessness in the lives of this sample may have been exaggerated. Future research needs to continue the exploration of gender inequality within hospital, and ideally research could include the examination of both male and female inpatients' experiences.

Examining McAdams' redemption and contamination sequences within women's stories about their hospital experience again revealed the vulnerability of the sick role and the importance of how women were treated by medical staff. The misuse of power on the part of health professionals impacted on female patients' perceptions of self and attitudes toward the health care system, often in adverse ways. In order to minimise the suffering caused by illness and hospitalisation, a sense of self needs to be maintained. This process is made up of two related elements: maintenance of personal control and compassionate treatment by staff. The results showed that participants who reported redemption narratives were more likely to tell stories with themes of Self Mastery though Control, Empowerment, and the opposite of Ignorance. The participants felt powerful and in control of some aspects of their hospital stay; for example, they played a part in treatment or were knowledgeable about their condition. They also showed themes of Caring/Helping and the opposite of Disillusionment about People, as they encountered compassionate and caring hospital staff which also impacted upon their sense of control and confidence, and renewed their faith in health professionals and the health care system. The attempt to understand how women want

to be treated by health professionals showed that women's values reflect traditionally feminine values, such as personalised treatment, sensitivity and listening, and that these behaviours contribute to positive outcomes. Understanding women's perceptions of power and its relationship to good outcomes is very important and needs to be clarified.

On the basis of this research it can be concluded that hospital experiences are important in the lives of women, and issues of power among female inpatients are widespread. The results broadened the idea of the role of power in hospital and highlighted the complex nature of power within the health professional–patient relationship. Additionally, the results highlighted the different dimensions of the power imbalance, such as between the sick and the healthy person, the high status doctor and the patient, and the gender related power imbalance of the male doctor/masculine orientated system and the female patient. The thesis also revealed that, as was assumed, hospital experiences consist of two related but distinct aspects of hospitalisation which both affect patients' sense of control: the medical condition and the manner in which patients are personally treated by medical staff.

The study of narrative was ideally suited to making sense of the disruptions that hospital experiences can cause in women's lives. Specifically, McAdams' theoretical framework was applicable for examining the issues women faced as hospital inpatients. The coding system was replicable as it showed high interrater reliability and high degree of agreement with Hermans' method. In addition, participants' affect patterns showed that communion was evident and played an implicit role in women's stories, highlighting experiences of isolation and a lack of contact and union as hospital inpatients. Future research would benefit from revising McAdams' coding system and including both currently coded themes and their reverse, and importantly, expanding ideas of agency to incorporate ideas encapsulating the theme negative of Self Mastery through Control.

Although medicine is a scientific field, it is a human profession. On Julie McCrossin's "Life Matters" program on ABC National Radio (McCrossin, 2001), Dr Andrew Marich, an intensive care registrar, spoke about his experience of the health care system from the patient's point of view, as he was receiving treatment for lymphoblastic leukaemia. He echoed the sentiments of the present sample when he noted the profound consequences which the behaviour of medical staff can have on patients. He stated that hospitals are places where people are often experiencing

physical and emotional pain and "a little bit of humanity would make it a little bit easier to bear". In today's health care system, patients' perspective of health care is a relatively new but important research area. The present research is a first step, and it is essential to continue this research as it has the potential to stimulate professionals to reassess the way in which they work, and to ensure that patients have continued faith and satisfaction in the health care system.

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Patient Power in Women's Hospital Experiences
Professor Sue Moore Anne-Maree Polimeni Swinburne University of Technology

Participants in the study will include women, who have had a hospital experience after 16 years of age, of at least one night. One aim of this study is to assess your opinions and preferences for the way you were treated and your level of control in hospital.

You are asked to complete a questionnaire on your attitudes about the degree of control you experienced during your hospital stay. The questionnaire takes approximately 30 minutes to complete.

Your contributions will be kept confidential and anonymous. The completed questionnaires will be stored in a locked filing cabinet and your responses will be kept on a computer protected by a password. The investigators will be the only two people with access to the questionnaires. We do not want you to put your name on the questionnaire. If you return the questionnaire, we will take that as evidence of your consent to participate. Please note that any data published as a result of this study will be in the form of group results and cannot be traced back to any individual.

Participation is entirely voluntary and you are free to withdraw consent and discontinue participation in the study at any time.

Your participation may ultimately contribute to research which will help inform the health care system of more beneficial ways of treating female patients like yourselves, as there is limited research assessing the perspective of women inpatients.

When you have completed the questionnaire, please return it to a designated box on the 7th floor of the BA building titled 'Women's Hospital Experiences'.

If you were dissatisfied with your treatment in hospital, and you would like to complain about a health service provider, you can contact the Health Commissioner's Complaint Line on (03) 8601 5200 or toll free on 1800 136 066.

Any questions regarding this project can be directed to Professor Sue Moore of the School of Social and Behavioural Sciences on telephone number 9214 5694. If you have any queries or complaints that Professor Sue Moore has been unable to satisfy, please contact: Head of School, Dr. Julie Mulvany, phone: (03) 9214 8209, or The Chair, Human Research Ethics Committee, Swinburne University of Technology, PO Box 218, Hawthorn. Victoria 3122, phone: (03) 9214 5223.

Demographic Information

1. How old are you?_____years

2. What is the highest level of education you have reached?

    1. Secondary school

    2. Diploma

    3. Degree

    4. other_____

3. What is your occupation?_____

4. What is your ethnic background?_____

5. If you have a religious affiliation, what is it? _____

6. Where did you see this study advertised? _____

At this point, I would like you to focus on a specific hospital stay which occurred after the age of 16, and was at least an overnight stay. If you have had more than one hospital experience, please focus on the one that you perceive as most significant in terms of your personal growth and development.

7. How old were you when you were in hospital ?_____

8. How long were you in hospital?____days____nights

9. Was it a public or private hospital? Please circle: Public / Private

10. Was it an Australian hospital? Yes / No

11. If yes, what was the name of the hospital?_____

12. Why were you in hospital? _____

13. What was the nature of your illness / condition in which you were in hospital for?

_____

14. On the scale below, please indicate the **seriousness** of the illness / condition in which you were in hospital for?

Minor   1   2   3   4   5   6   7   Life threatening

15. Was there any follow up treatment to your hospital stay? If yes, what did it involve?

_____

16. On the scale below, please indicate how **significant** you think your hospital experience was in your life as a whole, by circling the appropriate number?

Not at all significant   1   2   3   4   5   6   7   8   9   10   Extremely significant

Closed Answer Items

Below is a list of statements concerned with your view of your hospital stay, and the health care workers (for example, nurses, doctors, surgeons etc.) you encountered during your hospital stay. Beside each statement there is a scale which ranges from 1 ('Strongly disagree') to 5 ('Strongly agree'). For each item please circle the number that represents the extent to which you agree with the statement. Please answer every item and only make one choice per item. Please respond as honestly as you can and remember that your responses will remain confidential.

	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
1. The health care workers did not respect my dignity while I was bathing and dressing.	1	2	3	4	5
2. I believe I received clear and accurate explanations of my condition in terms I could understand.	1	2	3	4	5
3. If I wanted to, I felt free to refuse the presence of health care workers directly involved in my care (for example, feeling uncomfortable with a particular nurse).	1	2	3	4	5
4. I believe the health care workers respected my lifestyle preferences (for example, cultural, religious preferences, sexuality).	1	2	3	4	5
5. My care was compromised as I was discriminated against because of who I am (for example, my gender, age).	1	2	3	4	5
6. The health care workers did not respect my dignity when I was examined.	1	2	3	4	5
7. If I wanted to make decisions about my health care I believe I was well informed to do so.	1	2	3	4	5
8. I believe I was listened to when I explained my symptoms.	1	2	3	4	5
9. The health care workers did not respect my privacy when I was interviewed.	1	2	3	4	5

	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
10. I felt comfortable to access my medical chart and medical records.	1	2	3	4	5
11. If I wanted to I felt comfortable to refuse the presence of health care workers not directly involved in my care such as students or researchers.	1	2	3	4	5
12. I believe health professionals gave me explanations about my future health in a sensitive way.	1	2	3	4	5
13. I was satisfied with my medical treatment.	1	2	3	4	5
14. I received quality care regardless of my lifestyle preferences (for example, cultural, religious preferences, sexuality).	1	2	3	4	5
15. I was able to decide when to have showers, within reason.	1	2	3	4	5
16. I was able to decide when to eat my meals, within reason.	1	2	3	4	5
17. I believe I was treated with respect.	1	2	3	4	5
18. I believe I was listened to when I explained my concerns about my condition.	1	2	3	4	5
19. I believe I received sufficient information prior to any medical procedure or treatment that I underwent, in language I could understand.	1	2	3	4	5
20. I believe I had adequate access to health care professionals when I was concerned about some aspect of my health care.	1	2	3	4	5
21. Health care workers treated me in a patronising manner.	1	2	3	4	5

	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
22. I believe I had adequate access to health care professionals when I needed an explanation about some aspect of my health care.	1	2	3	4	5
23. If I wanted to I felt free to have someone such as a friend or family member with me throughout my hospital stay.	1	2	3	4	5
24. I believe I was understood when I explained my symptoms.	1	2	3	4	5
25. The health care workers did not respect my privacy while I was bathing and dressing.	1	2	3	4	5
26. I believe health professionals gave me explanations about my health in a supportive empathetic manner.	1	2	3	4	5
27. I was not asked for my permission before health care workers examined me.	1	2	3	4	5
28. I was not asked for my permission before health care workers interviewed me.	1	2	3	4	5
29. I believe the health care workers listened to me when I asked about my medical treatment.	1	2	3	4	5
30. I was able to express problems about aspects of my hospital stay without the fear that my health care would be disadvantaged.	1	2	3	4	5
31. I believe health professionals gave me explanations about my diagnosis in a sensitive manner.	1	2	3	4	5
32. The health care workers did not respect my privacy when I was examined.	1	2	3	4	5

	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
33. If I was not happy with a certain procedure I was able to withdraw my consent from the treatment without affecting my future care.	1	2	3	4	5
34. I felt embarrassed when health care workers examined me.	1	2	3	4	5
35. I was satisfied with the way I was treated as a person.	1	2	3	4	5
36. If I wanted to I was able to participate in decisions relating to my care.	1	2	3	4	5
37. I felt inferior when I spoke to health care workers.	1	2	3	4	5
38. The health care workers did not respect my dignity when I was interviewed.	1	2	3	4	5

Using the scale below, looking at things as a whole, please indicate how satisfied you were with the medical care that you received in your hospital stay?

Not at all satisfied 1 2 3 4 5 6 7 8 9 10 Extremely satisfied

If you would like to express feedback regarding the questionnaire or thoughts about your hospital experience, feel free to do so below.
Thank-you for completing this questionnaire.

APPENDIX B

THE PILOT STUDY: INVITATION AND CONSENT FORM FOR THE INTERVIEW

Would you be interested in meeting for an informal discussion to share your opinions about this survey?

Hospital experiences can be so significant that they may change the way individuals perceive themselves and their future health care.

My name is Anne-Maree Polimeni and I am undertaking postgraduate psychology studies at Swinburne. The aim of my thesis is to explore (a) how women make sense of hospital experiences, and (b) their level of satisfaction with the health care system. I am hoping to conduct some follow-up discussions to this survey to learn more about women's hospital experiences. The discussions will be held later in the semester, and they will take about 60 minutes. In the discussion I would like you to talk about your experiences in hospital. In turn, I can tell you about my study, and I will be happy to keep in touch with you, and let you know any future findings.

If you are interested in joining me for an informal discussion over drinks and nibbles, please complete the information section below. Your presence will be much appreciated. I look forward to meeting you!

Your first name: ………………………………………….
A phone number I can contact you on: ………………………………
Good times of the day to call you: …………………………………
An idea about the days and times of the week which would suit you for a discussion:
………………………………………………………………….

Thank-you!

Patient Power and Control in Women's Inpatient Hospital Experiences:
A Discussion about the Survey

Professor Sue Moore Anne-Maree Polimeni Swinburne University of Technology

One aim of this discussion is to talk about your opinions of the questionnaire you have completed, and ways it can be improved. Another aim of this discussion is to learn more about your hospital experience. Participants in the study will be women who have completed the survey.

The researcher has some general questions that she would like you to discuss. The discussion will take approximately 60 minutes. The intention is to tape the discussion. If you would like the tape recorder turned off at any time, let the researcher know and she will do so.

Your participation may ultimately contribute to research which will help inform the health care system of more beneficial ways of treating female patients, as there is limited research assessing the perspective of women inpatients.

Your contributions will be kept confidential and your name will not be used. Participation is entirely voluntary and you are free to withdraw consent and discontinue participation in the study at any time.

Any questions regarding this project can be directed to Professor Sue Moore of the School for Social and Behavioural Research on telephone number 9214 5694. If you have any queries or complaints about the way you have been treated, or there are queries that Professor Sue Moore has been unable to satisfy, please write to: The Chair, Human Experimentation Ethics Committee, Swinburne University of Technology, PO Box 218, Hawthorn Victoria 3122, phone (03) 9214 5223.
……………………………………………………………………………………
I (the participant) have read (or, as appropriate, have had read to me) and understood the information above. Any questions I have asked have been answered to my satisfaction.

I agree to participate in this activity, realising that I may withdraw at any time.

I agree that research data collected for the study may be published or provided to other researchers on the condition that my name is not used.

Name of participant…………………………………………………………….

Signature……………………………………………………Date

APPENDIX C
THE PILOT STUDY: QUALITATIVE COMPONENT

Participant 30
Researcher: So if you just want to start off by telling me about the experiences you have had in hospital.
Participant 30: I have been in the public hospital system in Australia, I was in the public hospital system in the UK and the US. Initially my first hospital experience, I found it very depressing and I didn't understand how things worked and so forth. I know the routine now, but it is quite disturbing at the beginning when you go into hospital. The routine is so different, meal times, times when doctors come around and it can be quite different in terms of the system, getting to know that and also you have a reasonable amount of free time. I have MS and so I wasn't there for intensive treatment, I was there for relapse and I was on a drip and that sort of stuff and it left quite a bit of time in the day free. So what to do in that time and not get completely bored with what's going on. And another thing is that being in the public system there are four to six beds to a room and you find that difficult because privacy is quite limited and you need to learn that the body is separate from the mind. I found a real separation from body and mind and not getting your own personal, oh I can't think of the word, you are not ashamed to take your clothes off and do certain things and you become quite immune to those sorts of things which other people obviously find difficult. The other thing is privacy, people can have visitors and that can be really annoying and disruptive, and just sitting and reading a book, they can be quite distractive. And you get angry about that because you want them to shut up but you need to realise that you are in a ward with five other people and respect their time and realise that maybe they are not used to it and they need that time, but you need to think about yourself, you still need some privacy and space. But on the other side you can make good friends and share treats that your family have bought in and share around, and you develop a communal spirit I think, if you go out and actually talk to the other people in the room.
Researcher: Can you tell me a little bit more about how you said the mind and body are separate?
Participant 30: If you are having things done to you and it hurts you have to say this is the body and they can do what they like but it won't affect me as a person, and you really have to strengthen your own personal view point of yourself. You gain a better perspective of what you find comfortable or annoying or painful or what ever, you can put up with it because it doesn't really hurt you, you the person, it doesn't change, and the body may change and might go through all sorts of difficulties but you essentially are the same person.
Researcher: And that sort of viewpoint, it helped you cope with your experiences?
Participant 30: Yes
Researcher: And, so you developed that viewpoint?
Participant 30: Yes I developed it, I didn't have it before.
Researcher: And how did you come about developing that?
Participant 30: I really don't know, it just come forward in my mind, I think, really, nurses and doctors came to do certain things to me and I am not really a part of it as such, mostly for self preservation.
Researcher: Can you tell me about aspects of your hospital stay which you really enjoyed or you didn't enjoy so much, really good experiences and bad experiences?

Participant 30: The good experiences were the other patients because I'm quite positive anyway, trying to help the other patients out, saying it's ok and we'll survive. My last hospital stay was 42 days, so most patients come and go a couple of times, so the good experiences was getting to know the other ladies that were in there. And in St Vincent's in their rehab ward, they had a men's and a ladies section, which is good but you do mingle for breakfast and lunch, so there were many people. And also meeting other people with the same condition as yourself, which is good, even though that quite a few people with MS, not many of them are my age, they are all much older, so it was a good experience to meet other women, and to see how they cope with the issues and so forth. So that side of it was really good. Um bad, I think because I did separate the mind and the body the bad didn't really affect me as much, might have been more the routine and the drudgery and having to go through all these things, but, I thought it doesn't matter what they do to my body they won't really hurt me. That's how I coped with it.

Researcher: So that's how you protected yourself?

Participant 30: Yeah

Researcher: While you interacted with the other patients, is that where that viewpoint of the mind and body separation developed?

Participant 30: No that was more from myself, rather than the others. Another point was that because I was there for a long period of time I got to know the staff as well and because my illness wasn't such that I was unable to communicate with them, I could communicate with them and be respected as a person rather than just a patient, so I think that really helped and I still know people there that are working at St Vincent's and so forth. So that helped being able to converse on their level, in my personal circumstances I think it would be incredibly difficult if you were in a real physical mess and unable to talk about things, that must be very difficult because you are treated less as a person.

Researcher: Is there anything else that really stood out for you, moments that really stood out for you?

Participant 30: No I think the first one was the first time I was in St Vincent's, the shock of a public hospital with a curtain just between people, no privacy, my first reaction was get me out of here, I want to go home, and I think a social worker, they must of said this patient is really concerned and she came to have a chat with me which I found very reassuring, I didn't quite believe everything she said because I was in a different situation, so I thought, wait and see, so I did stay and got through it, but there is a shock of going into a hospital system and the whole lack of privacy issue and having your own things around you. After 40 days I had so much stuff there, but you do, I mean, can you use a mobile phone, where can you go to get those, in touch with the outside world, that's the thing that is very difficult, being completely cut off, paying bills, how do you pay bills, how do you keep rent going and everything else that may come in handy, if you haven't got family around, that makes it hard, particularly when I was in the UK and US, I had no family, I had no family there so I was totally reliant on myself, so that was quite difficult, but I think that was certainly a moment that stood out for me when I became more familiar and comfortable with hospital, when I understood how I could do those things I needed to do.

Researcher: Did you do those things by yourself or did you get someone to help you?

Participant 30: First time someone helped me, I mean I now have a hospital bag sitting at home waiting for the next relapse and the next hospital admission so I know what I want, but back then you don't know what to say, you take a nightie but you are meant to

get dressed in the day, so clothes would be appropriate if you go to physio every day and make sure you have all the sorts of things you wanted, have you got the right shampoo, have you tampons, all these things need to be brought in and you need someone to do that for you if you are not planning on going into hospital, it makes things unsettling.

Researcher: So the initial shock, that's the main thing for you?

Participant 30: Yeah, the shock, and not being prepared with physical things to cope with it.

Researcher: Can you tell me about any particular interactions with the doctors or the nurses? How did you get along with them? Is there any particular doctor or nurse that stands out for you?

Participant 30: Well I have a particular specialist that it connected to the hospitals so there was that continuity there, so that was comforting, because he had seen me when I was well, while I was there, he knew of course we discussed the issue and so forth. And I knew he was watching the other doctors, what's going on, so there was some comfort there I think. I think if you had any odd doctor that was coming and going you would be questioning what they are doing and why they are doing it. I was so lucky in terms of having the specialist there in terms of coming to see me, so that really helped. And certainly this social worker which talked to me after the first episode, the initial shock decreased and also they have a sort of chaplain and even though I am not a religious person, it wasn't appropriate, it was just good to talk to someone from the outside world about anything rather than hospitals because you get sick of talking about it, so you want to talk about something else.

Researcher: So you had already developed a relationship with your doctor, so that was good for you, and can you tell me a little bit more about the social worker?

Participant 30: We went for coffee, down to the coffee shop, which was really good because we could do some normal things, so that was important. Even the man who would come down with the newspaper, so I could find out what is going on. And the social worker, it's just nice to talk to somebody about anything apart from hospitals and you can go out for a cup of coffee, there's the hospital shop on the grounds so it was not like going out out, but it was something and it was quite good.

Researcher: It sounds like the things that are important to you are keeping touch with the outside world.

Participant 30: Yes I wasn't so concerned about the medical treatment because I know I was in a hospital where that are well regarded, so I was not concerned about that, and I had the confidence that my specialist kept an eye on things, which was good, so it was more getting through it and not being so out of touch and maybe become cut off from not being paid and all those sorts of things that are still a concern.

Researcher: So to still be the person that you were outside hospital.

Participant 30: Hmm, yes.

Researcher: And what about any other doctors you encountered?

Participant 30: I sort of knew doctors, that is something that can be disorientating, I keep a diary about things that go on in hospital and all the different doctors. And also the students that come around and do their rounds, and the students can come around and do assessment and I learn more than they do I think, about the condition and you know that if they look at the eyes and see weather or not they are flickering and how much and I found that quite good because you felt more like you are on the other side, which was good. And I think personally being informed about your illness was part of the battle and therefore I can talk to a doctor about different symptoms and medication

and especially being from the UK and US, I was what you may call a challenging patient, I was more on their level rather than them speaking down to you, you have to at least feel that you have some respect and you are informed. I mean there is nothing worse than not being informed. I mean I had a bone density test a couple of years ago and the doctors did the test and I wanted to know what the result was, so I rang the doctor, because I had my phone and I had access to resources, and I rang them and I said look where is the result because if you don't get those sorts of things you get really edgy and panicky and that just makes you more stressed about the whole situation.

Researcher: And can you tell me a little bit more about the students that came around, how did you feel about that?

Participant 30: I felt ok because I was thinking they are the neurology specialists of the future, maybe they will be the person that finds a cure. So I thought that was good, I mean, just lying there and being surrounded by all these people, so you need to be pretty confident that you know your illness and you understand it. And ask questions if they use terms that you are not familiar with, and I think it could be quite difficult for someone if they weren't familiar with their condition. I found the students interesting.

Researcher: And what other health professionals did you interact with?

Participant 30: Physiotherapy, occupational therapy, and speech therapy. I think they were the three main ones.

Researcher: And how did you feel about them?

Participant 30: Good, I mean I think I liked the physical therapy because I could see an improvement, so I had faith in the physio to do what she was doing, and same with the speech and OT. I think if I doubted their ability to actually make a difference I would be concerned, but they seemed to know what they were talking about, which was good. So I could converse with them, and we could come to an understanding that they did know what they were doing and I would follow. I mean part of being in hospital sometimes patients don't want to follow, and don't want to do what they are asked. Often I have been in the room and there has been a patient that just doesn't want to get up and walk and move and that's what they have been told to do. And you think if you want to get better you have to get up and practice. I'm not the best because I don't practice my speech therapy and my handwriting like I should. But no I found them good. I probably respected the doctors because of their technical skills and I respected the physio, OT and speech therapist because I could see an improvement in what they were doing, but I knew that if I was really ill, I would need the specialists and the doctors to look after me and they tended to know what they were doing. But what they did was get me out of a relapse and a difficult position, but then the hard work started. And that's where the physical therapists come into it.

Researcher: So it's all about having faith and respect.

Participant 30: Yeah and confidence in them. And also I guess what you expect from them, you expect doctors to help you in an emergency and if things are going wrong, like if I had a relapse, I would ring my specialist and say "help", I know he will be able to and get me into St Vincent's within 24 hours. So that sort of immediate response is required from a doctor. Whereas the others were hard slog, you had to work so it's a gradual improvement whereas the doctors, I saw them rescuing you.

Researcher: So they fulfilled that role which you expected.

Participant 30: Hmm, if my specialist couldn't get me into St Vincent's or where ever in short notice, I would change specialist. Also if I went to him complaining about something and he thought I was a loony, so many women I have met don't necessarily think ok I will change specialists, go somewhere else, and that I think that is difficult, to

actually say to your specialist, if you are not able to appreciate how I am feeling, this is not visible from the outside, and he questioned whether or not it was really happening, you need a doctor to be supportive of the things that are going on and believe what you are saying.

Researcher: So the specialist you have the other health professionals you have encountered, you felt that that's how they treated you, that they understood where you were coming from, and they were supportive.

Participant 30: Yes, I mean certainly a couple of years ago I had a terrible speech difficulty, and I didn't realise how bad my speech was until the speech therapist audio taped it and I then I understood that I wasn't able to communicate as effectively, so that was quite encouraging.

Researcher: I understand that you have a good relationship with the health professionals you encounter, but sometimes patients feel that health professionals do not support them, so can you elaborate on that point?

Participant 30: I think that's got something to do with being involved in your illness, they can't fob you off so quickly, so I think that helped, I mean obviously I have researched all sorts of things, off the net and so forth, and I do all I can to communicate with them and understand them. I think also because this illness is so weird basically, you don't believe it yourself sometimes, your hands start tingling, or your feet start tingling, and you think that can't be right, but you have to develop that relationship I think, with the doctors and show that these things are happening. If you try to walk and fall over, that's obvious they can see that. But having confidence in your health professional I think is critical to your getting better.

Researcher: And is that hard to do, to develop that relationship?

Participant 30: If you encounter someone who you think is a bit sloppy, you wouldn't be able to do it if you think they don't answer your questions. I think some doctors are very formal and you can have difficulties with developing a relationship with them because they have that formal "I'm the doctor you should do what I say". I think, I have been lucky I have a specialist who is quite relaxed and so I can go in and cry for half an hour and he will take it seriously, whereas another specialist I have got, well dressed, nice office, but I don't think I could have that same relationship with him, I think the personas are different but they are just as capable. But I know people that are not happy with their specialist and want to change, the don't know if the specialist is paying attention to them and taking their concerns on board. They might not think it is important but it could be very important to you.

Researcher: Can you tell me about instances where your have felt that health professionals bossed you around, or didn't treat you with respect, or anything like that?

Participant 30: The only instance that comes to mind would be the orderly or food person, it was very much this is it, take it or leave it, type attitude. It was the attitude that this is how we do it and there is no flexibility and I think that is difficult because you have to realise that there is no flexibility, the meals have to be at 5pm and you if you don't want to eat then, you starve. You haven't got a lot of choice in there. There may be instances where some people at the end of the day, maybe I'm making excuses for them, they don't think what I perceive to be important is really important to my case, and they just treat you rudely, and that can be really difficult, and you think why am I here, these people don't care, my thought was, all I wanted is a little bit of kindness, and that's all it takes, sometimes it's like that.

Researcher: And how does that make you feel, being in hospital and encountering those sorts of people?

Participant 30: I want to get out of here and get away from hospital.

Researcher: And how does that make you feel about yourself, does that impact on you as a person?

Participant 30: I think because I have actually achieved what I wanted to in terms of getting out of that situation in European hospitals, I actually feel good, I actually resolved the issue.

Researcher: We'll move on now, I would like to talk about control and power in hospitals. So when I say control or power, what comes to your mind in regard to hospital experiences?

Participant 30: I think you have very little control, things can be done to you, when you go down for an x-ray, or a scan, you can end up waiting for hours, and the control is not there at all. I think that's why I have my personal things around like my phone, because then you have some control over your life, but within hospital, I think there is limited control and that is a difficult thing I think. And you are one of thousands, you have no power, you can complain but you don't want to upset the staff and risk getting even worse treatment down the track.

Researcher: Are there instances in which you felt out of control or helpless?

Participant 30: I think yes, especially when the body does not do what the mind wants it to do, you can feel very helpless. You can't get things organised like you want, you can't make yourself comfortable. And also the system that you have to abide by and there is no question, therefore you are helpless, because you can't do anything about it. And not having those things around you, like a phone, you feel helpless, how can you pay this bill, how can you do these things, you are completely helpless to do things that need to be done, and that your life is a disaster when you get back to it.

Researcher: So it seems that if you do maintain those controls that you have outside of hospital, like the phone, paying bills, that's when feeling out of control in hospital isn't as bad.

Participant 30: True. I think turning the control onto outside life, even though you can't control the hospital, you can control what's going on outside, and hospitals give you very limited scope in terms of visitor times, time to maintain the outside world while in hospital, at least you feel like you have some control or power of your future.

Researcher: In my questionnaire which you have completed, I have developed a scale which aimed to focus on the idea of control which we have been talking about, and I think your experiences have highlighted this idea of control. That is, if you maintain some personal control, the powerlessness one can feel in hospital might not be so bad. I was trying to focus on the idea of every day control in terms, meals, sleeping times, what you wear, who you see, and also control in terms of preserving dignity and the way you are treated. I was wondering if you could comment on the questionnaire at all?

Participant 30: This first question about maintaining dignity while bathing was good because that's when you need to develop a confidence in the nurses. I have situations where I have been in the shower and I have fallen, and the nurse had to come and dry and dress me, and you think a few years ago that would have been highly embarrassing, but now I have lost all sense of personal dignity, but if you think to yourself, it is just the body rather than the mind, it's not you, they can do that and it's alright. I think if that feeling that they do respect your dignity, I think it's important. I was also asked if I wanted to see students which was good because that felt like I had control rather than I was just the guinea pig, and you put up with it no matter what. I was always the youngest person there and I think they were nice to me because they thought that it shouldn't happen to a young person.

Researcher: So was being young ever a disadvantage?

Participant 30: No, I mean really young would be I would think, early teens, but late 20s and 30s, no it was ok, but every one around me was 50-60. I think having to use a 6-person shower you lower your standards a bit in terms of personal dignity. You don't worry so much, you're not quite at the same level as you used to be, it didn't affect me so much. I guess older women would be much more protective of their body, much more careful about letting male doctors do certain things. I mean I think compared to who I was with, I am more at an age where that was ok. I think I was involved in the decision making process. It is frustrating when something is supposed to happen, taking a certain medication and you are forgotten about, and it's all caught up in the hospital routine and you think I should have taken this at two o'clock and it's now three, and you get really uptight about it, so if their routine doesn't work, you will get stressed about it because you want to look after your own health. But I was always involved in the decision making which was good, and listened to and explained symptoms. They may have been weird symptoms but all the health professionals didn't think that I was going crazy so there was some understanding, which was good.

Researcher: Do you think the statements on the questionnaire all add up to the idea of personal control?

Participant 30: Yes. Even though you have to submit in a way to whatever is happening, if you feel that at least you are treated with respect and not belittled then you feel that you are in more control because you can say, "go away". Part of the difficultly would be that you couldn't speak and you couldn't convey your disapproval, that's when it would get very difficult. You have to feel confident enough to say "no thank-you" and get someone else, but you don't want a black mark against your name in a hospital when there are few people around and few staff members. But because they have been respectful and made allowances for me it hasn't been a concern for me so far.

Researcher: And do you think that your experiences in hospital have made you more assertive?

Participant 30: No I was reasonably assertive anyway. I certainly am a lot more tolerant person in terms of realising there are other people around and you are one of a group and you need to appreciate that. It has made me more tolerant, a hard lesson to learn at times. And continuing in the assertion, it was easy to be assertive at work, but being assertive about yourself, I find is actually quite different, so really saying no to certain things and putting standards on things for yourself, it's easy to hide behind the employment law at work, but certainly more tolerant.

Researcher: We are coming to the end of the interview so do you have anything more to add?

Participant 30: No I thought it was fascinating to do, only that I thought the questionnaire is fairly long and repetitive.

Researcher: Ok, yes I will be working on that as this is a trial and I have other participants comment on the length and the repetitiveness. Thank-you for your time.

Participant 17

Researcher: Would you like to start by telling me a little bit about your hospital experience, not necessarily why you were in there but how you were treated and felt about the experience.

Participant 17: I had one very bad experience which was at the Austin, I was about 20-21, my parents weren't there at the time, so I found that a lot more difficult because I was quite ill and then I had to be making decisions and finding out what was going on and I felt I wasn't treated with the respect that I should have been. Especially because I

was really sick. The doctor who examined me initially didn't introduce himself, he did an internal examination, without telling me what he was going to do, even when I was in unbearable pain, it was almost like I was inconveniencing him by having said that I was (in pain). I was given medication that I was allergic to which made me vomit, that went on for three days, until I finally said that wouldn't take it anymore and I wanted to see the doctor. So then it was put down that I had refused medication. But they didn't follow that up with getting the doctor to see me, and it was only because I refused the medication that finally a doctor did come the next day to find out why. I think that if I request a doctor that I should be able to see one and you shouldn't have to wait the next day for that to happen.

Researcher: And how did the doctor respond when he came to visit you the next day?

Participant 17: I don't recall any great concern for anything that had happened, it was just OK fine, so they put me onto another medication. I don't remember them even telling me what the new medication was, or that it would be better. It was actually a nurse that went through the medication with me, to say it had been change.

Researcher: Can you tell me about your day-to-day experiences?

Participant 17: I wasn't very mobile, I was in a lot of pain, I needed to nurse to have a shower or something. But I took the medication that made me really really sick so four times a day I ended up vomiting, I was on a drip which meant I wasn't able to move very much either. I had a boyfriend at the time, so he would come in and see me for a couple of hours a day, but I wasn't very coherent, 'cos the medication really affected me when I took it, I don't know if delirious is the right word, but I just wasn't really aware of where I was or I was just extremely ill when I took it. I wasn't hallucinating, but I couldn't really focus on things, I wasn't really with it when I took the medication so a lot of the time I just saw people come in and out. I was in a ward with five other people and the beds were constantly full. I remember there was a lot of noise.

Researcher: Can you tell me about aspects you enjoyed or that were really bad?

Participant 17: I didn't enjoy anything except for going home. The nurse on the final day was quite nice; she was the nicest out of all of the nurses. And she went through all my medication and what I had to take, so that good I suppose. Things like when I said that the medication made me sick, and so then they gave me milk so then when I was sick I had milk coming back up as well as the medication, which just made it worse, not being listened to, not being respected, requests like asking for a doctor not being listened to or actioned upon, and little things too, like people from work sent me flowers and they were left down stairs and didn't come up until the end of the day and they were half dead. The whole experience wasn't at all pleasant.

Researcher: And were there any other moments that really stood out for you?

Participant 17: Not really, only the ones that I have said. When I got there, the examination was ridiculous, it was really invasive, and being in the ward and not being listened to and being really ill, and then it turned out that when they changed my medication it did make it a difference, so I was annoyed that for three days I had been so sick, whereas if they had of listened to me straight away, that could have been avoided, so things like that I was really disillusioned about.

Researcher: How did you find the doctors and nurses?

Participant 17: My doctor was good he sent a referral letter to the hospital, because I was so sick and so when I got there they actually took me straight through. Which was good, because then I waited for about an hour or so for the doctor to come in and examine me, which was the one who just came in and didn't say who he was or any of that sort of stuff. And I think I saw another doctor once in the ward when I stopped

taking medication. I don't recall the doctors coming around on the daily basis and the nurses would just come and hand me my mediation and told me I had to have it and that was about the only contact with them unless they were walking past helping someone else and they might say "how are you today" and that was about it. There wasn't much contact with the nurses except for the medication.

Researcher: And can you tell me about your attitude to the health care system after that experience?

Participant 17: On that particular occasion I was very disillusioned, I was really upset about the way I had been treated, I had another occasion in hospital, where it was the complete opposite, I was treated really well, I had fantastic nurses, it was more a one on one sort of treatment, so that was good. My grandfather has been in hospital a lot recently, and he has been treated really well, but then I must admit I have also taken the initiative to make sure that he does, I will make sure that the nurses will do the right thing, I'll make sure that the doctors will answer questions, or that he tells them relevant information and so I think you need to be very assertive to get the correct care that you need and if you don't speak up for yourself that you can easily be bypassed as the victim and that you just fit into what they want, and I think things could be overlooked because of that. I am now more assertive and I will tell people what I think and if I am not happy with something I will make sure that they will listen to the fact that I am not happy with something. And that even goes with my GP in life in general, I have taken that attitude.

Researcher: When I say control what sorts of ideas come into your mind?

Participant 17: As in control for me or control for the medical staff?

Researcher: Whatever you would like to talk about.

Participant 17: On the occasion I stayed, I didn't feel like I had very much control at all, I felt that I was controlled by the staff, whenever I did assert myself or say I didn't like something, I felt I was ignored, so the control lay with them, requesting a doctor and not having that provided for, they had the control again. The doctor in the initial examination, even though he probably should have been asking me a lot of questions, he tended not to, he read the doctors letter and then did what he did and then I was told where to go, so it was very much that they were in control of me once I got there.

Researcher: In the questionnaire which you have completed, the first part asks questions relating to personal control in hospital, like issues about dignity and privacy. Do you think that these questions were difficult to understand or needed improving?

Participant 17: With the students coming around, when you are really sick, I think they should ask you if you want them there prior to them getting there and you should have the right to say no. And I think a doctor should be there while the students examine you and I don't think that they should diagnose you, in case the information is incorrect. I think all these questions are relevant, they are good questions.

Researcher: Ok, we have come to the end. Would like to add anything else? (Participant shakes head) Ok, thank-you.

Participant 97

Researcher: Can you start by telling me about your hospital experience?

Participant 97: Well on the whole I'm always impressed by nurses, I think nurses are lovely. The first time I was in hospital was for my tonsillectomy, and I had a really horrible surgeon. Not only obnoxious but I didn't think he was at all interested in my, I think he was interested in my health from a scientific point of view, but not at all from my feelings, or my pain. And I had another, when I had my other operation, I had another doctor who was much nicer but at the same time I didn't feel he was particularly

attentive, and in fact he didn't come and see me after my operation at all, and we had to go back to the hospital and say look, you have to have a look at this. Not that I was sick but I wanted him to make sure it had all been done probably. And so my general experiences have been that I get extremely frustrated with lack of follow up attention from doctors, from surgeons. I've had two really nice surgeons though, and so overall they've been pretty positive, but I think on the whole there is an element of fitting into their time schedule and they make it obvious to you that you have to feel privileged, you know, I'm very generously coming in and squeezing you in between my two session of golf.

Researcher: Can you tell me why the surgeon was nice? What makes them different from the others?

Participant 97: When I had my appendix out, and he wasn't, that was still at a private hospital, but he didn't have that aura of godlikeness, that the various misters have, and he was a very good listener, and he wasn't loud, he just sat down next to my bed and ask me how I was feeling in a perfectly normal nice way and he came and saw me afterwards, and not at all patronising, I mean fundamentally that's what it comes down to, the two other surgeons were patronising, one in a nice way, but he still was patronising, and the first surgeon, he was just a patronising bastard. And the first time I saw him when I went into his consulting room, that was when I walked in and he said "what seems to be the trouble" and I said "I have had a lot of" and I was about to say, tonsillitis, and he said, "boyfriends". And that just set the scene. And at sixteen, you can't, not that I didn't have anything to say, Mum was there and she went, and it was like what are you implying, are saying that I am a slut, or are you trying to say I'm pretty, like whatever it is, it's not appropriate. So that immediately put me on the back foot, and he was also the one that I was in a lot of pain after my tonsillectomy, which every one is, but I was sixteen and I wanted to whinge about it, and he came in three days after I had had them out and I had already started vomiting, and was vomiting continuously, and I was feeling like death, and he came in and said well how are we and I said go away I feel awful and he said quote, unquote "I am going to come back I and we are going to start that conversation again", like I was his daughter or something.

Researcher: And can you tell me about the nurses, what makes them different?

Participant 97: Well I think, well I haven't had any unpleasant nurses, I've had some unsympathetic nurses, but maybe I have more sympathy for them, I think on the whole they're the ones that actually listen to your problems, they're the ones that deal with the after effects of the operation, the vomiting or the pain, the temperature or whatever, they're the ones that are cleaning up after you're vomited or bleed or whatever, and I think that they're on the whole they're amazing, they do a lot of work and they get under recognised, and why should I came in and go doctor doctor thank-you so much when it's the nurse that has been there and helped me out at 2am, and with a smile on her face, most of them are pretty good. I had one with my tonsils that was forcing me to chew down on potato chips, but I hated her and she kept on trying to give me injections. And they talk to you as a person, and rather than a science experiment, they are looking at the whole picture.

Researcher: Can you tell me anything else about you day to day experiences in hospital?

Participant 97: I don't think I had that many issues with being sponged bath, most of the time I could get up and have showers by the time I wanted to get up and have a shower.

Researcher: And that was OK to get up when you wanted to have a shower?

Participant 97: Yeah, by the time it was safe for me to have a shower, I hadn't wanted to have one before that. I never wanted to get up when I probably shouldn't have. So there was never any issue about that. I think one time thinking that somebody should have been there to help me, 'cos I had to wonder down the hall, and I remember thinking that this is wrong, and feeling very very vulnerable, and sorry for myself, so that was one time. I remember having an issue about food with my tonsils because they were trying to make me eat, but it wasn't just that it hurt, 'cos I was vomiting I didn't want to eat. But in terms of day to day, I can't remember anything in particular, but my hospital stays weren't that long, and when I was (awake) I slept a lot.

Researcher: Can you tell me about aspects you enjoyed?

Participant 97: I can't think of anything, I mean I don't like being in hospitals, no one really does.

Researcher: Can you tell me about aspects that you didn't enjoy apart from the ones you have already mentioned?

Participant 97: I didn't have any major tests or anything, so there was nothing intrusive, no not that I have already mentioned.

Researcher: Is there any thing else that really stands out for you, whether it was really positive or really negative?

Participant 97: I can remember the ultrasound women, when I went to have my appendix out, the gave me a lot of water and gave me an ultrasound, and I was in a fair amount of pain, and they wheeled me up to the ultrasound place and I was feeling pretty sorry for myself, and she sat there and I had to hoist myself out of the wheelchair, onto the bed and she said, "come on, hop on", so I really didn't enjoy that, and she said, "OK get out, out you go". Being sent home after my tonsillectomy when I hadn't kept anything down for days, and I couldn't even have water. It was obvious I'd had an allergic reaction, because everyone vomits after a general anaesthetic, but this was ridiculous, and I continued to vomit for two weeks afterwards, I think that was bad, that stands out quite a lot because I was really sick after that. And they said to me we won't send you home until you hold something down, and I held something down for an hour and I went and vomited all the way home in the car, it was ridiculous.

Researcher: Can you tell me a little bit more about your ultrasound experience, the thoughts that were going through your mind and how you were feeling?

Participant 97: Well I thought she was really unsympathetic, it was the end of the night shift, it was 5am, but she was extremely unfriendly, and also, I wasn't just in pain, I was so full of liquid, I felt like I was going to wee myself, I mean I wasn't but it was that horrible feeling, and I thought you know what sort of situation, every one that comes in for an ultra sound, because I assume they do that to every body, so you would be nice to someone because you know they have made to drink water and they can't go to the loo, and I just thought, you're horrible, and because it wasn't, my appendix wasn't about to burst, but it did hurt a lot, and she was completely undervaluing my pain here, and just thought, I felt about two years old, and I was 21, so I should have been able to feel fine about it (saying something) but that's the thing about hospitals, everyone is reduced to a 12 year old person, by definition, you have no power, so it's that horrible feeling that you can't complain, because what are you going to say, they're health care professionals, and they're devoted serving members of the community, so you can't really get angry at them, they're doing a good job, by definition, there's never really the ability to dispute something because (a) with doctors, they know best and (b) there're noble and you're the loser who happens to be sick. That's the feeling, almost slightly ashamed of yourself for not feeling better, obviously she expects me to get from the

wheel chair to the bed without any trouble, so therefore, I must be able to, it must be my problem.

Researcher: And did you encounter any other health professionals apart from doctors or nurses?

Participant 97: No, I never had physio or anything like that. Anaesthetist, I have had good ones, maybe it's because people don't treat them like gods, so they don't act like gods, you don't go, oh here's the anaesthetist like you do with the surgeons. And they need to listen really carefully, and one really explained really carefully.

Researcher: Tell me a little more about the anaesthetists, what other things did you like about them?

Participant 97: I think they're demeanour. I can remember both of them, instead of standing there, he sat next to the bed and chatted at my level, and that's obviously a very good trick, in terms of physically they are on your level, they are not standing over you while you are lying flat on your back in a hospital bed. I think that is good. Similarly, that's what made the appendix doctor so good, he sat down next to my bed and was like, chat, that sort of body language thing.

Researcher: Did you have any instances where you felt you were bossed around?

Participant 97: You end up feeling squashed because you don't have a choice, I mean technically you do, but you don't feel like you have a choice, and certainly they are not often presented to you. So I get pissed off that I feel squashed, and (a) how dare you boss me around and (b) how dare I let myself get bossed around, but you realise that there's nothing else you can do in that circumstance, and it's not life or death, but there's different ways to do things. Like the nurse, I vomited once and she gave me some peppermint tea as a first option, and she said I can give you an anti-nausea injection, and I didn't want that 'cos they can hurt, and I said can you give it to me though the drip, and she said then I have to reattach you drip and check on it all night and I said that I didn't mind, and she said that she did, and she said that she'd give me an anti-nausea shot and put a bit of morphine in it, that sounds awful, but she only put a skerrick in, and I drifted off to sleep as happy as Larry and I had a joke with her, like she gave me the choices, and I could have said no and put the drip back in and she probably would have said OK and been cheerful about it, but it was that she had given me those options and that she had tried the peppermint tea first, and she could have gone right roll over (to have the injection) and so I think that that is the difference rather than someone coming in and going right you can take two panadol or lie awake all night, and I couldn't swallow a panadol at that point so I'd have to lie awake all night, and I think at one point with my tonsillectomy, I think I was asking for shots rather than panadol because I couldn't swallow it because I was vomiting, and I think it was that night nurses who wouldn't give me a shot, and I remember thinking that this is madness, it got to the point that I wanted injections, and I hate injections just as much as the next person. I mean that's the thing being presented with choices makes the fundamental difference between feeling crap about what's happening and at least you have choices even if they are crappy, it's still better than nothing.

Researcher: Did you have any instances where you were treated with a lack of respect?

Participant 97: Not any in particular apart from what I have mentioned. A lot of the nurses would ask me questions as an intelligent human being.

Researcher: Ok I'll move onto the next part, when I say control, what comes into your mind.

Participant 97: What as in lack of, well exactly, that's what I was saying before about being vulnerable.

Researcher: Can you tell me apart from what you have already said, times that you have felt out of control?

Participant 97: No

Researcher: Can you tell me about times you have felt in control?

Participant 97: I think when I was well enough, I think even knowing I had a nice surgeon, because with the others, I felt like I had to double check, is everything Ok, is this normal, should I be vomiting, the nice surgeon came in the next day and the day after that, that gives you a feeling of control because you can ask questions and you can get feedback, because that's all you can get, you can make the decisions, I think with that operation, as much as one can when in a hospital, I felt in control, and also I wasn't that ill. And also when I got the options from the nurses.

Researcher: We'll move onto the questionnaire, in the first part of the questionnaire, it is asking questions about control in day to day experiences and control in regard to the self including privacy, dignity issues, so does anything stand out that doesn't fit in with that idea? Even if you can see where I can improve any statements?

Participant 97: No I can see anything.

Researcher: Well I think that is about it, do you have anything more that you would like to add?

Participant 97: I think more women should be surgeons. I think that it makes a difference in terms of how you express yourself, I assume if I had a dominant bitchy female surgeon I would feel the same way, but I think that would be less likely. I think there is an element of irony that the majority of surgeons are men and men are notoriously bad listeners. And I think that it is ridiculous that nurses have that enormous amount of pressure to deal with all the family members, yet they don't have any ability to change any situations, it's completely inefficient. The nurses always have to say, I hear your problem and I now have to take that to a doctor to clear that, it's madness.

Researcher: Thank-you!

Participant 3: Most of the health care professionals were really really good except one (which I do remember). I had been in bed all day and was told not to wash because my surgeon had drawn on me (marked me) for the operation. It was a boiling hot day, my room had huge windows so I got very sweaty and this one nurse made a negative comment about my personnel hygiene when obviously there was not a thing I could do about it, situation being as it was. The other nurse that was with us looked upset (she was empathetic and a professional) while this nurse was not. I thought she was a bitch and wondered what she was doing in that hospital which other than her was excellent.

Participant 6: Didn't like being in hospital, so reliant on health care workers! Finally "allowed" to return home after insisting I could take care of myself and my recovery was slow whilst in hospital. Was resentful whilst staying in hospital so probably wasn't a good patient but I was mainly frustrated with the experience. Once home, I was far less stressed and recovered quickly. I tried to focus on hospital experience in general terms when answering questions however, I had some wonderful health care workers and became a bit confused whilst remembering them when answering questionnaire. One "bad" or "unsatisfactory" health care worker and/or conditions of hospital tend to stay in my memory.

Participant 17: When I stayed in hospital it wasn't a very pleasant experience. I was prescribed medication that made me physically ill and despite me informing the staff it took four days for it to be changed. I was reprimanded by a nurse for refusing medication. The experience of my operation three months later was completely

different and a much more pleasant experience. I was only a day patient when I had the operation.

Participant 31: It was my third child. The delivery staff were excellent. When I reached the ward I felt the care was lacking. I was never spoken to by any of the staff. I received no help with a tense breastfeeding situation. I was on my own. I have nursed for 12 years myself. So I know the requirements for professional behaviour. There was a lack of interest in dealing with patients. No empathy. This was 1990. Very disappointing.

Participant 34: My overall hospital experience was satisfactory however, after being readmitted for golden staph infection I was sometimes made to feel as though it was my fault.

Participant 60: My hospital experience was extremely bad. If the doctor had listened then would have done a Caesarean instead of almost losing both myself and baby. My own diagnosis was correct as to the baby being too big for my body, which proved when the placenta came out, the baby had kicked a hole in it near my ribcage. These days I nearly never go to the doctor's office unless very ill. I also have a good GP for my family and have an excellent relationship with the GP.

Participant 73: My background is in natural health, strong interest in mind and body medicine. I believe we can make a strong positive contribution to own health if we choose. My hospital stay was five days in maternity; I was a sole parent, so nurses didn't tend to fuss over me. One older nurse asked me if I understood why, and I told her yes, that I would be going home alone with my baby, so I should get used to it ASAP. In the labour ward, one nurse was very rude about me taking an herbal mixture and demanded to know who prescribed it and did my doctor know.

Participant 103: I think medical staff is working in an artificial environment where they can't really be empathic towards their patients because it would make it all too real. They need to step back a little and remember we are all people with needs and wants. Except to do that they take off the layers of brick walls that surround them and it is too hard to look after people with terrible illnesses. This is my theory – I find medical staff hard and standoffish but I was a nurse who did the same when I worked, until one day the people become someone's son, daughter, father, mother, husband, wife etc and I couldn't do it anymore. I was a better nurse but it was too much for me. I thought this might be a little insight into why medical staff takes control and power, to be able to cope because it is too real, you have to get out of nursing, and I have.
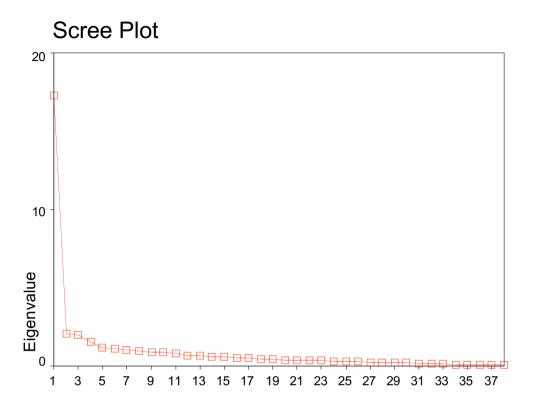
APPENDIX D

THE PILOT STUDY: COMPUTER PRINT OUT OF INITIAL 7-FACTOR ANALYTIC SOLUTION WITH 38 CLOSED ANSWER ITEMS

KMO and Bartlett's Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.913
Bartlett's Test of Sphericity	Approx. Chi-Square	3106.219
	df	703
	Sig.	.000

Communalities

	Initial	Extraction
PCHS1	1.000	.719
PCHS2	1.000	.746
PCHS3	1.000	.614
PCHS4	1.000	.655
PCHS5	1.000	.512
PCHS6	1.000	.688
PCHS7	1.000	.697
PCHS8	1.000	.787
PCHS9	1.000	.595
PCHS10	1.000	.705
PCHS11	1.000	.738
PCHS12	1.000	.608
PCHS13	1.000	.747
PCHS14	1.000	.684
PCHS15	1.000	.537
PCHS16	1.000	.688
PCHS17	1.000	.770
PCHS18	1.000	.767
PCHS19	1.000	.659
PCHS20	1.000	.722
PCHS21	1.000	.618
PCHS22	1.000	.720
PCHS23	1.000	.687
PCHS24	1.000	.742
PCHS25	1.000	.672
PCHS26	1.000	.695
PCHS27	1.000	.811
PCHS28	1.000	.738
PCHS29	1.000	.677
PCHS30	1.000	.600
PCHS31	1.000	.732
PCHS32	1.000	.620
PCHS33	1.000	.624
PCHS34	1.000	.551
PCHS35	1.000	.828
PCHS36	1.000	.703
PCHS37	1.000	.725
PCHS38	1.000	.740

Extraction Method: Principal Component Analysis.

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	17.315	45.565	45.565	17.315	45.565	45.565	6.541	17.212	17.212
2	2.032	5.347	50.912	2.032	5.347	50.912	6.351	16.712	33.924
3	1.960	5.157	56.069	1.960	5.157	56.069	4.097	10.781	44.705
4	1.526	4.016	60.084	1.526	4.016	60.084	2.549	6.708	51.413
5	1.167	3.071	63.155	1.167	3.071	63.155	2.461	6.476	57.889
6	1.109	2.917	66.072	1.109	2.917	66.072	2.372	6.241	64.130
7	1.014	2.669	68.742	1.014	2.669	68.742	1.752	4.611	68.742
8	.936	2.464	71.205						
9	.894	2.353	73.558						
10	.866	2.279	75.837						
11	.817	2.150	77.987						
12	.682	1.795	79.782						
13	.648	1.705	81.487						
14	.616	1.621	83.109						
15	.571	1.503	84.612						
16	.550	1.447	86.058						
17	.491	1.292	87.350						
18	.427	1.123	88.473						
19	.415	1.092	89.565						
20	.389	1.024	90.589						
21	.376	.990	91.579						
22	.343	.903	92.483						
23	.333	.876	93.358						
24	.296	.778	94.136						
25	.275	.724	94.860						
26	.264	.696	95.556						
27	.222	.584	96.140						
28	.205	.540	96.681						
29	.188	.496	97.176						
30	.186	.489	97.665						
31	.182	.479	98.144						
32	.150	.395	98.538						
33	.128	.337	98.875						
34	.104	.273	99.148						
35	8.844E-02	.233	99.380						
36	8.583E-02	.226	99.606						
37	8.176E-02	.215	99.821						
38	6.784E-02	.179	100.000						

Extraction Method: Principal Component Analysis.

Scree Plot

Component Matrix

Component

	1	2	3	4	5	6	7
PCHS31	.835	5.870E-02	.168	-4.946E-02	1.197E-02	-2.573E-02	1.954E-03
PCHS17	.808	-.120	5.176E-02	.217	-9.652E-02	.174	.112
PCHS26	.807	.147	9.595E-02	2.792E-02	-5.073E-02	2.847E-02	9.183E-02
PCHS20	.803	.106	9.103E-02	.178	4.663E-02	-.121	-9.611E-02
PCHS35	.801	3.183E-02	.279	.267	-.114	.133	6.884E-02
PCHS13	.801	8.183E-02	.197	-1.722E-04	-.196	2.294E-02	.144
PCHS22	.793	9.550E-02	7.410E-02	.173	-4.480E-03	-.153	-.152
PCHS18	.788	1.690E-02	.271	-.198	2.711E-02	2.764E-04	.183
PCHS19	.776	9.168E-02	7.132E-02	-5.452E-02	.137	-.121	-8.080E-02
PCHS36	.767	.307	-.105	-2.863E-02	-4.225E-02	-7.525E-02	-2.482E-02
PCHS12	.763	9.053E-02	4.504E-02	-2.842E-02	-4.297E-02	5.801E-02	9.735E-02
PCHS2	.763	.204	.127	-.136	-.120	-.264	-6.503E-02
PCHS7	.745	.230	-.110	-.239	9.954E-03	-8.915E-02	-.106
PCHS21	-.740	-6.413E-02	-.140	-.176	5.220E-03	-.115	-4.944E-02
PCHS8	.718	1.261E-02	.356	-.319	.123	-3.303E-03	.165
PCHS14	.698	3.765E-02	7.684E-02	.368	-1.239E-02	.199	.118
PCHS38	-.698	.394	-8.242E-02	-8.855E-02	4.779E-02	-.172	.228
PCHS29	.697	-7.082E-02	.296	-.171	9.263E-02	-2.265E-02	-.244
PCHS6	-.696	.396	.106	7.909E-02	-3.753E-02	-.149	8.079E-02
PCHS3	.679	.244	-.194	-.103	9.967E-02	8.583E-02	.168
PCHS25	-.676	.336	.158	6.780E-02	-.118	7.859E-02	.229
PCHS30	.675	.133	-9.011E-03	.289	-.126	.101	-.132
PCHS4	.665	8.783E-02	-3.493E-02	.177	-.140	-.334	.204
PCHS5	-.635	3.509E-02	-.284	.129	3.533E-02	-1.306E-02	9.631E-02
PCHS33	.623	5.288E-02	-7.632E-02	.402	.174	-.185	-3.433E-02
PCHS24	.619	-7.120E-03	.237	-.337	.374	1.467E-02	.222
PCHS37	-.617	-.199	5.851E-02	.139	.399	-.189	.295

PCHS28	-.586	.378	.357	.264	.152	9.629E-02	-.149
PCHS1	-.575	.315	.138	8.417E-02	-.354	.234	.288
PCHS15	.564	7.078E-02	-.332	.151	8.419E-02	-.239	.127
PCHS27	-.535	.334	.326	.222	.351	-7.973E-03	-.366
PCHS9	-.519	.513	-1.686E-02	.164	9.440E-04	-.187	-3.007E-02
PCHS11	.506	.388	-.404	-.340	.170	6.073E-02	-.137
PCHS23	.496	7.346E-03	-.298	.279	.367	.371	-5.016E-02
PCHS34	-.387	7.090E-02	.375	-8.252E-02	.303	.366	.152
PCHS32	-.513	.555	8.088E-02	-.202	2.447E-02	2.523E-02	-5.723E-03
PCHS16	.462	.122	-.520	.122	.285	4.449E-02	.301
PCHS10	.409	.307	-.410	-.197	-.175	.418	-.175

Extraction Method: Principal Component Analysis.
a 7 components extracted.

Rotated Component Matrix

	Component						
	1	2	3	4	5	6	7
PCHS35	.783	.388	-.206	7.696E-02	7.198E-02	4.729E-02	-9.314E-02
PCHS14	.729	.203	-.188	7.528E-02	3.356E-02	.248	-8.431E-02
PCHS17	.678	.285	-.347	.119	7.636E-02	.175	-.240
PCHS30	.636	.159	-.184	.269	.219	.126	1.806E-02
PCHS21	-.618	-.374	.204	-.131	-8.528E-02	-.163	6.306E-02
PCHS13	.587	.514	-.128	.169	.163	1.925E-02	-.257
PCHS20	.562	.427	-.243	.127	.338	.176	6.292E-02
PCHS26	.548	.497	-.140	.211	.181	.171	-.147
PCHS22	.547	.397	-.258	.153	.390	.126	6.769E-02
PCHS33	.510	.173	-.217	-4.773E-02	.374	.362	.119
PCHS12	.470	.466	-.178	.225	.144	.178	-.187
PCHS8	.277	.802	-.198	5.786E-02	-2.048E-02	4.136E-02	-.152
PCHS24	.117	.771	-.218	-1.120E-02	-.102	.261	-8.579E-02
PCHS18	.400	.709	-.200	8.929E-02	5.858E-02	7.761E-02	-.216
PCHS2	.362	.598	-9.719E-02	.228	.436	-2.519E-03	-7.209E-02
PCHS29	.307	.595	-.412	.164	.118	-8.155E-02	.105
PCHS31	.485	.585	-.258	.178	.195	.108	-8.554E-02
PCHS19	.362	.555	-.267	.173	.280	.198	3.316E-02
PCHS7	.226	.534	-.164	.424	.332	.198	-6.619E-02
PCHS5	-.354	-.520	.279	-.142	-8.240E-02	.101	3.223E-02
PCHS36	.413	.444	-6.000E-02	.370	.355	.251	-7.002E-02
PCHS38	-.463	-.217	.669	-.141	-5.502E-02	3.267E-02	8.442E-02
PCHS25	-.178	-.280	.654	-.153	-.280	-.167	6.787E-02
PCHS6	-.279	-.269	.653	-.177	-5.919E-02	-.149	.232
PCHS1	-1.387E-02	-.332	.649	-2.185E-02	-.331	-.248	-.128
PCHS32	-.329	-2.594E-02	.626	.146	-.159	-9.347E-02	.252
PCHS9	-.171	-.255	.619	-4.428E-02	.101	-1.625E-02	.325
PCHS10	.159	4.197E-02	-5.433E-02	.782	-7.855E-03	.214	-.132
PCHS37	-.394	-.233	.156	-.644	-.201	.152	.117
PCHS11	-4.684E-02	.360	-4.565E-02	.616	.210	.424	1.610E-02
PCHS34	-.130	6.347E-02	.204	-.180	-.641	-3.714E-02	.209
PCHS4	.461	.325	-3.603E-02	-3.667E-02	.492	.185	-.241
PCHS16	.168	8.141E-02	-7.608E-02	.143	.154	.749	-.204
PCHS23	.376	2.838E-03	-.342	.231	-.111	.591	.116
PCHS15	.260	.171	-.132	6.910E-02	.440	.448	-.153
PCHS3	.299	.422	-5.765E-02	.331	.132	.428	-.182
PCHS27	-.137	-.157	.301	-.157	-.184	-.123	.776
PCHS28	-2.920E-02	-.225	.476	-.169	-.284	-.178	.565

Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization.
a Rotation converged in 13 iterations.

APPENDIX E

THE PILOT STUDY: COMPUTER PRINT OUT OF FINAL 3-FACTOR ANALYTIC SOLUTION WITH 26 CLOSED ANSWER ITEMS

Descriptive Statistics

	Mean	Std. Deviation	Analysis N
PCHS8	3.8750	1.04083	112
PCHS18	3.7054	1.04527	112
PCHS35	3.7768	1.12874	112
PCHS31	3.5804	.94572	112
PCHS13	3.6786	1.20968	112
PCHS26	3.5000	.99549	112
PCHS2	3.7054	1.11208	112
PCHS29	3.7054	.83438	112
PCHS21	2.4286	1.20595	112
PCHS5	1.7679	1.06528	112
PCHS12	3.4821	1.09858	112
PCHS24	3.8929	.84210	112
PCHS19	3.6161	1.17209	112
PCHS14	3.8661	.97256	112
PCHS28	2.6964	1.09741	112
PCHS27	2.4554	1.08958	112
PCHS32	2.1429	.98509	112
PCHS9	2.0357	.90969	112
PCHS25	1.9911	.86468	112
PCHS1	1.9554	1.00797	112
PCHS34	2.6518	1.14459	112
PCHS16	3.2143	1.18115	112
PCHS10	2.9107	1.17445	112
PCHS11	3.2589	1.08840	112
PCHS23	3.6786	1.12478	112
PCHS15	3.7857	1.01723	112

KMO and Bartlett's Test

Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		.899
Bartlett's Test of Sphericity	Approx. Chi-Square	1862.236
	df	325
	Sig.	.000

Communalities

	Initial
PCHS8	1.000
PCHS18	1.000
PCHS35	1.000
PCHS31	1.000
PCHS13	1.000

PCHS26	1.000
PCHS2	1.000
PCHS29	1.000
PCHS21	1.000
PCHS5	1.000
PCHS12	1.000
PCHS24	1.000
PCHS19	1.000
PCHS14	1.000
PCHS28	1.000
PCHS27	1.000
PCHS32	1.000
PCHS9	1.000
PCHS25	1.000
PCHS1	1.000
PCHS34	1.000
PCHS16	1.000
PCHS10	1.000
PCHS11	1.000
PCHS23	1.000
PCHS15	1.000

Extraction Method: Principal Component Analysis.

Total Variance Explained

Component	Initial Eigenvalues			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	11.458	44.069	44.069	7.904	30.399	30.399
2	1.863	7.165	51.235	3.709	14.266	44.665
3	1.538	5.914	57.149	3.246	12.484	57.149
4	1.177	4.529	61.678			
5	1.055	4.058	65.736			
6	.925	3.559	69.295			
7	.830	3.192	72.487			
8	.765	2.943	75.430			
9	.731	2.812	78.242			
10	.681	2.621	80.863			
11	.595	2.290	83.153			
12	.524	2.017	85.169			
13	.510	1.961	87.130			
14	.448	1.723	88.853			
15	.420	1.615	90.468			
16	.371	1.425	91.893			
17	.332	1.278	93.171			
18	.312	1.200	94.371			
19	.294	1.130	95.501			
20	.255	.981	96.481			
21	.220	.846	97.327			
22	.171	.659	97.986			
23	.159	.610	98.596			
24	.143	.552	99.148			
25	.119	.456	99.604			
26	.103	.396	100.000			

Extraction Method: Principal Component Analysis.

Component Matrix
a 3 components extracted.

Rotated Component Matrix

	Component		
	1	2	3
PCHS8	.808		
PCHS18	.792		
PCHS35	.780		
PCHS31	.776		
PCHS13	.762		
PCHS26	.728		
PCHS2	.708		
PCHS29	.707		
PCHS21	-.676		
PCHS5	-.666		
PCHS12	.666		
PCHS24	.662		
PCHS19	.659		
PCHS14	.585		
PCHS28		.758	
PCHS27		.695	
PCHS32		.669	
PCHS9		.629	
PCHS25		.617	
PCHS1		.558	
PCHS34		.443	
PCHS16			.713
PCHS10			.687
PCHS11			.669
PCHS23			.544
PCHS15			.536

Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization.
a Rotation converged in 6 iterations.

<center>APPENDIX F</center>

<center>**FINAL 26 CLOSED ANSWER ITEMS**</center>

Below is a list of statements concerned with your view of your hospital stay, and the health care workers (for example, nurses, doctors, surgeons etc.) you encountered during your hospital stay. Beside each statement there is a scale which ranges from 1 ('Strongly disagree') to 5 ('Strongly agree'). For each item please circle the number that represents the extent to which you agree with the statement. Please answer <u>every</u> item and only make <u>one</u> choice per item. Please respond as honestly as you can and remember that your responses will remain confidential.

	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
1. The health care workers did not respect my dignity while I was bathing and dressing.	1	2	3	4	5
2. I believe I received clear and accurate explanations of my condition in terms I could understand.	1	2	3	4	5
3. My care was compromised as I was discriminated against because of who I am (for example, my gender, age).	1	2	3	4	5
4. I believe I was listened to when I explained my symptoms.	1	2	3	4	5
5. The health care workers did not respect my privacy when I was interviewed.	1	2	3	4	5
6. I felt comfortable to access my medical chart and medical records.	1	2	3	4	5
7. If I wanted to, I felt comfortable to refuse the presence of health care workers not directly involved in my care, such as students or researchers.	1	2	3	4	5
8. I believe health professionals gave me explanations about my future health in a sensitive way.	1	2	3	4	5
9. I was satisfied with my medical treatment.	1	2	3	4	5

	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
10. I received quality care regardless of my lifestyle preferences (for example, cultural, religious preferences, sexuality).	1	2	3	4	5
11. I was able to decide when to have showers, within reason.	1	2	3	4	5
12. I was able to decide when to eat my meals, within reason.	1	2	3	4	5
13. I believe I was listened to when I explained my concerns about my condition.	1	2	3	4	5
14. I believe I received sufficient information prior to any medical procedure or treatment that I underwent, in language I could understand.	1	2	3	4	5
15. Health care workers treated me in a patronising manner.	1	2	3	4	5
16. If I wanted to I felt free to have someone such as a friend or family member with me throughout my hospital stay.	1	2	3	4	5
17. I believe I was understood when I explained my symptoms.	1	2	3	4	5
18. The health care workers did not respect my privacy while I was bathing and dressing.	1	2	3	4	5
19. I believe health professionals gave me explanations about my health in a supportive empathetic manner.	1	2	3	4	5
20. I was not asked for my permission before health care workers examined me.	1	2	3	4	5

	Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
21. I was not asked for my permission before health care workers interviewed me.	1	2	3	4	5
22. I believe the health care workers listened to me when I asked about my medical treatment.	1	2	3	4	5
23. I believe health professionals gave me explanations about my diagnosis in a sensitive manner.	1	2	3	4	5
24. The health care workers did not respect my privacy when I was examined.	1	2	3	4	5
25. I felt embarrassed when health care workers examined me.	1	2	3	4	5
26. I was satisfied with the way I was treated as a person.	1	2	3	4	5

APPENDIX G

THE MAIN STUDY: INTERVIEW PREPARATION BOOKLET

Hello! Thank-you for expressing an interest in participating in this research. I believe this study may be very valuable, not only for you, but also for the health care system. From the interview you may learn more about yourself, or for some of you, it may be the first time that you are talking about your hospital experience, and this may be therapeutic for you. Hopefully, from this research, health care professionals can learn about the needs of women inpatients.

The idea of this booklet is to prepare you for the interview and therefore, to make the interview easier for you! Please read through the booklet and spend some time thinking about each exercise. There is no pressure to complete the exercises however, jotting down a few notes may clarify your memories of your hospital stay and therefore may make the interview flow better.

To begin your interview preparation, I would like you to think of your life as a book. Most books are divided into chapters. Certainly your book is unfinished at this point; still it probably already contains a few interesting and well-articulated chapters.

I would like you now to divide your own life into chapters in any way you see fit. Each chapter tells a kind of story; that is, it has a plot. Think about this for a while. Then, divide your life into between four and seven chapters. It may be helpful to give each chapter a name. It may be helpful to list the chapters by name and for each provide a short plot summary.

Try to capture the uniqueness of your biography in this exercise. Every body's life 'divides up' differently, so it is probably best to think about how your chapter structure is different from other people.

Try to think about the major events in your life as 'turning points' leading from one chapter to the next. These turning points should be unique to you.

Your biography: Plot, Chapter 1, Chapter 2, Chapter 3, Chapter 4, Chapter 5, Chapter 6, Chapter 7.

Now let's move onto your hospital experience and put it into context.

Think about where your hospital experience fits into your book. Is it a chapter by itself? Or is it part of a chapter?

Put your hospital experience into context – By that I mean, think about the chapters that precede and follow your hospital experience: think about what was going on in your life before and after your hospital experience. Think about the person you were before the hospital experience, and the person you are after the hospital experience. Think about your thoughts about the health care system before the hospital experience and your thoughts about the health care system after the hospital experience.

What were the most critical memories you have about your hospital experience which had the most impact on you as a person? As a result, do these memories still affect you today?

Think about the people around you in your hospital experience which were of major importance for you. Why were they so important? Do the memories of these important people still affect you today?

Put you hospital experience into context: How was you life like before the hospital experience? The person you were … Your thoughts about the health care system … How was your life like after the hospital experience? The person you are … Your thoughts about the health care system … Critical memories … Important people …

Peak experiences
Many people report occasional 'peak experiences'. These are generally moments or episodes in a person's life in which he or she feels a sense of transcendence, uplifting, and inner joy or peace. Indeed, these experiences vary widely. Some people report them to be associated with religious or mystical experience. Others may find such a 'high' in vigorous athletics, reading a good novel, artistic expression, making love, or simply talking with a good friend. These experiences have been characterised as ones of wholeness, perfection, completion, aliveness, richness, beauty, uniqueness, or insight.

I would like you to think if there is something akin to a peak experience that you have experienced in your hospital stay. If there is, think about it in detail.
During the interview I will be asking you to describe your peak experiences in detail, so it may be helpful to have a think about the questions on the next page.

I would also like you think if there is something akin to a peak experience that you have experienced before your hospital stay. If so, please be prepared to discuss one of them in the interview. If you do not recall your peak experience, just move on to the next exercise.

Peak experiences
Set the scene as you remember it: What happened? Where did it occur? Who was there? What were you doing? What you were thinking? What were you feeling? What were you wishing? Did the experience change you? If so, how?

Low Points
I would like you now to think about a low point: a low point would be opposite to a peak experience.

Please think about your hospital experience. Do you remember a specific experience in which you felt a sense of disillusionment and/or despair? This would be one of the low points of your hospital experience.

Even though this memory is undoubtedly an unpleasant one, during the interview I would still appreciate very much an attempt on your part to be honest and

straightforward here and to provide for me as much detail as you can. Try to remember specific details about your low point(s).

I would also like you think if there is something akin to a low point that you have experienced before your hospital stay. If so, please be prepared to discuss one of them in the interview.

During the interview I will be asking you to describe your low points in detail, so it may be helpful to have a think about the questions on the next page.

Low Points
Set the scene as you remember it: What happened? Where did it occur? Who was there? What were you doing? What were you thinking? What were you feeling? What were you wishing? Did the experience change you? If so, how?

Just to summarise
Finally, I would like you to think again about your entire life in terms of a book with chapters. When we read chapters in a book, we are often able to excerpt from it some kind of message or philosophy which summarises the overall meaning of the text. In the context of your book so far, what is the underlying theme of your hospital experience? What is still meaningful for you today? Feel free to jot down a few ideas below.

Thank-you for taking the time to read this booklet. I look forward to meeting with you at the interview. Please remember to bring this booklet with you to the interview.

APPENDIX **H**

THE MAIN STUDY: INTERVIEW SCHEDULE

Thank the participant: Thank-you, I appreciate this very much
Remind the participant that the interview will be taped and they can request the tape be turned off at any time. Remind the participant that the information they provide during the interview will remain confidential and they will remain anonymous.

I just want to let you know before we begin that it's only natural when people start to talk about negative hospital experiences that some emotions can arise and that some particularly painful memories or unresolved issues may come up.

How did you find the information booklet? Any questions? Any problems?
Any suggestions?

The interview is basically about me asking similar questions to those in the booklet. Keeping that in mind and that I only want to keep you an hour, can you begin by briefly telling me about why you went into hospital so you can put your experience into context for me? What was the condition you went into hospital for? How old were you? How long were you in hospital?

Now if we turn to the booklet I asked you to think of your life as if it were a book. Most books are divided into chapters. In the booklet I asked you to divide your life into chapters and to think about the major events in your life as 'turning points' leading from one chapter to the next. I would like you to describe to me where your hospital experience fits into your book about your life story. Is it a chapter by itself? Is it part of a chapter? What chapters come before it? How was your life like before the hospital stay? What chapters come after it? How was your life like after the hospital stay? Tell me about the person you were before the hospital stay? Tell me about the person you were after the hospital stay? Tell me about your thoughts about the health care system before the hospital stay? Tell me about your thoughts about the health care system after the hospital stay?

In the booklet I asked you to think about the peak experiences and low points in your hospital stay and in you life before the hospital experience.

Can we start with the low points? Do you remember a specific experience in which you felt a sense of disillusionment and/or despair where you felt that it may have been the lowest point of your life? I know that they maybe very difficult for you to speak about, but I would really appreciate it if you can try your best. I would like you to discuss a low point in your life before your hospital stay? Set the scene for me so we can both feel like we are in the scene.

Can you please now tell me about a peak experience in your life before your hospital experience? Keep in mind that these are generally moments or episodes in a person's life in which he or she feels a sense of transcendence, uplifting, and inner joy or peace. These experiences have been characterised as ones of wholeness, perfection, completion, aliveness, richness, beauty, uniqueness, or insight.

Can we move onto the low points in your hospital stay? How many did you think of? I would like you to describe to me those low points that instantly come into your mind. Set the scene for me. Who was there? Specific behaviours of people involved? Time period? What were you doing? What were you feeling during the experience? What you thought about during the experience? What was the impact of the experience at the time? What affect the experience has on you now? How is it affecting your existence now? Did the experiences change you as a person? Did the experiences change your attitude to medical system? What would you have liked to happen? What could the health professionals involved have done differently? Were other experiences/behaviours that were helpful from other health professionals? Where there other experiences/behaviours that were not helpful from other health professionals? What was the outcome? How does that memory end for you? What feeling does that memory leave you with? Did the experience impact on relationship with others?

Can we move onto the peak experiences? How many did you think of? I would like you to describe to me those peak experiences that really stand out for you, that just instantly come into your mind. Set the scene for me. Who was there? Specific behaviours of people involved? Time period? What you were doing? What you were feeling during the experience? What were your thoughts about during the experience? What was the impact of the experience at the time? What affect the experience has on you now? How is it affecting your existence now? Did the experiences change you as a person? Did the experiences change your attitude to the medical system? What would you have liked to happen? What could the health professionals involved have done differently? Were other experiences/behaviours that were helpful from other health professionals? Where there other experiences/behaviours that were not helpful from other health professionals? What was the outcome? How does that memory end for you? What feeling does that memory leave you with? Did the experience impact on relationship with others? Has it changed your views about hospitals? Has it changed your views about the health care system? Has it changed your views about health professionals?

We are coming to the end of the interview and I have one more issue that I would like us to discuss. I would like you to turn to the last page of your booklet and we'll concentrate on the last exercise. Once again, think of your life as a book with chapters. When we read a book we often take some kind of message from it, a message which summarises the overall meaning of the book. Would you agree with that? Do you know what I mean by that?

Think specifically about your hospital experience, what do you think is the underlying message or theme of your hospital experience? Is it still having an impact on you today?

Summarise and give feedback. Reiterate confidentiality and appreciation. Are there any other parts of the experience that you would like to share with me either by discussing it or writing it down? Acknowledge emotion and ask them if they would like to debrief and talk about it. How are feeling right now? What are you going to do after this? What would be the best way for you to have closure from your experience? Remind participant that sometimes closure is not possible. Suggest that the participant not put so much energy into it.

THE MAIN STUDY: QUESTIONNAIRE

Women's Hospital Experiences
Professor Sue Moore   Anne-Maree Polimeni   Dr Glen Bates
Swinburne University of Technology

Many people are aware that hospital experiences can be so significant that they may change the way individuals perceive themselves and their future health care. The present study aims to explore (a) how women make sense of hospital experiences and (b) their level of satisfaction with the health care system.

Who: Participants in the study will include women aged between 20 to 75 years, who have had an adult hospital experience of three nights or more, which has occurred at least one year ago, and which they perceive as significant in terms of how they have developed as a person.

What: You are asked to participate in an in-depth discussion about your hospital stay with a female researcher. You are asked to describe in detail the significant moments in your hospital stay, which have had a great impact on your personal growth and development. The discussion may take one hour to complete. The intention is to tape the discussion: if you would like the tape recorder turned off at any time let the researcher know and she will do so. You are also asked to complete a questionnaire on your feelings during your hospital experience. The questionnaire takes approximately 30 minutes to complete, and you may complete it at your leisure.

Why: You may benefit from the discussion as you may learn more about yourself, or for some of you, it may be the first time that you are talking about your hospital experience and this may be cathartic. Also, you may help to broaden the scope of research regarding women's perceptions of their hospital stays and thus the proposed study may have the potential to inform the health care system of more sensitive ways of treating women inpatients.

Note: Your contributions will be kept confidential and your name will not be used. Participation is entirely voluntary and you are free to withdraw consent and discontinue participation in the study at any time.

If you were dissatisfied with your treatment in hospital, and you would like to complain about a health service provider, you can contact the Health Commissioner's Complaint Line on (03) 8601 5200 or toll free on 1800 136 066.

Any questions regarding this project can be directed to Professor Sue Moore of the School of Social and Behavioural Sciences on telephone 9214 5694. If you have any queries or complaints about the way you have been treated, or there are queries that the Senior Investigator has been unable to satisfy, please contact to: The Chair, Human Experimentation Ethics Committee, Swinburne University of Technology, PO Box 218, Hawthorn Victoria 3122, phone: (03) 9214 5223.

Agreement:

I (Insert name and address of the participant)…………………..

………………………………………………………………………………………………

…………………………………….. have read (or, as appropriate have had read to me) and understood the information above. Any questions I have asked have been answered to my satisfaction.

I agree to participate in this activity, realising that I may withdraw consent at any time.

I agree that the interview may be recorded on audiotape as data on the condition that no part of it is included in any presentation or public display.

I agree that research data collected for the study may be published or provided to other researchers on the condition that anonymity is preserved and that I cannot be identified.

Name of participant

Signature………………………………….Date……….

Name of investigator: Anne-Maree Polimeni

Signature…………………………………Date………

Demographic Information

1. How old are you?_____years

2. What is the highest level of education you have reached?

    1. Secondary school

    2. Diploma

    3. Degree

    4. other_____

3. What is your occupation?_____

4. What is your ethnic background?_____

5. If you have a religious affiliation, what is it? _____

6. Where did you see this study advertised? _____

At this point, I would like you to focus on the hospital stay which you discussed during the interview.

7. How old were you when you were in hospital ?_____

8. How long were you in hospital?____days____nights

9. Was it a public or private hospital? Please circle: Public / Private

10. Was it an Australian hospital? Yes / No

11. If yes, what was the name of the hospital?_____

12. Why were you in hospital? _____

13. What was the nature of your illness / condition in which you were in hospital for?

_____

14. On the scale below, please indicate the seriousness of the illness / condition in which you were in hospital for?

Minor   1   2   3   4   5   6   7   Life threatening

15. Was there any follow up treatment to your hospital stay? If yes, what did it involve?

_____

16. On the scale below, please indicate how significant you think your hospital experience was in your life as a whole, by circling the appropriate number?

Not at all   1   2   3   4   5   6   7   8   9   10   Extremely
significant   significant

This exercise involves relating a list of 30 emotions to the peak experiences and low points which you discussed in the interview. Firstly concentrating on the first peak experience which you discussed in the interview - to what extent did you feel each of the emotions listed in the table below while you experienced this specific episode? Please rate each emotion according to the scale below and place your rating in the table.

0 = Not at all	1 = A little bit	2 = To some extent	3 = Rather much	4 = Much	5 = Very much

Peak Experience: …………………………………………………………

Emotion	Your rating	Emotion	Your rating	Emotion	Your rating
1. Joy		11. Love		21. Inferiority	
2. Powerlessness		12. Self-alienation		22. Intimacy	
3. Self-esteem		13. Unhappiness		23. Security	
4. Anxiety		14. Tenderness		24. Anger	
5. Happiness		15. Guilt		25. Despondency	
6. Worry		16. Solidarity		26. Pride	
7. Strength		17. Self-confidence		27. Energy	
8. Stress		18. Loneliness		28. Disappointment	
9. Enjoyment		19. Inner warmth		29. Inner calm	
10. Caring		20. Trust		30. Freedom	

Please continue to indicate the extent you felt each of the 30 emotions in relation the remaining peak experiences which you discussed in the interview.
Now let's move onto the low points you discussed in the interview. According to the scale below, please indicate the extent you felt each of the emotions during the time you experienced each of the low points.

0 = Not at all	1 = A little bit	2 = To some extent	3 = Rather much	4 = Much	5 = Very much

Low Point: …………………………………………………………………

Emotion	Your rating	Emotion	Your rating	Emotion	Your rating
1. Joy		11. Love		21. Inferiority	
2. Powerlessness		12. Self-alienation		22. Intimacy	
3. Self-esteem		13. Unhappiness		23. Security	
4. Anxiety		14. Tenderness		24. Anger	
5. Happiness		15. Guilt		25. Despondency	
6. Worry		16. Solidarity		26. Pride	
7. Strength		17. Self-confidence		27. Energy	
8. Stress		18. Loneliness		28. Disappointment	
9. Enjoyment		19. Inner warmth		29. Inner calm	
10. Caring		20. Trust		30. Freedom	

Please continue to indicate the extent you felt each of the 30 emotions in relation the remaining low points which you discussed in the interview.

Referral Information

Thank-you very much for participating in this research, I believe that it is very important to explore how hospital experiences can affect the lives of women, and your contribution is very much appreciated. I also believe that it is very important to identify what women want from the health care system. As a researcher and a health professional I strongly believe that I am in a position to ensure that patients experience satisfactory hospital stays.

As I said before the interview, I understand that discussing particularly negative hospital stays may awaken painful memories or issues that you may not have had a chance to think about. You have given me something very personal by sharing your experiences with me, so I want to make sure that you do not feel bad after the interview. If you are feeling distressed, consider calling Lifeline which provides 24-hour telephone counselling by trained counsellors (telephone 131114).

If you think that more formal counselling can help, please call the Swinburne Centre for Psychological Services at 26 Wakefield Street, Hawthorn on 9214 8653. At the Centre the counsellors are postgraduate students at Swinburne who are training to be registered psychologists. If you would prefer a fully qualified psychologist, you can call the Australian Psychological Society who will provide you with a list of registered psychologists in your local area (telephone 8662 3300).

Alternatively, if you were dissatisfied with your treatment in hospital, and you would like to complain about the health service provider, you can contact the Health Services Commissioner's Complaint line on (03) 8601 5200 or toll free on 1800 136 066.

APPENDIX J

THE MAIN STUDY: EXAMPLE OF RESULT MATRIX

Table 12

The Number of Agency and Communion Themes in Nuclear Episodes during

Hospitalisation by Participant

Agency and Communion themes		Participants										
		1	2	3	6	7	8	9	10	11	12	13
Agency themes												
Self Mastery	Equal	1				1	1	1			1	
	Opposite	1		1	1	1	1			1		1
Status/Victory	Equal											
	Opposite											
Achievement/Responsibility	Equal		1			11						
	Opposite											
Empowerment	Equal		1						1		11	
	Opposite	1			1					1		
Failure/Weakness	Equal	1	1									
	Opposite											
Losing Face	Equal		11									
	Opposite											
Ignorance	Equal		1				1		1		1	
	Opposite		1								1	
Conflict	Equal		1									
	Opposite											
Communion themes												
Love/Friendship	Equal											
	Opposite											
Dialogue	Equal											
	Opposite											
Caring/Helping	Equal			11		1					1	
	Opposite	1								1		
Unity/Togetherness	Equal									1		1
	Opposite		1									
Separation	Equal											
	Opposite											
Rejection	Equal											
	Opposite											
Disillusionment About People	Equal	1	1	1			1	1				
	Opposite											
Another's Misfortune	Equal											
	Opposite											

Table 12 shows part of the matrix that was created to organise the coding of McAdams' themes found in nuclear episodes which occurred during participants' hospital stays. The rows represented the eight agency themes and eight communion themes respectively and the columns represented each participant. Along each row, a box was ticked if the corresponding theme appeared in the participant's transcript. For example, the table shows that Participant 6 recounted nuclear episodes which showed two agency themes. Specifically, her stories of hospital showed themes opposite to Self Mastery and opposite to Empowerment, signifying that the dominant theme within this participant's hospital stay was a lack of control. Participant 9 recounted nuclear episodes which showed one agency theme, consistent with McAdams' description of Self Mastery, and one communion theme, consistent with Disillusionment About People. The matrices were useful in writing the results, as quotes of each theme were easily located. For instance, for an example of a story showing themes of Disillusionment About People, simply examine that particular row and it is clear that the transcripts of Participants 1, 2, 3, 8, and 9 show the theme.

APPENDIX K

THE MAIN STUDY: AGENCY AND COMMUNION THEMES IN NUCLEAR EPISODES PRIOR

TO HOSPITALISATION

Agency Narratives

Self Mastery

Narratives, which had agency themes of Self Mastery, were the most common type of narrative recounted in the participants' lives before the hospital experience. There were 12 narratives which showed themes of Self Mastery, with four narratives showing themes of Self Mastery through Insight, three narratives showing Self Mastery through Control and the remaining five narratives showing themes negative of Self Mastery through Control, such as and helplessness, powerlessness and constriction.

Positive of Self Mastery (Insight)

The four narratives that showed Self Mastery through Insight (reported by Participants 13, 15, 17 & 19) provided participants with a profound insight into their identity. Two participants reported realisations that they experienced while travelling overseas. For example, Participant 17 described her peak experience while visiting the Louvre in Paris and it was closing time but she did not want to leave:

> (I) walked out and I thought "It's okay, I've got the rest of my life to come back." And it's a sort of **wonderfully exciting feeling that you don't have to do it all at once**. There will be other occasions and just feeling like a lot of things have opened up in front of you ... even though they're closing the door of the museum I was actually feeling like **I've got my whole life** ahead to do these sorts of things and make the most of the one you just have (Participant 17, p. 135).

This narrative captures the freedom that this woman felt by understanding the bountiful opportunities that exist for her in the world, that the world is her oyster! Another woman had a similar realisation when she was travelling in Venice:

> I became more myself … **I realised I could make choices** … So there was just this enormous freedom … because I could spend all day just staring at the art … I wasn't pleasing anyone else, **I was just being** and that was really new (Participant 19, p. 152).

The latter experience differed in comparison to the former, as the participant emphasised freedom within herself, to be whoever she wanted to be, rather than freedom of opportunity. Participant 15 reported a different narrative. She described a low point when she was first diagnosed with a congenital abnormality of the structure of her ear, and she had a realisation that "**there are certain things within my control, but some things just aren't**" (Participant 15, p. 113). This woman's realisation helped her to accept her condition, and part of that acceptance was changing her lifestyle to work within the limitations of her condition and being able to live with it.

Positive of Self Mastery (Control)

Of the three narratives (reported by Participants 12, 14 & 15), which showed Self Mastery through Control, two narratives were very similar in that they highlighted a greatly enhanced sense of control over the future. Participant 12 and 14 described peak experiences where they were accepted into a university course and school scholarship program respectively, and they felt increased control over their future. For example, Participant 12 said that acceptance into university "generated a lot of hope" and she was "moving towards the future" (Participant 12, p. 90).

The remaining narrative was a common example of Self Mastery through Control as the participant described feelings of deep satisfaction in being able to manage the pain of labour during the birth of her third child. She is able to master the self by controlling her own pain. She described the experience as "**having control of what was happening**. So while I was certainly experiencing the contractions, and the pain associated with that, it was manageable" (Participant 15, p. 113).

Negative of Self Mastery (Control)

Five narratives (reported by Participants 6, 8, 10, 19 & 20) showed themes contrary to Self Mastery though Control such as helplessness, powerlessness and feeling restricted. For example, Participant 6 reported the nadir experience of her twin brother being in a coma, "**just being there and not knowing, and not being able to do anything**" (Participant 6, p. 36). Also, Participant 8 spoke about a relationship break-up and an occasion where she tried to discuss the break-up with her ex-boyfriend but he was not being cooperative. She described her "**feeling of helplessness** because there was **nothing I could do**" (Participant 8, p. 50). The above two excerpts show the participants experiencing a total loss of power.

One narrative reported by Participant 20 highlighted helplessness due to restriction of choice. She described a point in her life when her nephew became very ill and she was caring for her own children plus her sister's two other children to enable her sister to attend medical appointments. She realised that by taking care of her sister's two children and raising her own three children she lacked freedom: "My whole life had changed … all the things I was going to do … but I couldn't … **I was suddenly restricted … a loss of freedom**" (Participant 20, p. 165).

Positive of Achievement/Responsibility

Table 7 demonstrates that two narratives (reported by Participants 12 & 20) showed themes of Achievement/Responsibility, such as reports of considerable accomplishment, pride and confidence. For example, Participant 20 recounted a bushwalking experience when herself, her sister and her husband climbed Mt Bogong, which is the highest mountain in Victoria. The woman found the physical challenge rewarding:

> **There's something in being able to do something that a lot of other people can't do.**… I'll be honest, **not only can you do something, you can do something that's really hard** … I could have probably out walked nearly any man … and I could carry all my stuff. A lot of the women had other people carry stuff … **no man carried our things and we were really strong**. So it was sort of a real thrill to be good.… I guess it's almost like "Look at

me, aren't I fantastic and look what I can do!" (Participant 20, p. 166).

This quote showed enormous pride in climbing the mountain.

Negative of Achievement/Responsibility

Participant 13 reported a low point which showed themes contrary to Achievement/Responsibility. She recalled that at the age of 14 or 15, she was diagnosed with achillis tendonitis, which is where the tendon that connects the calf muscle to the heel bone in the foot, is inflamed. She had been practicing ballet until that time and wanted to gain entry into a particular ballet company.

> **I was just so so so depressed because I thought that's my whole future, that's all I wanted to do at that stage in my life was dance**. I thought "If I've got this injury now, I am screwed and I'm never going to be a dancer" (Participant 13, p. 100).

The passage shows that the participant was not able to achieve her goals, thereby feeling despair.

Positive of Empowerment

Table 7 shows that participants recalled four peak experiences which showed themes comparable to Empowerment. Participant 10 described two peak experiences and Participants 19 and 21 described one each. These experiences showed participants feeling empowered and made better through their association with loved ones, nature and God. McAdams (1992a) describes that religious experiences may show themes of Empowerment, for example when the subject reports that God or another larger force was made manifest to him or her. Participant 21 reported a religious experience which occurred when she was working as a nurse on evening shift at a nursing home. She was washing an elderly man with an intellectual disability, who had previously fallen and broken his hip, and subsequently developed pneumonia. The patient was in extreme pain:

> I was just in the room holding his hand and I just said a prayer. I just said "Please God, take (patient name) out of his pain." And before the other nurse came back he died. It was totally amazing. And she came back in and I said, "He's dead! He's dead." And I couldn't believe it, I was just in shock. **It was just an amazing thing, it was like God had listened immediately**…. I just felt "Thank God!" literally, someone's listening, someone cares about him and also that he wouldn't have to suffer any more – that he could be taken out of that place (Participant 21, p. 179).

Positive of Failure/Weakness

Participants 13 and 21 reported nadir narratives that showed themes of Failure/Weakness, with both women explicitly stating that they felt a weakness within themselves. For example, the nadir experience previously described by Participant 13, when she was diagnosed with achillis tendonitis, showed that the woman felt weakness within herself. She was unable to dance which she considered her "whole future" and

she thought that this inability "was **a weakness in my body**, and my body wasn't able to handle the dancing" (Participant 13, p. 100).

Positive of Ignorance

Participant 15 described a low point, which showed themes of Ignorance when she was diagnosed with a disease in the bone of her ear and was told that she needed surgery. Her thoughts included, "Is this going to be the death of me? Is it ever going to end? How many more times? And why, why me?" (Participant 15, p. 112). This narrative showed themes of Ignorance as the woman was unable to know why she had the disease, why she needed the operation, and how many more operations she would require. The woman was confused and consequently she was unable to experience mental strength and felt weakened and vulnerable.

Communion Narratives

Positive of Caring/Helping

Table 8 shows that there were three peak narratives (reported by Participants 10, 11 & 15) showing themes consistent with Caring/Helping. For example, Participant 15 described a common manifestation of Caring/Helping as she recalled the care and love she felt while giving birth to her third child. Participant 10 described another aspect of Caring/Helping, which involved developing empathy for other people through her own health problems:

> And also I would like to get in the medical profession, to take an interest to help people in the best way I can, if the door opens that way I would pursue it because I feel that it is extremely important, **it's almost like a calling, hey you've been through this, you're got something to give the next person because you know how it feels**. In one respect it has come out in a positive way, I want to help people (Participant 10, p. 77).

Negative of Caring/Helpful

Participant 11 described a low point in her life that showed themes negative of Caring/Helping. She described one occasion before she was married, when she lived alone and was very sick: "I felt really terrible, and I thought is this all there is to life? All I do is work, I'm home on my own, **I've got nobody to look after me**" (Participant 11, p. 81). This account showed an absence of care.

Positive of Separation

The communion theme of Separation involves the subject feeling separated from friends, family or a lover. This separation can occur through a variety of ways such as a relationship break-up, and other circumstances where one has no control such as death (McAdams, 1988b). The narrative must specify negative affect about the separation or feeling alone caused by being apart from the other (McAdams, 1988b). Participant 14 reported a narrative that showed themes of Separation. The participant described a low point in her life when she came home from school and she found that nobody was home, her mother had moved out and taken the two youngest children, and left her and her father. The participant expressed sadness about the separation and it was a circumstance that she could not control.

Positive of Rejection

McAdams (1988b) states that narratives, which show themes of Rejection, describe experiences where somebody who has been a friend or lover has rejected the subject, and that person wishes to terminate a previously loving and caring relationship. The person must express negative affect about the rejection. Participant 8 and 12 reported narratives showing themes of Rejection. For example, Participant 12 described a low point when her three children all moved out of the family home at the same time without discussing it with her. This narrative scored for Rejection as opposed to Separation, because the woman did not express negative affect about the separation, but about the rejection. She felt that she had been "left out of the plan" (Participant 12, p. 90). She expressed sadness, surprise and shock about being excluded from the plan: "I guess I was shocked in that they only told me they were going to do it after they planned it, **I felt that there was a big line drawn between us**" (Participant 12, p. 90).

Positive of Disillusionment about People

Two women described low points in their life that showed themes of Disillusionment about People. Participant 21 described a period of her life when she worked in the aged care system and she was disillusioned with her work colleagues. She described them as "lost causes … defeated people … took no pride in what they were doing, and a lot of them mistreated the elderly" (Participant 21, p. 178). Participant 8 described a different low point which involved a relationship break-up where she "**felt I'd been betrayed and really let down**" (Participant 8, p. 49).

Positive of Another's Misfortune

McAdams (1988b) states that the communion theme of Another's Misfortune involves an experience where the person vicariously experiences the plight of another. Participant 18 recounted a low experience which is a common example of a narrative showing themes of Another's Misfortune: she reported her father's death and the two years prior to his death where he was continually ill, and the difficulty of that period in her life.

APPENDIX L

THE MAIN STUDY: MATCHES AND MISMATCHES BETWEEN MCADAMS' THEMES AND

HERMANS' INDICES

The following section will present descriptions of peak experiences and low points which demonstrated a match between McAdams' themes and Hermans' indices. The matches will be illustrated by examples from interview transcripts. Table 10 shows that eight participants (Participants 7, 8, 9, 11, 12, 15, 17 & 19) described peak experiences which were calculated as +HH valuations. These experiences were varied as some participants explicitly expressed references to both agency and communion, while others explicitly expressed one motive and only implicitly referred to the other motive through their ratings of affects. Participants 12 and 15 rated +HH valuations and explicitly referred to both motives. For example, Participant 12 went to hospital for a hip replacement and described a +S experience after surgery when she learnt to walk and felt a real sense of achievement with made her feel strong and confident. The same experience also showed +O ideas, as she felt it as a "real treat" to be surrounded by caring hospital staff.

Participants 7, 8, 9, 17 and 19 described peak experiences that scored as a +HH experience and explicitly expressed self-enhancement, while implicitly referring to contact and union with others, as demonstrated by the scoring pattern. These high points could be separated into two types of experiences. For example, Participants 7 and 17 made simple references to self-enhancement. For example, having survived her illness, Participant 7 expressed a sense of accomplishment, which gave her strength and confidence. This participant also referred to this experience as a "mixture of prayer and revelation" (Participant 7, p. 43), which explained the +O element. Hermans states that valuations pertaining to a spiritual experience or a particular philosophical fulfilment often relate to the positive fulfilment of the need for contact and union with other. The participants also found more complicated and less transparent routes to self-enhancement. Some participants recalled memories where they experienced a realisation about their life, which clearly made them feel strong, and in control. For example, Participant 9 went to hospital to have a tumour removed from her ovary and after the surgery she was told that the tumour was benign and that her fertility had not been affected. She recalled her feelings:

> Wow to have your health is so good and so valuable that it's the most precious commodity that you can ever have and it's just not worth worrying or stressing about anything else – because ultimately, **if you have your health, you've really got a lot** … **I remember feeling that would have been like transcendence** (Participant 9, p. 68).

Since the participant explained the moment as transcendent, it could also be considered a spiritual experience, which explained the affective pattern of the valuation.

Two participants recalled peak experiences that were rated as +LL, which Hermans identified as rare occurrences. Participant 13 described a time when she was a teenager and she had moved out of home, as it was quite turbulent. She woke up in her new place to the sound of birds and was happy. As Hermans describes it, this participant may have been experiencing passive enjoyment. Her description of the

experience suggested that she was able to enjoy a sense of peace without fulfilling the two motives of agency and communion.

Participant 1 described a peak experience which showed more agency themes than communion and was categorised as S, as the P and N indices were not significantly different. The woman recalled that she was in hospital and was about to undergo a traumatic diagnostic test. She did not know how to cope with it and the nurses were not giving her advice. She devised her own coping method and coped well, which made her feel proud and confident. She described it as a real accomplishment, "I had relied on myself to get through it and I was able to" (Participant 1, p. 8). The P and N indices were not significantly different as she may have felt ambivalent toward the situation, as the circumstances of the experience were negative, but the experience in itself was somewhat positive.

Regarding nadir experiences, Table 11 shows that the sample recalled 24 low points, which showed a –LL affect pattern. Six of the low points were experiences before hospital, while 18 of them were experiences during hospital, implying that the hospital environment and sickness may give way to disempowering and isolating experiences. The –LL type of valuation shows high levels of negative affect and low levels of both self-enhancement and contact and union with another. Some of the experiences explicitly verbalised a lack of fulfilment in one motive and implicitly referred to a lack of fulfilment in the other, while other experiences explicitly referred to a lack of both motives. For example, Participant 1 recalled she was fearfully awaiting an invasive diagnostic test, which she believed she did not require. She recalled that she had a terrible night because she was dreading the test and the following morning when the doctor visited her, he did not acknowledge her distress. The doctor "**wasn't making eye contact … he wasn't paying attention** … he was dismissive … and he didn't look at my face" (Participant 1, p. 6). This passage indicated a clear lack of contact and union with another. The doctor was not mentioning the test, so the participant raised the topic and he dismissively explained that the test was not necessary, but did not acknowledge that she had previously expressed similar opinions. This part of the experience indicated that the woman felt powerless, and that her opinions did not have authority, rather, her fate, while in hospital, was in the hands of her doctors.

Participant 8 rated her low point as –LL and explicitly referred to themes of agency. She was admitted to hospital for a third time in two months for breast cancer. She was continually told that the lump was benign, but the pathology results showed it was malignant. After the third surgery, in which lymph nodes were removed from under her arm, she was alone and waiting for the pathology results. She was thinking about the outcome of the surgery and the uncertainly of her future and she felt that there was nothing she could do about her situation, which indicated a diminished sense of control over the future. This participant did not explicitly mention her isolation, rather she emphasised powerlessness. However, the experience of regaining consciousness after surgery, feeling pain, and thinking about death, could be considered a lonely experience, because no one can share the powerlessness and fear felt at that moment. The isolation was compounded by the fact that the woman was alone in a room by herself.

Participant 16 described a low point, which scored as a –LL valuation and explicitly expressed both a lack of self-enhancement and contact and union with another. The woman recalled the behaviour of the oncologist who "**was very blunt with me and rude … barely talked to me**, she'd bark instructions at me … and kick me out the door" (Participant 16, p. 122). As the oncologist was not personable in such

a difficult time in the participant's life, her description clearly shows a lack of contact and union with another. The participant also explained that the oncologist gave her some treatment options, but disagreed with the participant's choice and said, "If it (the cancer) ever comes back **you're going to die**" (Participant 16, p. 123). Consequently she felt powerless and lost hope, "I just automatically think that way … and it's a terrible way to have to think … and it makes me really upset" (Participant 16, p. 123). This passage demonstrates a lack of self-enhancement.

One woman described a low point, which showed more agency themes than communion, and showed an affect pattern of S. The value of the S index was significantly higher than the value of the O index, and although the N index was slightly higher than the P index, the values were not significantly different. The participant recalled after her surgery she attempted to use the bedpan but was unable to urinate, so she asked the nurses to insert a catheter.

> (The nurses said) "you should be able to do this, you're taking the easy way out"… nurses were actually **laughing at me**, they actually **made a fool of me** for needing a catheter. They said, "at least you don't have to do this" … there were people drifting in and out … I can't go in this environment (Participant 2, p. 12).

This experience showed that the patient was in opposition to the nurses as they were threatening her self-esteem and she was trying to defend herself by explaining her reasons for not being able to urinate. As indicated by the woman's ratings, she felt extremely angry, which Hermans suggests may represent attempts to restore a threatened self-esteem.

The following section will present descriptions of peak experiences and low points which demonstrated a mismatch between McAdams' themes and Hermans' indices. Table 10 shows that three participants (Participant 7, 10 & 19) described a peak experience during hospital which showed more agency than communion themes but scored as a +O valuation. For example, Participant 7 rated her peak experience as a +O, signifying a large degree of affect referring to contact and union with another, but it was inconsistent with her articulation of the experience. She recalled that she woke up from surgery and realised that it was a success. She had suffered multiple brain haemorrhages due to a vascular malformation, and the operation involved many risks such as death and blindness. As her uncle was an anaesthetist, he acquired access to the intensive care unit and was at her bedside when she woke. In her account of the experience there was evidence of McAdams' agentic theme of Achievement/Responsibility as she said, "that was a big hurdle over" (Participant 7, p. 43), but the account lacked explicit evidence of communion. Hermans' indices have added to the understanding of this peak experience, as it appeared that even though the participant's account did not explicitly show a communal aspect, it did exist. For example, the woman woke from surgery in the presence of her uncle, and more importantly, she was alive and could see, signifying union with the surrounding world in general.

Participant 10 described an experience which she perceived as a peak prior to hospitalisation. The participant was told she had an ovarian cyst which had twisted around her gallbladder. Prior to her diagnosis many doctors did not take her case seriously, so she was grateful to have found a doctor who believed her. After surgery, her doctor entered the recovery room dancing, which made everyone smile. The account was scored for an agency theme as the experience strengthened her and

increased her self-esteem. However, the woman rated the experience as +O. Although the participant did not explicitly describe her feelings of contact and union with another, in reading the entire hospital experience, it would seem that the doctor offered her comfort and consolation, thereby fulfilling communion needs.

Participant 10 described another peak experience which showed more themes of agency than communion but was rated as a –O experience. One night while Participant 10 was lying in bed in extreme pain she heard her daughter crying because she thought her mother was going to die. The woman perceived it as a peak experience because she reflected on her daughter's immense help and encouragement throughout her illness. The account was scored for an agency theme as the woman felt strengthened by her daughter's presence. However, the participant scored it as –O. Although the woman perceived it to be a peak experience, the negative affect outweighed the positive affect, as it was a low time in her life. The presence of a high degree of negative affect referring to contact and union with another indicated that her illness may have been preventing her from expressing her love and appreciation for her daughter, she had to go to hospital and leave her daughter, or the possibility that she was going to die and leave her daughter.

Participant 16 described two peak experiences while in hospital for chemotherapy. Both her accounts explicitly showed one agency theme and one communion theme. One experience was when she saw a different doctor because her regular doctor was on leave. She did not like her regular doctor as she found her insensitive, but she liked the new doctor so much she decided to change. There was a communion aspect as her faith in doctors was renewed and an agency aspect as she felt empowered by the doctor's behaviour. However, the participant rated the account as +S highlighting that the self-enhancement aspect of this valuation was more significant than the communion aspect. This could be due to the high self-esteem that she felt in the presence of the new doctor, and the courage and strength she may have felt in changing doctors. The second peak experience involved attending chemotherapy alone for first time. She was apprehensive about being alone but she surprised herself and had a good experience. The communion aspect was evident in that she appreciated the support of the nurses, and the agency aspect was that she felt empowered by the information which the nurses gave her about chemotherapy. The woman rated the experience as S which may suggest that the experience of attending chemotherapy alone increased her self-esteem and strength. In addition, chemotherapy is not a positive experience, but for this woman, it was not overly negative because it increased her self-esteem.

Participant 3 described a low point which occurred the day after surgery involving laparotomy and removal of a tumour from the right ovary. She recalled that she had complete lack of control since she was unable to move because she had "tubes and wires everywhere" (Participant 3, p. 27). She also felt extremely nauseous and was sick just as the nurses were changing shifts. The nurse stayed with her, washed and cleaned her. The account was scored for an agency theme due to her perceived powerlessness, and a communion theme because she described that she was very grateful for the nurse's help. However, the participant scored the valuation as a –O, highlighting negativity and contact and union with another. As the woman rated the anxiety affect very highly, the participant may have felt anxiety of the –O type, which resulted from being overly dependent on the nurse, thereby emphasising her lack of control and loss of autonomy.

Participant 7 described a low point, which occurred when the nurse was putting a central line into her chest, which is potentially fatal, in preparation for surgery the following day. The account was scored for an agency theme of powerlessness, as the nurse left the room while in the middle of the procedure and the participant looked down at her chest and panicked and felt "completely vulnerable and in someone else's hands about to face surgery" (Participant 7, p. 43). It was also scored for a communion theme, as the nurse returned and she appreciated his comforting behaviour, as he was very reassuring. The woman scored the experience as –O type anxiety because she was completely powerless, and overly dependent on the hospital staff.

Finally, Participant 12 described a low point in her life prior to hospitalisation. She recalled her children moving out of home without prior notification. A communion theme was evident as she felt rejected, and a loving relationship with her children had come to an end. The woman rated the experience as –S type valuation as the experience may have threatened her self-esteem. She also rated moderate feelings of anger but did not explicitly express such emotions. It is generally culturally unacceptable to express anger, especially for women, however feelings of anger may have signified an unconscious attempt to regain self-esteem.