THE EXPERIENCE OF BEING AN INFORMAL CAREGIVER TO AN EARLY DISCHARGED CARDIAC SURGERY PATIENT

by

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Family members/informal caregivers of post-surgical patients are, by necessity, taking on the caregiving role sooner without any specified resources to help them. The input of these caregivers is essential so that nurses can understand their concerns, needs, struggles and rewards, and develop strategies to support the caregivers in their caregiving role. The purpose of this study was to increase nursing knowledge regarding the experience of being an informal caregiver of a cardiac surgery patient who had been discharged early from hospital. The qualitative research method of interpretive description guided the study. Unstructured interviews with eight informal caregivers of early discharged cardiac surgery patients were the major source of data. The findings of this study revealed that the experience was molded by the caregiver’s past participation as a caregiver, as well as the caregiver’s and care recipient’s outlook on life and their interpersonal relationship. From the caregiver’s frame of reference the caregiving experience was not always perceived as just the at-home recovery period but incorporated other significant milestones in the recovery journey. The caregivers often described their experience as it related to the care recipient’s encounter with the disease process, diagnosis, surgery, in-hospital recovery and the at-home recovery period. The caregivers engaged in the process of caregiving which can be conceptualized as the course that accompanied the care recipients’, and often as a consequence the caregivers’ return to normal. This process involved: being vigilant and monitoring the care recipient’s recovery, implementing strategies and techniques to assist the recovery process, and taking on a role to provide care and seek help as required. The encounter with caregiving affected all realms of
the caregivers' lives, and the caregivers experienced feelings of stress, vulnerability and having to put their own lives on hold. The rewards of caregiving included the care recipient's return to health, and his/her appreciation of the care received. Further investigation is required to develop and study interventions which assist caregivers of early discharged patients. The findings of this study offer one perspective for such investigations.
TABLE OF CONTENTS

Abstract......................................................................................................................... ii

Table of Contents.......................................................................................................... iv

List of Figures................................................................................................................ vii

Acknowledgments.......................................................................................................... viii

Dedication....................................................................................................................... ix

CHAPTER ONE: INTRODUCTION............................................................................. 1

Background to the Problem............................................................................................. 1

Purpose........................................................................................................................... 3

CHAPTER TWO: REVIEW OF THE LITERATURE ..................................................... 5

Early Discharge............................................................................................................... 5

Early Discharge and Cardiac Surgical Patients............................................................... 8

Caregivers - Who are They?......................................................................................... 9

Caregivers of Postoperative Cardiac Surgery Patients - Who are They?.................... 11

Caregivers - What Motivates Them and What are Their Roles?............................... 13

Impact of Caregiving...................................................................................................... 17

Impact of Cardiac Surgery on Family Members........................................................... 19

The Impact of Cardiac Surgery on Family Functioning............................................... 22

Conclusion..................................................................................................................... 24

CHAPTER THREE: METHODS................................................................................. 26

Qualitative Methods..................................................................................................... 26

Interpretive Description................................................................................................. 27

Sample selection............................................................................................................ 29
CHAPTER FOUR: FINDINGS

Description of the Participants.................................................................39
Previous Experience of Caregiving .............................................................40
The Caregiver and Care Recipient's Outlook on Life ....................................41
The Caregiver and Care Recipient's Relationship..........................................45
Milestones in the Caregiving Experience.....................................................47
The Process of Caregiving at Home............................................................51
Vigilance/monitoring.....................................................................................51
Keeping Things on Track..............................................................................54
Seeking Help and Support............................................................................59
Returning to Normal.....................................................................................65
The Impact of Caring for a Cardiac Surgery Patient Immediately Post-Discharge...66
Being Stressed and Tired..............................................................................66
A Sense of Vulnerability...............................................................................68
LIST OF FIGURES

Figure 1: Schematic Representation of the Experience of Caring for an Early Discharged Cardiac Surgery Patient ................................................................. 78
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CHAPTER ONE: INTRODUCTION

Background to the Problem

Cardiac surgical procedures such as coronary artery bypass grafting (CABG) and mitral valve replacement are common surgical procedures (Artinian, 1993). Recently, as a result of advances in anesthetic and surgical technology, and changes in health care delivery brought about by fiscal restraints, individuals who have undergone cardiac surgery are being discharged earlier from hospital and are being cared for by family members/informal caregivers in their homes.

Hospitals have developed rapid recovery protocols which enable cardiac surgery patients to be discharged within 4 days after surgery instead of the previous longer and variable length of hospital stay (Wu, 1995). When instituting rapid recovery programs patients are ventilated postoperatively for shorter periods of time, have a shorter length of stay in both the intensive care unit and the ward, and are mobilized more quickly. These interventions have the basic aim of safely reducing the length of the cardiac surgery patient’s stay within the hospital (Riddle, Dunstan, & Castanis, 1996). The research concerning the outcomes of rapid recovery programs is still very sparse, and up until recently has been conducted predominantly in the United States of America (USA). Recently, however, a study was conducted at a facility in British Columbia which was primarily directed towards medical and financial outcomes, with patient satisfaction being addressed as a secondary component (B. Budz, personal communication, August 9, 1996). This study was terminated in November 1996 when the rapid recovery protocol was instituted as the regular clinical pathway for CABG patients (D. Fofonoff, personal communication, January, 1997).
The research that has been conducted around recovery from cardiac surgery has mainly focused on the patients themselves, and has commonly used time frames late (12 to 24 weeks post discharge) in the recovery process (Gortner & Jenkins, 1990). Consequently, studies which incorporate data collection during the first two weeks after discharge are lacking. The studies have consisted predominantly or exclusively of male patients (Moore, 1995) with female spouses, and when including the family, examined such areas as family and marital functioning. Many of the studies were conducted before the implementation of rapid recovery protocols which are now being instituted worldwide (Riddle, Dunstan, & Castanis, 1996). Additionally, none of the studies identified on which postoperative day the patient was actually discharged, and the role of the informal caregiver was not investigated.

The limited research related to rapid recovery programs, although giving some consideration to patient and family satisfaction in terms of information and readiness for discharge (Riddle, Dunstan, & Castanis, 1996), has in no way addressed the impact on the family member or informal caregiver who is now required to maintain these still-acute surgical patients at home. As a result of the early discharge programs the cardiac surgery patients and their caregivers may find that they have to cope and deal with problems and concerns that were previously addressed while in hospital (Wu, 1995). While “there are few published studies of postdischarge concerns of CABG patients” (Wu, p.1), research related to the caregivers of, and caregiving for early discharged surgical patients including cardiac surgery patients is particularly sparse.

Whereas, the nature of caregiving for the elderly and the chronically ill, is beginning to be understood (George & Gwyther, 1986; Sayles-Cross, 1993), and strategies implemented to
address the needs of these caregivers (Hagen & Gallagher, 1996), this is not so for caregivers of post-surgical patients. Caregiving for newly discharged surgical patients has not been a focus of study. Nurses have also not had an identified role in attending to the needs of informal caregivers of early discharged surgical patients as the recovery period is moved out of health care institutions and into the home. For the caregivers of cardiac surgery patients who are a part of a rapid recovery protocol, a first step was a study directed at understanding the experiences of those involved in becoming informal caregivers during the first two weeks after early discharge of a family member/significant other.

**Purpose**

As family members/informal caregivers of post-surgical patients are, by necessity, taking on the caregiving role sooner without any specified reallocation of resources to support them, nurses need to understand their concerns, needs, struggles and rewards. The input of caregivers is essential so that nurses can understand and take action to develop strategies to support caregivers and caregiving.

The purpose of this study was to increase nursing knowledge regarding the experience of being an informal caregiver to a cardiac surgery patient who was discharged early from hospital. The study will assist nurses in gaining a fuller understanding of the effects of a reduced in hospital recovery period on the family member/informal caregiver and ultimately identify ways in which nurses can support these individuals in their caregiving role.

The study had two objectives:

1. To describe the experience of taking on the caregiving role.
2. To identify the impact on family members/significant others of looking after postoperative cardiac surgery patients who are discharged 'quicker and sicker' from the hospital to their home.
CHAPTER TWO: REVIEW OF THE LITERATURE

The focus of this chapter is an examination and critique of existing research literature that addresses the move to early discharge of cardiac surgical patients and the shifting of care to informal caregivers. The parameters employed in the literature search included use of the Cumulative Index to Nursing and Allied Health Literature (CINAHL) (1994-1996) and Medline Express (1991-1995) data bases using the search terms “caregivers” and “family” as descriptors. A further search was conducted using the CINAHL (1982-1996) data base, in which the descriptor term “caregivers” was used, but limiting the journal type to research journals only. Many of the articles reviewed were identified by the ancestry method, particularly those relating to cardiac surgery patients. A search of CINAHL (1982-1996) using the search terms “cardiac patients” and “early discharge” identified only two articles. This examination of the literature helped to identify what is already known about the topic under study. The review also sought to identify any gaps in the research surrounding the topic and provide rationale for the proposed research. The principal findings from the literature review will be discussed in relation to five content areas: (a) early discharge (b) caregivers - who are they? (c) caregivers what motivates them and what are their roles? (d) impact of caregiving, and (e) impact of cardiac surgery on family members and family functioning.

Early Discharge

"Quicker and sicker" is a catch phrase that is frequently applied to patients who are discharged from hospital in the 1990's. The early discharge of patients from hospital to the community is just one of the changes that is occurring in health care policy as governments
attempt to control the costs of Canada's health care system (Deber, Baker, & Mhatre, 1992). This change in health care delivery has resulted in the early discharge of patients following surgery and has taken place because of advances in anesthetic and surgical technologies, as well as decreases or limitations in resources such as hospital beds (Deber, Baker, & Mhatre, 1992; Smith, 1992; Moran, 1995). As institutional care is expensive, many hospitals have been forced to initiate cost saving measures such as early discharge programs. This has resulted in a shift in caregiving responsibility from professionals to the family and/or informal caregivers at home. Moreover, as de Meneses and Perry (1993) argue "society has yet to see caregiving as a major problem" (p.11). These authors noted that family members continued to respond when care was required for a family member discharged from hospital. Consequently, there is little incentive for any government action to develop programs of assistance.

One of the outcomes of the early discharge of patients from the hospital is that family members "are rapidly becoming unpaid givers of complex care" (Jackson, 1994, p. 497). Family members play a key role in the care of newly discharged surgical patients, with many still acutely ill patients being released into the care of informal caregivers at home (de Meneses & Perry, 1993). A survey in one institution that set out to analyze the effectiveness and quality of the discharge planning process identified that short term delays in the discharge process resulted because family caregivers were unable to pick up the patients (Edwards, Reiley, Morris, & Doody, 1991). Additionally, an audit conducted in Britain reported that a component of community costs related to shortened length of stay occurred as
a result of caregivers needing to take time off work or to travel some distance in order to provide the required care (Moran, 1995).

Other concerns related to early discharge and the shift of care to informal caregivers are that individual patient needs may be ignored and that patients may be put at risk (Casey, 1994; Simon, Showers, Blumenfield, Holden, & Wu, 1995). Bull (1994) pointed out that the presence of informal caregivers generally was associated with less or no use of formal caregiver services. Furthermore, a study conducted by inpatient social workers in the USA identified that "patients who lived with others following discharge experienced greater delays in service (home care) than those who lived alone" (Simon et al, 1995), which increased the stress for the informal caregivers. In a descriptive longitudinal design pilot study, which used a convenience sample of ambulatory surgery patients and their caregiver helpers, researchers found that the caregiver helpers identified the provision of care to post-surgical patients as a source of anxiety (Frisch, Groom, Seguin, Edgar, & Pepler, 1990). Using a questionnaire completed at one, two and seven days after surgery, and telephone interviews on days two and seven, this study revealed that the caregiving role also resulted in concerns about the patient's pain and abilities to carry out activities of daily living (Frisch et al, 1990). Recognizing similar concerns, Gilliss and Belza (1992) commented on the need to offer enhanced information to caregivers in order for them to more capably participate in the postoperative care of their family member, and to have their voices heard and their questions answered.
Early Discharge and Cardiac Surgical Patients

Patients who have undergone coronary artery bypass surgery (CABG) and/or valve replacement are by no means immune to the changes in the patterns of health care delivery, partly as a result of the fact that "cardiac surgery consumes more healthcare resources than any other single treatment..." (Riddle, Dunstan, & Castanis, 1996, p. 152). As was reported by Wu (1995) a move from a lengthy and often variable recovery in hospital for cardiac patients has resulted in "...patients stay[ing] in the hospital only 4 to 6 days after surgery and spend[ing] most of their recovery period at home" (p.1). In order to achieve the goal of early discharge for cardiac surgery patients, hospitals have established rapid recovery protocols (Riddle et al., 1996). "Common to rapid recovery programs are interventions that decrease intubation time and ICU length of stay, resulting in discharge in 4 to 7 days after surgery without compromising patient outcomes" (Riddle et al. p.153). Additionally, patients are mobilized more quickly during all postoperative phases, and educational programs adapted to reflect earlier time of discharge (Riddle et al.).

A search of the nursing literature identified two papers, one an opinion article and one a research study, that addressed the topic of early discharge and cardiac surgery patients. Riddle et al. (1996) described a rapid recovery program that has been instituted at a health center in the United States of America, and noted that after the first year "... high quality outcomes have been maintained along with high patient and family satisfaction, whereas cost, resource consumption and length of stay have deceased" (p. 156). Gross (1995) examined early extubation in the cardiothoracic patient population and concluded that "the preliminary findings demonstrate that early extubation is a safe and effective practice in
selected cardiovascular surgical patients" (p. 262), and can result in a reduced postoperative length of stay. The conclusion, however, that early discharge of patients is safe and effective needs to be considered with caution. Gross' study had a number of limitations, including that the sample size that met the inclusion criteria was small $n = 44$, and although the reported findings included reduced weight gain, earlier mobilization and improved psychological recovery, the tools used to measure these factors were neither included or discussed.

The rapid recovery program and the early extubation of patients under going cardiac surgery both resulted in an earlier discharge than with other cardiac surgery patients (Gross, 1995; Riddle et al., 1996). In a study to assess the postdischarge concerns of CABG patients Wu (1995) reminded us that hospital length of stay can have a major impact on postdischarge recovery since “patients discharged early may experience many difficulties at home that patients discharged later experience while in hospital”(p. 2). Early discharge and the deinstitutionalization of care into the community setting, i.e., the patients' homes, assumes that individuals are willing to take on the role of caregiving (Anderson, 1990). The questions that require investigation are who are these caregivers and what are the processes that they use in managing the care of newly discharged cardiac surgery patients.

**Caregivers - Who are They?**

The primary source of caregiving in the home is the informal caregiver, who is often a member of the family unit. Informal caregivers and their role in the provision of care to elderly family members or those family members with a chronic illness have received much attention in recent years (Cartwright, Archbold, Stewart, & Limandri, 1994; Davis & Grant, 1994; King, Collins & Liken, 1995). The informal caregiver within the family was specified
from a variety of research studies as including a parent, a spouse, an adult child with or without family, a relative, a significant other of the opposite or same sex, or friends and neighbors who provided assistance to the old or young who may live alone, to those with physical and mental illnesses, and to those with permanent or temporary disabilities (Gaynor, 1990; Gilliss & Belza, 1992; Bull, 1994). It was often in the absence of both spouse and children, that siblings, grandchildren, nieces and nephews, friends and neighbors became the caregivers (Pasquale, 1988; Gaynor, 1990; Ward & Carney, 1994; Skinner, Tennstedt, & Crawford, 1994).

The literature reviewed suggested that most often the primary caregiver was a woman caring for a disabled spouse, parent, parent-in-law, or child with varying degrees of support from other family members (Bull, 1994; Gilliss & Belza, 1992; Opie, 1994). In an ethnographic study, Anderson and Elfert (1989) set out to examine how families manage the care of a child with a chronic illness at home. These authors found that it is not the family as such that takes on the caregiving role but the women in the home. Two additional qualitative studies that specifically studied women as caregivers also indicated that traditionally, women are expected to assume uncompensated caregiving roles to dependents while maintaining household responsibilities (Guberman, Maheu, & Maille, 1992; Ward & Carney, 1994). In their Canadian based study, Guberman, Maheu, and Maille interviewed 40 francophone Quebecois family (women) caregivers of frail elderly or mentally ill relatives to explore the process and elements that motivate “...women’s decision (or nondecision) to become caregivers of dependent adult kin”(p.608). Ward and Carney used phenomenological methods and analysis to examine the experiences of caregiving in a convenience sample of
10 low-income women providing care to a frail elder in the USA. Both investigations revealed that many of the women in the studies identified that circumstances resulted in them taking on the caregiving role, and that they had little choice in the decision to take on the role.

In addition to caregiving duties many women often must work to meet and support the family's financial obligations (Angus, 1994). Despite this increase in women in the work force, and the potential impact on the future availability of caregivers for an ever increasing number of elderly and chronically ill family members, only limited research on the implications of this trend was found. Brody, Kleban, Johnson, Hoffman and Schoonover (1987) asserted that the emotional strain associated with caregiving for some employed individuals may lead to work distress. An interesting finding was described by Skaff and Pearlin (1992) who, as part of a longitudinal study of 555 spouses and adult children caregivers of a relative with Alzheimer's disease, used qualitative methods to examine self-loss and role engulfment. The researchers found that not only were those caregivers without employment outside the caregiving role more likely to experience self-loss, but that being employed outside the caregiving role seemed to protect the caregivers in the study against self-loss. Whether such a finding could be applied to caregivers of postoperative surgical patients where there are shorter time frames involved remains to be explored.

**Caregivers of Postoperative Cardiac Surgery Patients - Who are They?**

Gortner and Jenkins (1990) maintained that the reality for cardiac surgery recovery is one “...in which patients and families take on the hard work of recovery at home, with their own resources, and usually without frequent contact with attending clinicians” (p.1133). The
family caregivers were specifically described in a study conducted by Gilliss and Belza (1992) to identify family caregivers' recovery work after cardiac surgery. Of the 75 patient-family member pairs, 67 or 89.3% of the caregivers were spouses, 4 were adult children, 1 was a sibling and 3 caregivers were described as significant others. However, a scarcity of literature pertaining to the caregivers of postoperative cardiac patients and of discharged surgical patients in general appears to exist.

There are a number of studies that have examined the impact of the experience and the consequences of nursing interventions on spouses of patients who have undergone cardiac surgery (Gortner et al., 1988; Miller, Wikoff, McMahon, Garrett, & Ringel, 1990; Tack & Gilliss, 1990; Gilliss, Neuhaus, & Hauck, 1990; Artinian, 1991; Artinian, 1992; Gilliss et al., 1993; Moore, 1994). Although two of these studies purported to examine family health and functioning, both study samples were limited to patient-spouse pairs. (Gortner et al.; Gilliss, Neuhaus, & Hauck, ). No other family members were looked at.

Not only were the caregivers either unidentified or limited to spouses, there was also a strong gender bias in that the majority of the spouses included in the research studies were women. For example, in the studies by Artinian (1991; 1992) all of the spouses in the study n = 86, and n = 49 respectively, were female. Moore (1994) reported that 86% of the spouses (n=76) in her study of psychological distress of patients and spouses after CABG surgery were female. Similarly, the study populations used by Gortner et al. (1988) n = 67, Tack and Gilliss (1990) n = 75, and Gilliss, Gortner, Hauck, Shinn, Sparacino and Tomkins (1993) n = 156, were made up of at least 80% male patients who were assumed to have female spouses. With the rise in the number of women undergoing CABG surgery (Artinian &
Duggan, 1995) to include "...nearly a fourth of individuals..." (Moore, 1996, p. 97), there is a need to expand the research to include the caregivers of female patients who have undergone cardiac surgery.

**Caregivers - What Motivates Them and What are Their Roles?**

Caregivers are motivated by a variety of factors. Often the decision to adopt a caregiving role is based on the individuals' sense of moral duty or responsibility to assist another person during the recovery period following hospitalization (Gilliss & Belza, 1992). In particular caregivers were often concerned that the person is unable to cope on his/her own and needs assistance through the convalescent process (Gilliss & Belza). Some caregivers sensed that either professionals or their family member expected them to provide the necessary care at home, and as soon as possible (Gilliss & Belza; Raatikainen, 1991; Skinner, Tennstedt, & Crawford, 1994). Finally, some were motivated by a sense of guilt as in the case of mothers having given birth to children with chronic disabilities or illnesses (Anderson & Elfert, 1989).

There are many factors that influence the nature of the caregiving role. Certain characteristics of informal caregivers can influence the role of the caregivers, and the length of the patients' hospitalization (Skinner, Tennstedt, & Crawford, 1994). A study of 181 frail elders, all of whom had been hospitalized at least once in the previous 18 months, and their informal caregivers revealed that those elders who lived with offspring caregivers had a reduced length of hospital stay when compared to those elders who lived in a different household from their offspring (Skinner, Tennstedt, and Crawford). As the distance between the offspring caregiver and the care recipient increased so did the length of hospital stay. It
should be noted, however, that with non-offspring caregivers proximity was not found to be statistically significant (Skinner, Tennstedt, & Crawford). The age, health and capability of the caregivers to provide the necessary care also affected the patients' hospital stay (Raatikainen, 1991; Skinner, Tennstedt, & Crawford).

In addition to the geographical proximity of the caregivers to the patients, obligations placed on the caregivers such as full time or part time employment, child care commitments, and the caregivers' availability to meet the patients' needs were important considerations for hospital discharge (Bull, 1994; Gaynor, 1990; Skinner, Tennstedt, & Crawford 1994; Varricchio, 1994). The convenience of responsible persons to care for the patients at home (Wetchler, 1987) is part of the selection criteria for ambulatory surgery, as those patients who have undergone significantly less complex surgery than cardiac surgery patients still "require care even though they are ready to go home" (Frisch, Groom, Seguin, Edgar, & Pepler, 1990, p.1002).

Further factors that influence the caregiving role include specific patient care requirements. These care needs often depended on the patients' functional limitations and cognitive impairments which then dictated the nature and time demands of the caregiving tasks (Baillie, Norbeck, & Barnes, 1988; Barusch, 1988; Lindgren, 1993). Baillie, Norbeck and Barnes and Barusch used qualitative methods to explore stress, social support and psychological distress of family caregivers of impaired elders, and problems and coping strategies of elderly spousal caregivers respectively. The convenience sample consisted of 87 family caregivers who were recruited at a county health department meeting set up to educate caregivers. The findings indicated that because of the care requirements of impaired elders,
the caregivers became confined in their homes, and lacking social support, they may become depressed or distressed over time (Baillie, Norbeck, & Barnes). Barusch used a selective sample of 89 caregivers and conducted interviews to measure problems confronting the caregivers and the coping responses used. An interesting finding in the Barusch study is that these caregivers generally preferred to manage situations and problem solve through their own efforts. How best to support these caregivers presents a challenge to health care professionals. Lindgren used a descriptive qualitative study to determine what was happening in the lives of a convenience sample of 10 spouse caregivers of patients with Alzheimer's disease. She identified three different stages, encounter, enduring, and exit during which the caregiver learnt new skills and restructured his/her life to accommodate the needs of the spouse.

Informal caregivers believe that it is their responsibility to coordinate and deliver health care to persons with whom they share an emotional bond (Gaynor, 1990). Bowers (1987) proposed that caregiving should be organized according to "the meaning or purpose a caregiver attributes to an activity" (p. 21). She described observable and nonobservable processes, such as emotional support, planning and decision-making. Gilliss and Belza (1992), when studying cardiac patients and their family caregivers' involvement, identified that the caregivers' role included functional activities such as, organization of meal preparation, grocery shopping, and cleaning; monitoring activities such as, supervision, coordination and decisions about medications, diet, exercise, wound care, and health appointments; and comfort and supportive activities such as, attainment of daily physical and psychological needs of the patient. As part of a study by Tack and Gilliss (1990) cardiac
patient and caregiver pairs received telephone calls weekly from nurses for the first four weeks and biweekly up to eight weeks after discharge to help facilitate recovery. This study identified from the telephone conversations with patients and caregivers that they both "...engaged in activities to minimize the effects of the symptoms and return to a "normal" state" (p.497). The symptoms they attempted to manage included pain, difficulties with coping, a poor tolerance for activity, sleep disturbances and nutritional concerns. These two studies of cardiac patients and their caregivers provide a preliminary classification of concerns faced by patients and their caregivers, and consequently inform us about the role of the cardiac surgery patient caregiver.

Other factors that effect the nature of the caregiving role have also been studied. The findings, however, are equivocal. For example, the nature of the relationship between the caregivers and the patients has been associated with the amount and type of care required and provided (George & Gwyther, 1986; Skinner, Tennstedt, & Crawford 1994; Varricchio, 1994; Fink, 1995). In contrast, using a nonrandom sample (n = 65) to test a conceptual model advanced to explain strains and well-being of caregiving families involved with caring for an elderly parent, Fink found that the amount of care provided did not contribute to the variance in family strains. Whether this result can be explained by the fact that the family unit is the focus of the research rather than individual family members remains to be explored further.

George and Gwyther (1986) studied caregiver well-being (physical health, mental health, financial resources, and social participation) in family members caring for older memory impaired adults. The investigators used survey instruments mailed to 510 members of a family support group for informal caregivers of individuals with Alzheimer's or related
disorders. The results from this nonrandom sample cannot be generalized but for this particular sample identified that "the relationship between the patient and caregiver is one important aspect of the caregiving context" (p. 258). Specifically, spouses reported lower levels of well-being than other relatives who acted as caregivers. Moreover, intimate personal care was most often furnished by caregivers who were close relatives, and were often spouses (Lindgren, 1993; Varricchio). Caregivers who were normally in passive roles with the care recipients may also become the decision-makers and may take responsibility for the care of the patients as well as onus for the personal affairs (Ward & Carney, 1994). The taking on of new and different responsibilities was also described by Artinian (1992) in a study that exposed that women spouses of cardiac patients "...reported taking on new roles such as cutting the grass, working full time, or doing heavy work to free their husband from burden or the chance of injury" (p. 40). In many of the studies, however, especially those addressing the recovery of cardiac surgery patients, the family members and potential caregivers were ignored as a source of information. An understanding of the perceptions of these caregivers in regards to what motivates them and what role they play would contribute significantly to the body of knowledge which to date has been found to be limited.

Impact of Caregiving

The impact of caregiving in relation to elderly or chronically ill family members has been associated with stress and burden. A number of studies identified stress and burden in terms of any one or more of mental, physical, social, political and economic factors (Anderson, 1990; Anderson & Elfert, 1989; Baillie, Norbeck, & Barnes, 1988; Barusch, 1988; Gaynor, 1990; Lindgren, 1993). Gaynor reported from her case control study, which used a
questionnaire to test for the effects of long-term caregiving at home, that in comparison to short-term caregivers, long-term caregivers experienced more stress and feelings of burden. An interesting component to the Gaynor study was that she used short-term caregivers of husbands who had undergone uncomplicated transurethral prostatectomy for a nonmalignant condition, as one of the control groups. In discussing her findings Gaynor proposed that "the belief that a spouse would recover and the caregiving tasks would eventually end, provided short term caregivers with stress mediators that were unrealistic for the long-term caregivers" (p. 211). Anderson (1990) found that the socio-economic situations of individuals and the unavailability of health care resources that could meet the needs of immigrant families often affected how caregivers managed chronic illnesses. Not all caregiving, however, was perceived as a negative experience as was noted in four recent qualitative studies of caregiving circumstances with elderly or chronically ill family members (Guberman, Maheu, & Maille, 1992; Langner, 1993; Opie, 1994; Ward & Carney, 1994). For example, the caregiving experience may be viewed positively in that it sometimes provided the caregivers with feelings of accomplishment, self-satisfaction, increased self-esteem and respect as fulfilling a valued responsibility, and gave meaning to the situation and value for the caregiving (Guberman, Maheu, & Maille; Langner). Whereas, the studies discussed here are a part of the substantial body of literature regarding caregiving as it relates to the elderly, there has been little study of caregiving as it relates to early discharged cardiac patients. Consequently, more research needs to focus on this ever increasing population.
Impact of Cardiac Surgery on Family Members

The impact of cardiac surgery as with most other surgical experiences extends beyond the individual patient to affect the family. As noted previously, there is a fairly well developed body of literature that considered the impact of the surgery and the recovery on, for the most part, female spouses of individuals undergoing CABG and/or valve replacement surgery. Increased anxiety levels, psychological distress and stress have been noted in quantitative studies that examined the recovery of cardiac patients and/or family members, namely spouses (Artinian, 1991; Moore, 1994; Buls, 1995).

Artinian (1991) conducted a longitudinal study that described the stress experience of spouses of patients undergoing CABG surgery during hospitalization and at six weeks after discharge. She also identified the problems and concerns of the spouses at both time intervals and the spouses’ perceptions of nurse support. The results of note from this study were that there was no significant changes in measures of hardship and demands, social support and the spouses’ perception of the severity of their husbands’ illness between the hospital and six weeks post discharge. There was, however, a significant change in the spouses’ symptoms of physical and mental stress, both of which were less. Marital quality was found to be significantly less at six weeks. “Husband’s self-care activities, uncertainty and husband’s physical and mental symptoms were concerns that spouses frequently reported [at the 6 week time interval]” (Artinian). While this study does start to identify some aspects of the impact of cardiac surgery on spouses, an important limitation as reported in the study was the difference between those subjects who agreed to participate and those who refused was not known.
Artinian (1992) extended her research to study the spouses’ adaptation to their husband’s CABG surgery at a one year postoperative time interval. The study used mailed questionnaires to measure the spouses’ experience of life stressors during the 12 months prior to the one year measurement interval, the spouses’ social support, perception of the severity of their husbands’ illness, physical and psychological symptoms of stress, role strain and marital quality. The results at the one year time interval were then compared to results measured at the previous two time intervals. Although the role of the spouse as a caregiver was not specifically described, Artinian found that the women continued to experience symptoms of mental and physical stress and also that they “...had significantly greater role strain than during the first two periods” (Artinian, p. 36). The wives were reported to have accepted new responsibilities at home or in the work place often at the expense of their own life goals in order to accommodate their husbands’ health needs (Artinian). The study attrition rate, however, was significant with only 49 of the 86 subjects followed at 12 months. This loss of study subjects limits the generalizability of the findings. In addition, because of the time intervals chosen for measurement, the impact during the first weeks after discharge is unknown, and yet in studies of patients’ recovery, the early days following discharge have been identified as often the more anxiety producing and symptomatic (Beckie, 1989; King & Parrinello, 1988; Wu, 1995).

As patients and their spouses attempt to deal with the stress of post-hospitalization recovery from CABG surgery they may experience alterations in psychological functioning (Moore, 1994). In order to develop a greater understanding about psychological distress Moore interviewed patients and spouses in their homes six weeks after surgery. The
interviews for patients and spouses were conducted separately so that comparisons could be made. The results identified that spouses, the majority of whom were female, experienced more stress than the patients at the six week time interval. A concern regarding a gender bias of the Profile of Mood States (POMS) instrument was raised by the researcher, with the researcher concluding that in normative studies no gender bias of the tool had been identified (Moore). The existence of studies that include male spouses of any significant number, however, are very limited, and certainly as noted previously the topic requires further investigation. Anxiety and anger were also identified in spouses in the Moore study with more anger reported amongst the younger spouses than the older ones (Moore).

Buls (1995) introduced the intervention of home visits by a home health care nurse when studying the anxiety levels of postoperative CABG patients and their family members. Buls compared the group who received the intervention of home visits with a group who did not. The group receiving home visits were reported to have significantly lower anxiety levels than the control group who did not receive visits (Buls). An additional point of interest from the Buls study is that the home care nurse was required to intervene in relation to four significant problems that she identified with the intervention group n = 30, while in the control group n = 30, four of the patients “…were rehospitalized within the first 7 to 10 days after discharge because of incisional problems and dysrhythmias that required additional nursing care and medication adjustment” (p.28). The Buls study provided a hint of some of the caregiving factors that informal caregivers may be required to deal with in the early days following discharge.
Although the three studies discussed above start to identify the impact of cardiac surgery on the family in terms of anxiety and stress and the spouses’ concerns, they do not address the role of the spouse as the caregiver, or the impact of the caregiver role especially in the first two weeks following discharge. Additionally, despite some important insights, the findings should be viewed with caution as they are based on convenience samples in the United States. It is, therefore, not clear if these findings are generalizable to other populations, particularly Canadian populations since the health care systems in the two countries differ.

**The Impact of Cardiac Surgery on Family Functioning.**

Two quantitative studies were found in the literature search which examined family health functioning after cardiac surgery (Gortner, Gilliss, Shinn, Sparacino, Rankin, Leavitt, Price, & Hudes 1988; Miller, Wikoff, McMahon, Garrett, & Ringel 1990). The study by Gortner et al. involved exploration of the effectiveness of in-hospital teaching, counseling and post discharge telephone follow-up for patients and spouses randomly assigned to the experimental group \( n = 32 \). The control group \( n = 35 \) received only the in-hospital teaching program. Using a variety of paper and pencil measurements and self reports, family functioning, family resources, marital satisfaction, expected benefits from surgery and self efficacy and activity were measured at a variety of points, the key ones being a baseline, and at three and six months following surgery. The hypothesis that the interventions would significantly improve postoperative recovery at home was not supported. One of the findings of interest, however, is that at both three and six months the spouses’ scores for both measures of family functioning and family resources were lower than those of the patients.
This finding suggests that for spouses the surgery had a disorganizing impact (Gortner et al.). In the early weeks after surgery the authors suggested that "the primary caregiver, i.e. the spouse is irrevocably caught up with aspects of physical and emotional recovery for his or her spouse" (Gortner et al., p. 659). Consequently, the authors proposed in the discussion section that the three and six month time intervals selected for the study might be inapplicable since most of recovery for the patient occurs in the first six weeks, although family recovery may continue for a longer period of time (Gortner et al.) Once again, the sample size was a limitation in this study and although the reported study was planned as a pilot study for a larger study, the larger study was never completed due to lack of funding and the availability of subjects (Gilliss, Neuhaus & Hauck, 1990).

A second quantitative study that considered family health functioning after cardiac surgery examined "...the relationship between spouse anxiety, coping methods, couple responsibility for compliance and reported compliance with marital couple functioning agreement..." (Miller, Wikoff, McMahon, Garrett, & Ringel, 1990). As in many of the other studies most of the spouses were female. One of the inclusion criteria was first time cardiac surgery within the last year, so the time frame for the study was yet again at a point well along in the recovery process. Paper and pencil instruments were mailed to the patients' home. Both the patient and spouse were requested to complete the Health Behavior scale, the Marital Responsibility and the Marital Functioning scales, while the spouse only completed the State-Trait Anxiety scale and the Jalowiec Coping scale. The number of instruments returned and the need for patient-spouse pairs once again was a limitation of the study n = 136 questionnaires. The result of interest was that the hypothesis that marital functioning
agreement would increase as the spouse’s anxiety decreased was partly supported. This result led the authors to conclude that “...preparation of spouses for the convalescent period appears to be essential” (Miller, Wikoff, McMahon, Garrett, & Ringel, 1990, p.60). Whereas the study discussed above again alludes to the role of the spouse in the recovery process, the spouse’s role is not delineated as that of primary caregiver. Consequently, the impact of a role as the primary caregiver is not considered, and any study of the early recovery process is once again missing.

Conclusion

There is a great deal written about the identity, and needs of the informal caregivers of the chronically ill. These caregivers are predominately women and are closely related to the care recipients. Many informal caregivers are thrust into the caregiving role suddenly, sometimes unwillingly, and often with very little information or understanding of the patient’s needs. Caregiving responsibilities vary with the needs of the patients, the capabilities of the caregivers and the number of available caregivers. The burden and impact of caregiving over the years, i.e., the physical, psychosocial, and economic aspects, is well-documented. What is not clearly articulated in the literature, however, is who is taking on the role of caregiver for the newly discharged cardiac surgery patient. Very little is known regarding the effects of early discharge of cardiac patients on their caregivers and the care that is required to maintain these still-acute surgical patients at home. Any studies found that were related to recovery from cardiac surgery were predominantly quantitative in design, included mostly female spouses, and used time frames at points at least six weeks after discharge.
Today, many cardiac surgery patients are discharged from the hospital to their homes after only four to six days following a major surgical intervention. The families of these patients are now expected to take on the caregiver role sooner, during a time in the recovery process which was previously experienced in hospital with all the associated resources, including the availability of skilled health care professionals. To date, few if any of the resources available in the hospital have been redirected to provide support to these patients and family members in their homes. In an attempt to support the needs of the early discharged cardiac surgery patients and their caregivers, there is requirement for nurses to determine what the experience of these family members/ informal caregivers is like so that nurses can better understand how to advocate for them. Research directed at understanding the experience and the impact of being an informal caregiver following a family member/significant other having cardiac surgery would provide a valuable addition to the limited body of knowledge on the role of informal caregivers during the first two weeks following early discharge.
CHAPTER THREE: METHODS

The primary research question for this study was ‘What is the experience of being an informal caregiver to an early discharged cardiac surgery patient?’. This question centered around the problems with early discharge of cardiac surgery patients to the community, and a shift in caregiving responsibilities from professionals to informal caregivers during the early stages in the recovery process. The purpose of the research study was to understand the experience of being an informal caregiver to a cardiac surgery patient who had been discharged early from hospital. Burns and Grove (1993) state that “the primary goal of nursing research is to develop a scientific knowledge base for nursing practice” (p.4), and that specifically qualitative research aims to produce knowledge that can be used in theory development rather than theory testing. Consequently, since little was known in relation to the experience of being an informal caregiver of early discharged cardiac surgery patients, and there was a need to generate knowledge for nursing practice around this phenomenon, a qualitative interpretive description research method was selected. In this chapter qualitative research and the utilization of the interpretive description method will be discussed, including sample selection, data collection and analysis of the data. The issue of ensuring rigor, and ethical considerations will also be outlined.

**Qualitative Methods**

The decision to focus on the experiences of the informal caregivers of early discharged cardiac surgery patients was based on the literature that identified a scarcity of studies, and gaps in nursing knowledge related to the change in health care delivery and the ensuing impact on informal caregivers when caring for still-acute surgical patients at home. A
qualitative (naturalistic) research method was selected since this method of research "... is usually conducted to explore problems about which relatively little is known" (Morse & Field, 1995, p.2). Towards this end, the use of a qualitative research method allowed initial description of the caregivers’ experiences.

The selection of a research method was also primarily directed by the research question to be answered. Because the research question posed was to understand the experience of caregivers of newly discharged surgical patients, the question fitted within the definition of qualitative research proposed by Munhall and Boyd (1993) "...as involving broadly stated questions about human experiences and realities..." (p.69). The features of a qualitative design include: 1) a holistic approach and the recognition that there are multiple constructed realities, 2) a focus on the human experience in the setting in which the participants usually spent their time, 3) the researcher and the participants are interactive and inseparable, 4) a description of the participants living through events in situations is produced from the data, and 5) any emerging theory must be from (grounded in) the data (Lincoln & Guba, 1985; Munhall & Boyd). Consequently, a qualitative research method was selected for this study as it was appropriate both in terms of the amount of information available on the topic of informal caregivers of early discharged cardiac surgery patients, and the question posed regarding the caregivers’ experiences.

Interpretive Description

An interpretive description approach (Thorne, Kirkham, & MacDonald-Emes, 1997) was used for data collection and analysis. Interpretive description is a method that has been specifically articulated for the development of nursing knowledge and the clinical application
of this knowledge. This method gives recognition to the contextual and constructed realities of the health-illness experience, and has been developed to help avoid the “mixed” and “slurred” methods that have been used by nurse researchers in their attempts to study nursing problems using methods grounded in the philosophies of other disciplines (Thorne, Kirkham, & MacDonald-Emes). General principles are provided to guide the research so as to help provide a credible process. The qualitative interpretive description method is one in which there is “... a respect for the knowledge about aggregates in a manner that does not render the individual case invisible” (Thorne, Kirkham, & MacDonald-Emes, p. 171). The use of such a method therefore allowed for description of and interpretation about the shared components of the experiences of the informal caregivers of early discharged cardiac surgery patients, while providing recognition for the individualized experiences of each caregiver. In a practice profession such as nursing, the interpretive description approach also provided latitude to not only describe the experience of the caregivers, but also to interpret components of that experience in regards to clinical nursing practice.

Underpinning the interpretive description method are the following foundations regarding the generation of nursing knowledge (Thorne, Kirkham, & MacDonald-Emes, 1997):

1) Experiences of health and illness are made up of intricate interactions between biological and psychosocial components.

2) Common patterns within human health and illness are central to nursing’s practice knowledge, and principles developed from such patterns can be applied within the context of an individual case.
3) The health-illness experience is influenced by the context as well as the individually contrived meanings related to the encounter, yet that experience can also provide shared understandings that are applicable to other individuals.

In seeking knowledge for the practice of nursing, Thorne, Kirkham, and MacDonald-Emes (1997) stress that today’s focus is on “a set of ideas that have application potential, but remain amenable to reconsideration in light of varying contexts, new concepts, new ways of understanding, and new meanings” (p. 172). The use of an interpretive description method enabled this researcher to gain an understanding of the experiences of informal caregivers of early discharged cardiac surgical patients with recognition for both the individual and the common perspectives that were provided. Additionally, the knowledge gained was considered in terms of clinical nursing practice and what nursing can do to make a difference.

Sample selection.

Purposeful selection of the research participants is suggested by Thorne, Kirkham and MacDonald-Emes (1997) as the most appropriate technique to generate data for an interpretive description research study. Caregivers who had cared for early discharged cardiac surgical patients were expected to be able to provide descriptions of their experiences. However, as is recognized by Thorne, Kirkham and MacDonald-Emes, some individuals are better able to share their thoughts and feelings related to an experience than others, and to operate outside pre-existing assumptions about life. Consequently, some purposeful selection of the caregivers allowed for richer accounts of the caregiving experience.
The participants were drawn from the group of informal caregivers who cared for early discharged cardiac surgery patients at home and could address the proposed research question. The criteria for inclusion into the sample were: 1) caregivers of patients who had been selected for early discharge (postoperative day 6-7) from an urban hospital in British Columbia, and 2) an ability to speak English. The sample was composed of two groups: the primary informants were five caregivers actively involved in caring for an early discharged cardiac patient in the first eight days after leaving hospital, and the secondary informants were three caregivers who provided care to early discharged cardiac patients approximately one year earlier, and who were enrolled in the original study for the rapid recovery program. The purpose in selecting the two sets of informants was that the secondary informants had had the opportunity to reflect on the experience and to offer a perspective that might be different from those caregivers who were immersed in the experience.

The two male caregivers who agreed to participate did not meet all of the criteria outlined. For one caregiver, the patient was not discharged until postoperative day ten. The reason for the delayed discharge was that assistance was required in organizing transportation, and a statutory holiday restricted the ability to set up the travel arrangements. The second male caregiver was not interviewed until twenty-eight days after his spouse was first discharged from the hospital because his spouse experienced complications, and had to be readmitted to a hospital on day four after discharge. However, because there were considerably less male participants available for recruitment into the study; the literature had identified that there are gender differences in recovery after heart surgery (Moore, 1996), and since the male voice was considered important in offering an alternate perspective, these two
participants were included in the sample. Additionally, one participant was also able to offer a further perspective in that he experienced the rehospitalization of the care recipient.

Data collection.

The usual data collection techniques used with the interpretive description method are that of interviewing and participant observation (Thorne, Kirkham, & MacDonald-Emes, 1997). In this study, unstructured face-to-face and telephone interviews were used to allow the participants to tell their story, and for the researcher to actively listen and learn about the topic (Morse & Field, 1995). Initially, a pilot interview was conducted and reviewed by the thesis chairperson for interview style and beginning attempts at data analysis. All but two interviews were audiotaped and transcribed. One participant requested that the researcher only take notes, and for the other participant technical difficulties resulted in blank tapes. Second interviews were requested of five participants in order to permit clarification of any points and to answer questions that arose from the initial interviews. Since specific questions were identified by the researcher, the second interview was more structured in order to expand on particular areas of interest and resolve any unclear concepts. Field notes were also used by the researcher to keep track of the physical setting of the interview, and to record any of the researcher’s impressions and thoughts experienced in response to the interviews.

As a way of enriching the data, two participants were also requested to keep a semistructured journal or oral diary of their everyday life as a caregiver during the first seven days after the patient’s discharge. Specifically, the participants selected to keep a semistructured journal and were asked to address four questions in their journal
According to Morse & Field (1995), diaries are used "as either a semistructured or unstructured method of data collection" (p. 119). In this research study, semistructured journals in which the participants were requested to address specific questions rather than journal freely about their experience, were used as a primary source of data collection. Furnishing particular questions for the participants to answer provided direction to the participants, and offered a contrast to the unstructured interview data collection method.

In addition to the interviews and the use of journals to gather data, observation of the context of the in-hospital experience for the patient (care recipient) was completed. Observation included a visit by the researcher to the preassessment clinic, and one perioperative follow through from admission to the operating room through Critical Care Recovery to the patient’s return to the ward respectively. Nursing case reports, such as the follow-through, are one additional data source that Thorne, Kirkham, and MacDonald-Emes (1997) suggest be considered for providing supplementary support in a study. Furthermore, the researcher watched cardiac patients participating in the nursing unit exercise program. Observation with a focus on the context "enables the researcher to view the society objectively and assists in validating and interpreting information provided by the participants" (Morse & Field, 1995, p.107). Being more aware of the care recipients’ in-hospital experience helped the researcher to better understand the context of the experience of caregiving for the participants.

Data analysis.

In qualitative studies the researcher is simultaneously involved with data collection and data analysis (Polit & Hungler, 1993). Also in line with the qualitative tradition, the
interpretive description method uses inductive rather than deductive analysis (Thorne, Kirkham, & MacDonald-Emes, 1997), and is an active process in which the researcher is constantly required to ask questions of the data in order to understand and analyze the data. The cognitive processes central to qualitative data analysis include comprehending, synthesizing, theorizing and recontextualizing (Morse & Field, 1995), and were applied by this researcher to the data analysis. For interpretive description, analytic techniques “...that encourage immersion in the data prior to beginning coding, classifying or creating linkages” (Thorne, Kirkham, & MacDonald-Emes, p. 175) are recommended. Towards this end, the first step in the analysis, identified as a component in the Giorgi method (Omery, 1983), was to read through the data transcript in order to gain an overall sense of the description of the experience. Data analysis then proceeded following steps outlined by both Knafl and Webster (1988), and Lincoln and Guba (1985):

1. Identifying and naming categories (coding) from the data which included the constant comparison of one piece of data with another to see if it fit within an identified category (constant comparative method)

2. Describing properties for each of the categories that could be used to warrant the inclusion of specific information within that category (identification of themes within categories)

3. Constructing linkages between the categories to help identify common themes (identification of themes across categories)

4. Reviewing of emerging themes with selected participants

5. Weaving the themes into a formation, pattern, or integrated structure
In keeping with the aim of interpretive description analysis the researcher focused on coming to know and understand the individual caregiver’s experience in detail while recognizing emerging shared themes within these experiences (Thorne, Kirkham, & MacDonald-Emes, 1997). More specifically, the interview tapes were transcribed verbatim. These transcriptions and the participant’s journals were then read a number of times in order to acquire a sense of the overall experience of being a caregiver to an early discharged cardiac surgery patient. Coding of the data consisted of identifying and naming categories from both small units (line-by-line) and larger units (passages) of data. During examination and sorting of the data, the constant comparative method was used in which one piece of data was compared with another to see if it fit within an identified category. Once a number of categories had been identified, questions were asked of the data in order to identify links between and among the categories to clarify emerging themes.

Following the initial interviews, the themes and conceptual pattern distinguished to date were discussed with the thesis chairperson in order to assist in planning the second interviews. Questions were developed around the emerging themes and conceptual pattern for the participants to refute or validate, so permitting clarification of the themes and expansion of the conceptual understanding of the important aspects of the caregivers’ experience. Finally, the data generated at the second interviews were incorporated into the conceptual pattern.

**Ensuring Rigor**

When using the interpretive description method, Thorne, Kirkham, and MacDonald-Emes, (1997) stress that the processes used to ensure rigor must be “above reproach” (p.176).
Rigor or trustworthiness was addressed in this research study by the four criteria of credibility, transferability, dependability and confirmability. These criteria can be attributed to Lincoln and Guba (1985) who, when describing naturalistic inquiry were two of the originators of the idea of these criteria being applicable to qualitative studies.

Credibility

A qualitative study is credible when it provides such an authentic account of human experience that it is immediately recognizable as that experience by others who have had the experience, and the findings are identified as being “well grounded in the life experiences studied and reflect their typical and atypical elements” (Sandelowski, 1986, p.32).

Techniques suggested by Lincoln and Guba (1985) to increase the credibility of a study include triangulation, prolonged engagement, persistent observation, and debriefing with peers and participants. Triangulation is referred to as “…the use of multiple referents to draw conclusions about what constitutes the truth” (Polit & Hungler, 1993). Triangulation can include multiple methods for data collection, and multiple perspectives in not only obtaining the data but also in interpreting a single experience described in the data. Sandelowski identified that credibility is primarily threatened by the closeness of the relationship of the researcher to the participants. The use of field notes that keep track of the physical setting of the interview, and record any of the researcher’s impressions and feelings experienced in response to the interview, are noted by Thorne, Kirkham and MacDonald-Emes (1997) to be a useful means of focusing on how the researcher and the participants may have influenced each other.
In this research study several strategies were used to ensure credibility. Field notes were used as described previously to provide a check against personal bias. Triangulation in the form of interviews, diaries, and observation were employed to accomplish the use of multiple methods to address the research question. Input from the thesis chairperson in reviewing the transcribed data helped to achieve the use of multiple perspectives for interpretation of the data. Additionally, debriefing with both the thesis chairperson and some of the participants was instituted. A credibility check with the participants is recommended as being more useful when the initial conceptualizations from all rather than an individual participant are employed (Thorne, Kirkham & MacDonald-Emes, 1997). Therefore, the second interviews were conducted after analysis of data and the initial identification of themes from the first interviews.

**Transferability**

Transferability as a criterion is sometimes referred to as fittingness since it is evaluated by how well the findings from the study can be transferred or fit into a context outside the study situation, and to the extent that those planning to transfer the findings conclude that the findings are meaningful and applicable (Sandelowski, 1986). Polit and Hungler (1993) note this could be considered more a sampling and design issue than an issue relating to the data. As is stressed by Lincoln and Guba (1985), however, the responsibility that rests with the researcher is to provide a “thick description” so that other individuals can decide on how applicable the findings are to other contexts.

In this study, steps towards ensuring transferability included attempts to maintain a proper perspective in regard to the individual descriptions provided by each of the
participants so that no one experience was overweighed. The use of the constant comparison method in data analysis assisted in establishing “...the position of all subjects in relation to the group of which they are members and the meaning of their slice of life” (Sandelowski, 1986, p.32). Additionally, the threat of presenting the data as more congruent or patterned than they are, referred to by Sandelowski as ‘holist fallacy’ was curbed by having the thesis chairperson scrutinize the data analysis. Finally, the generation of “thick description” was assisted by the purposeful selection of caregivers who could provide rich accounts of their caregiving experience.

**Dependability**

Dependability is determined by an audit of both the process and the product of a study (Lincoln & Guba, 1985), and is referred to by Sandelowski (1986) as the auditability or consistency of a study. A study can be evaluated as being auditable when a second researcher can clearly follow the “decision trail” used in the research process, and could reach similar but not opposed conclusions given the data of the study (Sandelowski, 1986). Steps for achieving auditability are clearly outlined by Sandelowski and these steps, in combination with direction from the thesis committee, were used as a guide for this researcher in preparing the proposal and were also incorporated into this subsequent report. For this study, the researcher requested that the thesis chairperson review the transcript from the pilot interview for both the interview style and first attempts at data analysis in order to assure auditability. Furthermore, the use of field notes helped in the identification of the process used in reaching decisions throughout the data collection and analysis.
Confirmability

Confirmability or neutrality applies to the research findings and is achieved when “...there would be agreement between two or more independent people about the data’s relevance or meaning” (Polit & Hungler, 1993, p.255). According to Sandelowski (1986) confirmability is achieved when credibility, transferability and dependability are instituted. The institution of these criteria for this study have been discussed previously.

Ethical Considerations

Several strategies were used to maintain the ethical standards of this research study. Ethical approval was obtained from the University of British Columbia Behavioural Research Ethics Board, and the Hospital used to recruit participants. To ensure informed consent, both the information letters and consent forms clearly outlined how confidentiality was maintained, and that the participant was free to withdraw from the study at any time without affecting the services that he/she received. (See Appendix B). The informed written consent was obtained prior to the first interview. The participants were informed verbally and in writing about the nature of the research. Confidentiality was assured by the audiotapes, printed interview data and notes having all identifying information removed. Access to the data was limited to the researcher and her thesis committee, and participant names were not used in the written report.
CHAPTER FOUR: FINDINGS

The findings that relate to the experience of being an informal caregiver to an early discharged cardiac surgery patient (care recipient) are presented in this chapter. This experience is often shaped by the caregiver’s past participation as a caregiver, as well as the caregiver’s and care recipient’s outlook on life and the sort of relationship that they share. Consequently, these components will be presented first. Because the time at which the caregiving role begins is often individually perceived, significant episodes in the caregiving journey will also be reviewed. Following this review, the participants’ exposure to caring for a discharged cardiac surgery patient during the immediate post discharge period will be the focus of the presentation. The essence of the caregiving experience will be described in relation to both the work of caregiving, and the affect that taking on the role and accepting the responsibility can have.

The major findings and the similarities and differences among the participants will be illustrated using verbatim quotations. In order to protect the anonymity of the participants, all identifying characteristics have been removed or altered. To begin, a brief description of the participants is given.

Description of the Participants

Eight individuals participated in this study, five primary and three secondary participants. The primary informants were actively involved in caring for an early discharged cardiac patient in the first eight days after leaving hospital, and the secondary informants had provided care to early discharged cardiac patients enrolled in the original study for the rapid recovery program, approximately one year earlier. They ranged in age from 58 to 80; six of
the participants were female, two male, and all were husband and wife dyads. Only one of the participants was employed outside the home. These participants provided care to their respective spouses, six of whom underwent CABG surgery, one of whom underwent valve surgery, and one who underwent both CABG and valve surgery. The day of discharge for the care recipients was postoperative day six or seven for all but one, who was discharged on postoperative day ten due to the need to organize travel out of town.

**Previous Experience of Caregiving**

Most of the participants had previous caregiving experiences, such as looking after an elderly relative or caring for a family member with an acute or chronic illness at home. All of the participants who had had previous experience in a caregiver role described their earlier encounters with caregiving, often making comparisons to their present experience. For example, both the male caregivers noted that the caregiving experience was not new since they had taken care of their wives during previous illnesses. Other participants specifically noted how their previous experiences prepared them for their current role.

Oh, I felt, well, prepared because as I said I had done that for my mother right up until she went into the nursing home in August and up till then I'd had her for years, and the last, the last year she needed a lot of care ... so no, looking after him, it's okay and anyway as I say he's trying so hard to be independent himself that he's at least a week ahead of schedule according to how the schedule goes.

Well I've had so much in my life I suppose I sort of, I can deal with anything almost now, you know, I mean I had a son who had muscular dystrophy ... he was totally paralyzed in the end and I had to carry him about physically, that was one of the worst things in my life. .... This is nothing because [husband] is able to walk and the weight of some of the physical side of [caring for my son] that was absolutely devastating. .... You do these things so I knew I could cope with this.

Another woman indicated that the experience of being a wife and mother prepared her for this role: "I'm coming through it, I've had a large family, I'm used to it..."> These previous
experiences of caregiving offered a stance from which the participants could appraise their current caregiving situation, and insights into some of the experiences of the caregiver role.

One participant described the current caregiving experience as being different from previous caregiving experiences involving her mother and child because this time the heart was involved. Those who had little or no previous experience with caregiving identified a variety of expressed feelings of stress, frustration and inadequacy. One expressed inadequacy at failing to recognize symptoms of her husband’s initial heart attack:

I was more scared when he did have his heart attack and I was upset because I didn’t recognize it as being a heart attack and strangely enough the same thing had happened to my mother, she had a heart attack while I was with her and I didn’t know ... and it really bothered me that I didn’t know and I felt inadequate.

A caregiver who stressed that she had no previous exposure to looking after sick people indicated that her expectations were unrealistic. When asked if she had felt ready to have her husband home she stated “Oh yes, you know, I just felt well it’s going to be a week of looking after someone full time and not, but I thought it would only be a week, you know, I didn't think.” Previous experience with caregiving not only provided a perspective for the current caregiving situation, but also in most instances helped to prepare the caregivers for the experience of caring for an early discharged cardiac surgery patient.

The Caregiver and Care Recipient’s Outlook on Life

Many of the participants viewed the caregiving experience in terms of their overall life experience, the influence of significant people in their lives, and their expectations regarding the outcome of surgery. One participant expressed her gratitude that her spouse’s surgery had happened in Canada rather than in their country of origin where the techniques were not considered as advanced. The fact that the surgery was performed in Canada allowed this
participant to have a much more positive outlook about the outcomes of her spouse's surgery. Others saw the experience in relation to their own or their other family members' experience with illness.

I've lived that way for most of my life, you see I have a balance of polio which I had when I was, I guess I was twenty, .... I've been used to sick people so that's why I'm not too bad when I go to [the nursing home] because people find nursing homes stressful but I don't ... I see everybody in their walkers and they've got their canes, ... and I've always lived with something like that.

I worked for the muscular dystrophy for twenty odd years ... we have always been connected with disabled people and you know they do, you know they give you an inspiration ...

These women's positive experience with their own and others illness helped to motivate them in their caring for an early discharged cardiac surgery patient.

In contrast, one caregiver indicated that she had little patience with people who are sick or infirm:

As a youngster we had grandma living with us for awhile and I remember she would sit in her wheelchair and be so unhappy all the time and I thought I'll never get like that, I'll never do that, I will never sit in a wheelchair.

This participant's experience with her grandmother seemed to make her determined never to be in such a situation herself. Consequently, she indicated she took special care of her own health in order to reduce the possibility of ever having to undergo heart surgery. She viewed illness as something to be resolved by the individual him/herself, accordingly her attitude towards taking on the caregiving role was that it would only involve a short time period, but in fact this was not the situation. Hence, she found the experience of caring for her spouse after his heart surgery "just terrible."
Other caregivers spoke of how their own parents’ attitudes had influenced them during this caregiving experience. One noted how her mother’s optimism and her father’s realistic view of preparing for the worst had helped shape her outlook about the surgery. Another participant in summing up her experience stated:

And as my mother always said, you do what you have to do and you find the strength and she’s quite right, because you really do. You always say I can’t do this, I’ll never be able to do this and then all of a sudden your mind sort of clears up and I can, I just have to do it and you do, I live by that.

Despite this attitude, this participant identified that “staying as positive as I could” during the initial weeks of the at-home recovery process, when she was tired and stressed, was her biggest challenge. At the same time, for one of the male caregivers the surgery and subsequent recovery was perceived in a positive light since as he explained: “The cardiologist said she’d be a new woman and [I] expect that that is so.” Being aware of some of the realities of being a caregiver, and focusing on the potentially positive outcomes from the surgery assisted the caregivers during the recovery period.

The participants’ expectations also appeared to have an influence on their experience. For example, a caregiver who knew that she would be expected to look after her husband for two months seemed to accept her role more readily than the caregiver who expected that everything would be fine after two weeks, and then found there were unexpected complications which made the experience “restrictive” and “bizarre.” Another participant who had been told by the surgeon that her husband would be “good for another ten years” gave a positive report about the experience. When questioned about her greatest challenge of the caregiving experience she recalled: “I don’t think it was very challenging really, I took it in my stride, it didn’t sort of worry me because I knew that he, you know I was certain he
would be okay." In contrast a women who was given the same information, but whose spouse had not changed his diet, experienced her role as much more difficult. This participant had hoped and expected that her spouse’s eating habits would change as a result of the example she provided when she prepared meals as the caregiver, however this did not happen. Consequently, her husband’s eating habits remained a source of concern and animosity that she associated with her caregiving experience.

The experiences of the women appeared to differ from those of the men. The male participants were not only more reticent and objective when discussing their experiences of caregiving, but both men also emphasized that their wives either did not complain or were eager to progress in the recovery process. In addition, both the male participants had supplementary support for their role as a caregiver in that a nurse was visiting to dress the spouse’s wound in one home, and in the other a cleaning person came twice a week. In comparison, women reported that caring for their male spouses offered some special challenges. One participant described the experience as similar to having to care for a two year old, while another noted the difficulty her spouse had in depending on her for care. This woman reported “It was very difficult for him to get up out of bed and I guess for a man it’s difficult to rely on a woman to help.” Another caregiver explained that her spouse’s verbal abuse and unrealistic expectations were “his way of trying to be the man.”

The attitude of the spouse also influenced the caregiving experience. One caregiver who described his spouse as “not a complainer” referred to how his spouse’s disposition assisted in making his experience easier. In contrast, others indicated how their spouse’s more pessimistic disposition often affected both the process and their experience of caregiving. For
example, one caregiver expressed how her husband’s attitude limited his exercise program and hence his recovery process:

Well I tried to get him to do his daily exercises and things but he's never been one to exercise or be active at all, you know, he thinks it a waste of time, everything you do must have a purpose you know and he doesn't think that walking or doing any of those things is important to life, it’s an old fashioned idea, you must be productive.

Another participant described her spouse as “quite stubborn and quite adamant as to how he wants things done” and also emphasized how his disposition further influenced the caregiving experience:

I would have to reassure him that just because he experiences something and the other person didn't or vice versa that they experienced this, and it wasn't as bad as his; or as I say, him being such a worry wart he took from everybody’s operation and related it to himself but made it difficult, very difficult and that’s still happening now, almost a year down the road.

All of the participants shared how their own and their spouse’s disposition influenced their experience of caregiving. A positive outlook often helped the caregiver overcome some of the stress of caregiving. Additionally, those participants whose spouses had a more positive outlook found this attitude helped them in their caregiving role, while those caregivers whose spouses were more pessimistic in their outlook noted the difficulties their spouses’ outlook could produce. Thus, their own and their spouses’ outlook on life either facilitated or complicated the participants’ experiences of caring for an early discharged cardiac surgery patient.

The Caregiver and Care Recipient’s Relationship

The relationship that existed between the caregiver and the care recipient also affected the caregiving experience. Caregivers who felt close to their spouse talked about wanting to “be there” for their partner. One participant, who had been married for 52 years, described how
when her spouse asked her to remain sleeping in the same bed after surgery had said “since you want me there I will be there.” This sense of “being there” was sometimes reciprocated by the spouse. For example, one women described how her husband laid out her night clothes as a sign of his appreciation.

I had laid out his pyjamas and everything but when I came up to bed there were mine laying at the bottom of the bed all neatly spread out (laughs) he really wanted to do something and couldn’t think of what he could do so thought the least I could do is lay out yours since you laid out mine and that’s what he did but I always lay out the night clothes every night, not my own but always his, for some reason or other we always seem to like that.

The other participants who shared what was interpreted to be a more mutually considerate relationships with their spouses used expressions such as “we shall cope”, “we did it (the washing) together”, and “we do it [food preparation] together”. The caregivers in these mutually satisfying relationships talked of how they cooked special meals or provided treats in the form of favorite foods to tempt their spouse’s appetite. For example one woman stated, “Well he fancied melon today so I bought him melon and then he fancied apples so I got him some apples, it’s just little things he fancies, you know.”

Other participants described how there was little or no consideration in their spousal relationships. One of these participants referred to the “verbal abuse” that she and her daughter received from her husband during the journey home from hospital, and how he refused to let her accompany him to the hospital following his heart attack which she described as “hurtful at the time.” Another noted how her husband when given encouragement with his walking remarked that “well I don’t have to do that it’s silly,” and also how he did not “tend to want to do anything that’s fun anyway.” A third explained that:
Even though I asked him not to, he did plant a garden, ... he would say the flowers haven't been watered today, you know, you've got to water the garden, the flowers, he didn't want to see his vegetables or anything die so it was hard for me.

This participant went on to note how their diet had become a “bone of contention” since her spouse did the cooking and she had gained weight over the last 18 months, and yet both she and her husband should have been watching their diet because of their heart conditions. This woman acknowledged that the issues around diet led to friction in her relationship with her husband. Since they disagreed about the need to follow a more healthy diet any suggestions she made were perceived as “nagging.” She also indicated that her spouse gave no consideration to her needs concerning her own diet, and her need for help with the work around the home.

In summary, the caregiver and care recipient’s relationship also had an influence on the participant’s experience. A more mutually satisfying relationship helped to support the caregivers in their role, while a less considerate relationship sometimes thwarted the caregivers in their efforts during the recovery process.

**Milestones in the Caregiving Experience**

When asked to discuss their caregiving experience, different participants referred to significant episodes during the caregiving journey. These episodes provided a frame of reference for the caregiving experience. For some participants the caregiver role was initiated at the time of discharge from hospital, while for others it was initiated with the care recipient’s initial symptoms and continued through diagnosis, the wait for surgery, the surgery and in-hospital recovery, to the discharge home and the at-home recovery period. Not
surprisingly, the caregiver’s experience was frequently described in relation to what was occurring for the care recipient.

At some point during the interview all of the participants shared experiences that related to the various stages in their and the care recipient’s journey. Several participants began their stories about the caregiving experience with the initial heart attack. As one participant stated:

It was, it was a terrible shock that night, you know, I mean he got up and he said oh I’ve got terrible pain in my chest, he said I’ll go out into the living room, he didn't want to disturb me and I thought I don't like the sound of that so I got up as well, by the time I got into the living room he was bent over in agony, he was holding his chest and that’s when I got him into the car and just got him within ten minutes I think, I don’t know I broke the speed limit I'm sure and we were at the hospital you see and they said yes, it was a heart attack taking place and I got him there just in time.

This participant identified that for her the caregiver role was initiated the night her spouse experienced his heart attack when he needed to be taken to the hospital.

Another significant episode in this experience involved the wait for surgery.

Well actually it got funny, you know, we got so used to him going out for a walk and having to take the spray or going shopping because he does the shopping I can't lug things around, I guess it was beginning to seem like a normal way of living, he'd wake up in the night with the angina and he'd just take a nitro spray and in a few seconds he'd be fine and he'd go back to sleep and I was even getting so I could go back to sleep, I'm not worrying anymore which was terrible but it was getting to that.

We waited nine months and one day, ... but for seven months this creates severe tension never knowing, at the beginning it’s a fact that one is scared to leave the house in case a phone call comes, now if we had known it was going to take that nine months, we would have had more freedom to do, you know, our own thing, even walking, it came to the stage we had to exercise, we were fortunate to have an answering machine, some people don't ... and then finally near the end then you’re told oh in so many days, in so many days and then you find you’re set back, on no there's six before you, oh no, there's five before you, oh no, there's a wait, ... it goes on and on and on, this creates terrific stress on the patient, on the spouse, the relatives, the children and everything.

The in-hospital experience was depicted from a variety of perspectives in relation to both the caregiver’s and the care recipient’s experience. Some participants specifically expressed
relief at seeing their spouse after surgery which provided a great sense of reassurance. When describing the care recipients’ experiences the participants referred to the health problems that their spouses encountered whilst in hospital, such as a fall or a dysrhythmia. For some of the care recipients this also included their lack of appetite, episodes of vomiting and weight loss. The fact that the food offered on the ward did not follow a low cholesterol diet was mentioned by half the participants. Even though the care recipients were under the care of health professionals during their hospital stay, some of the participants identified that they had a role in monitoring the progress made by their spouses during this stage of the recovery journey. This monitoring was seen as a part of the caregiver role.

Another significant milestone for some was the journey home. For those participants who lived a distance from the hospital the journey home offered challenges not experienced by those who had only short distances to travel. For two participants the journey home involved a plane flight, and for a third a ferry ride. Although the plane journeys went according to plan, there was great uncertainty related to this experience. For one dyad this was their first experience flying which added to their anxiety. In answer to the researcher’s question about bringing her husband home one participant commented:

I was a bit [nervous] really because I didn't know how I, I knew here at [City] that there's a flight of stairs out of the aircraft and I couldn't think for the life of me how they were going to get him down them but it was like a chair and two, one guy at the back and one at the front and they carried him down and then the wheelchair was at the bottom so there was no problem really.

The ferry journey was just one component of the whole discharge process which was described as “causing great stress” for one participant. This participant shared in great detail in the diary and during the interview all the factors that contributed to the discharge which
was an “absolute disaster” for both herself and the care recipient. The unexpected discharge (the family had been repeatedly told by the health care providers that the care recipient would be staying in hospital for at least two more days) meant there was last minute, poorly conducted teaching; unplanned delays with the need to reschedule plans and travel at heavy traffic periods; and extreme discomfort for the care recipient who had been given an enema earlier and who had no ready access to a bathroom. The participant wrote that the “consequent result for patient was increased anxiety, heated verbal exchanges and prolonged haemorrhoidal pain which lasted for a week.” During the interview this participant recounted how this experience had caused her to “breakdown.” Subsequently, during the second interview this participant identified that “the separation from the hospital” was her greatest challenge of the caregiving experience.

Living some distance from the hospital increased the focus of the discharge and journey home, in the participant’s overall experience of caring for an early discharged cardiac surgery patient. The logistics related to traveling raised questions for the participants, and for one participant the unexpected timing of the discharge and a lack of planning had a major impact.

The final milestone of the caregiving journey, which was the planned focus of the study, is the at-home recovery period. Generally, the participants described caring for an early discharged cardiac surgery patient as an experience which affected all realms of their lives. Emerging from the interview and diary data are three themes related to the work of caregiving which can be conceptualized as the process of caregiving. The process of caregiving focused on: 1) vigilance/monitoring of the care recipient’s recovery, 2) strategies and techniques used to keep things on track, and 3) seeking help and support.
The Process of Caregiving at Home

The work of caregiving frequently involved the participants taking on specific roles and responsibilities during their caregiving experience.

Vigilance/monitoring

Vigilance by the caregiver can be described as being both watchful and also on alert especially to guard against harm or error. Closely allied with vigilance is the need for the caregiver to check on the care recipient to monitor his/her progress. All of the participants when describing their experience of caregiving provided examples of how they were vigilant during their spouses' recovery at home. Although the word 'vigilance' was never actually used, the participants described not only the steps they took to check on their spouses, but also how they were alert to guard against harm or error. The caregivers commented on how they would listen for and check on their spouses, particularly at night. One caregiver commented on how since her husband slept with his bedroom door open she was able to check on him when he was sleeping. Similarly, another participant said:

When I first arrived home I sort of watched him every five minutes, you know, I didn't want him out of my sight, I didn't know whether he was going to fall because I don't know if I told you he had a fall the day before in the hospital because he's getting these dizzy turns.

This same participant also commented on her concern about hurting her husband, “I was a little bit sort of scared of in the night in case I might put my arm over him, his chest or something.” Yet another participant journaled on two occasions about how he was watchful of his spouse at night. He wrote, “Checked three times through night as I heard her moving about in bed.” When a return to work was necessary vigilance continued via the telephone.

I would call him at ten o'clock and at noon and if I called at noon and he didn't answer that usually meant that he was sleeping because the phone didn't ring in the bedroom so
then he would call me when he woke up so at least when I went back to work there was communication back and forth.

Two of the participants described situations where their vigilance waned. One participant intentionally chose to ignore or downplay problems. She thought her spouse was overstating his symptoms and recounted her experience of her spouse’s first weeks at home in the following way:

But I just had the feeling that every weekend we’d end up in emergency at [the] Hospital, I mean it was just bizarre .... Yes, so, you know, I just didn’t pay too much attention to it, I thought oh dear.

Another participant, who reported that he was watching his spouse very carefully during her first days at home, noted how he played down her symptoms of a minor stroke as a result of lack of knowledge. His lack of vigilance appeared to be less intentional. He stressed:

Certainly the speech business, if I had seen it I might have approached it a different way, I tended to gloss over it and that’s one thing to know, to watch for because you haven’t any knowledge of that sort of condition, really don’t know what it is.

While both of these participants monitored the care recipient’s progress, they were less vigilant in their caregiving roles possibly because of a lack of understanding of what was happening during the recovery process.

The participants’ vigilance and monitoring also involved their spouses’ diet and exercise/activity regime. The caregivers’ watchfulness concerning diet involved ensuring that their spouses were not only eating, but that the food that they ate was both tempting and incorporated foods that were low in cholesterol and fat. The following statement describes the essence of vigilance around diet, “Now he’s had this operation he lost ten pounds while he was in there [hospital] so it’s taking us awhile, so I said well you can eat almost anything you like as long as it’s not too fat.” Other participants described how their spouses often
fancied and some even continued to eat all the things that were considered to be the wrong foods. For one secondary participant the issues related to diet continued to be identified as a concern a year after the surgery. She elaborated:

He didn't change his diet at all, he was going to do that after he had the operation and I was trying to convince him that now is the time to start, you know, ...and I still have difficulty trying to convince him to eat healthier, ... I really don't get anywhere as far as the diet is concerned and I can't be nagging him all the time.

This participant had continued to be vigilant in relation to the care recipient’s eating habits more than a year after his diagnosis of heart disease and subsequent surgery.

Vigilance was also seen in relation to the care recipients’ exercise programs and their general activities. Even the two participants who did not specifically identify that they were being watchful of their spouses’ exercise regime made comment on their spouses’ posture and/or their walking speed when sharing information about their caregiving experience. These comments indicate that these participants observed their spouses in order to make the comparison between their spouses’ presurgical and postsurgical activities. Other participants were very specific with their descriptions of their vigilance around exercise and activities.

I only have to look at him to see that he is tired but he hasn’t been walking on the weekends for a long time, so I have a feeling he hasn’t been doing it during the week either.

I've been watching very well and I can see and I have no problem telling him to sit down and be quiet ... so no he knows he can lay down whenever he feels like it and does and then I don't wake him up I just leave him to wake up when he's ready.

I've been observing him all the time, watching his sleep patterns and so on, every other thing and if visitors come, be careful, I mean he's fine, he doesn't stay too long with them.

For all of the participants vigilance was a component of the caregiving process and included regular checks on their spouse when he/she was first discharged. Vigilance also occurred
predominantly around their spouses' diet and activity regime and was often ongoing. For all three of the secondary participants the vigilance continued almost a year after their spouses' surgery for specified components such as diet and exercise.

**Keeping Things on Track**

Keeping things on track refers to the general running of the household and meeting any immediate demands in order to sustain the care recipient's recovery. Keeping things on track incorporates both the physical and visible, and the psychological and invisible techniques and strategies employed by the caregivers during their spouse's at-home recovery period.

For most of the participants the physical and visible techniques and strategies involved taking over most, if not all, of the household responsibilities previously performed by their spouses. These responsibilities included housecleaning and gardening, as well as meal planning and preparation. Some of the participants reported that they were responsible for food shopping and preparation which was not a usual part of their role. One participant saw this as an opportunity to encourage her spouse to improve his dietary pattern. A second participant summed up his responsibilities when he wrote, "Paying more attention to eating habits now. If a person plans ahead with meals it works better." The household duties taken on by the caregiver depended not only on what their spouse had been accountable for prior to their surgery, but also on the ability of the caregiver to take on the task. Some participants identified that their spouses had previously done the vacuuming and that they were unable to take on this activity because of their own health challenges. Only one of the caregivers felt that there was no shift in the tasks performed in relation to household responsibilities. This participant explained:
We have someone to cut the lawns and he doesn't do anything like that, he never has gardened so you know, that part didn't bother me at all, no, there wasn't anything that, you know, the roles didn't change at all.

Other actions that the caregivers found themselves involved with included driving their spouse to appointments with the doctor or at the hospital, and picking up prescriptions.

Several of the female spouses did not drive or did not have a car so had to depend on other family members or public transportation. These restrictions in relation to transportation required additional organization on the part of the caregiver to ensure that their own and the needs of the care recipient were met. One participant expressed her frustration by saying:

I think they [hospital personnel] assume that you have cars available, you have loads of relatives just there, sisters aunts, brothers, everybody to help you, children to help you, this is not always the case.

Interestingly, this participant decided to take driving lessons about three months after her spouse’s surgery.

Additionally, some caregivers provided assistance with any activities of daily living that their spouses had difficulty with when they were first discharged from the hospital. These activities included bathing, which was a problem for one care recipient since the home did not have a shower, and for another, whose spouse suffered bouts of dizziness, helping him up and down from the chair or bed.

Other strategies and techniques used by the caregivers to keep things on tract were often not visible and focus on reasoning processes. These included finding solutions to any health problems that the care recipient experienced, as well as discovering answers for how to complete unfamiliar household tasks. Caregivers also employed techniques and strategies to
motivate their spouses to follow recommended dietary and exercise schedules during the recovery period.

The problem solving activities varied for each of the individual caregivers. Some caregivers described how they needed to find solutions to their spouses difficulties with sleeping.

That next day of course he couldn't sleep and neither could I but he couldn't find a place to put his body, he didn't know which way to lay and they said you have to lay on your back, we put cushions under his feet, and we did everything and I kept saying I must go in the other spare bedroom and you sleep here because it will maybe make you more comfortable, he wouldn't let me do that.

Well the second night I slept in the other room because he was so restless the first night he was home, he was just, his arms and legs were just going, you know, and I don't know why that was, but he hasn't been like it since, so I went in the other room to sleep.

One caregiver, whose spouse suffered with constipation, offered a variety of solutions from prune juice to patent medicines. The caregivers also specifically described how they sometimes involved the care recipients in the problem solving process. One directly involved his spouse with getting the task (the clothes washing) done, while the others got the directions they needed, “I can keep referring [to my wife] and say well I’ve done this, how do I do this? or how much should I do of this? so it works out that way.” One woman explained:

Well what I do if I don't know how to do something I ask him and he usually tells me what to do, you know, that's the only way I can get round things I don't know what to do.

The caregivers offered verbal encouragement to their spouses and made suggestions of ways to do things. The need for encouragement was often dependent on the care recipient’s disposition. For example, the caregiver who described her spouse as “a worry wart” and a “perfectionist” was required to provide support and advice in relation to his return to driving and to cutting the lawn. This participant noted:
I said well look it, just for the first time just get in my car because my car is really easy to handle like drive around the block the first time, the first couple of times, the first few times and then once you feel more comfortable, you know, drive over to Safeway because he likes to shop so I had to convince him that yeah maybe he could just drive around the block .... So he did start cutting the lawn before winter ... but it’s such a big lawn and I said well, why don't you do half of it one day and half another day, it’s not going to make a difference but he’s such a perfectionist you know, he wants it to all look the same so you know, he felt he had to do it in one day and I had to convince him that no it wasn't important to do it all at once.

Whereas, the caregiver who described her spouse as “a very competitive person” declared to her husband “you don't have to be a hero here” and noted that she had “no problem telling him to sit down and be quiet.” Consequently, the encouragement and suggestions offered by the caregivers were often connected to the care recipient’s nature and attitude.

At the same time, many of the female caregivers stressed that they felt that it was difficult for them to give advice or suggestions to their spouses, and that the suggestions would have been accepted better if they had been provided by health care professionals. As one participant explained:

I don’t know how other patients react to suggestions from family members, I’m not just sure of that, whether or not my husband will take direction from other people but not from a family member. .... We got a sheet from them [the hospital personnel] saying this is what you should do everyday and everything and if there was someone else here to read it to him a nurse or somebody I’m sure it would have worked out much better.

This woman confirmed during a second interview that her greatest challenge as a caregiver was related to her role in providing encouragement to her spouse. She affirmed:

The most challenging really was the difficulty in trying to cajole him or persuade him that if you did this or this or this, things would progress better and you [the care recipient] would be better.

One of the male caregivers, however, expected that he and his spouse would disagree when he needed to tell her to slow down. He explained, “Now our difficulty is trying to stop her
from doing things, she’s so anxious to do this, that and the other and from time to time we fall out over that but (laughs) that’s to be expected.”

Both the primary and secondary participants spoke specifically about how they saw their role of keeping things on track as being limited to a specific period of time. One woman commented “I presume as time goes on this [the feeling of total responsibility for the work load] will disappear but it’s a slow process.” Furthermore, the participants talked about how their spouses slowly made a return to normal, and started to resume some of the activities they had previous responsibility for.

I guess probably at about fifth, six weeks he started doing some of the cooking again so then that made life a little easier for me, not every night at first but little by little he got, that was the first thing he started to do was getting back into the cooking and then eventually the cleaning up of the dishes after, he found it difficult to bend over well that was fine, he would rinse the dishes and I would do the rest, you know, but little by little it became easier for me.

Other participants described how early in the at-home recovery process the care recipients were already starting to help with household tasks and how this was beneficial to the care recipient: One women specified, “He does most things, he gets up if he wants a coffee or he wants a drink, he gets up and gets it, you know, so he exercises a little bit.” Other participants commented:

He'll start the salad or something at lunch time, he gets up from his rest and he'll take out the lettuce and stuff and start putting it on the plate and I'll just finish it off, no, he's trying very hard to do things and they did say on those things [pamphlets]to try to do small household chores.

He must be shown to do things himself, to help his independence when he gets healthy again which he accepted reluctantly but accepted so from that point of view he's very good, he does his own thing and so forth, and it helps to increase his activity in walking and what not.
Data analysis revealed that the caregivers had a role in keeping things on track as a part of the process of the at-home recovery period. The tasks taken on by the caregivers varied among the participants but in most instances were temporary in nature. Although temporary the tasks that were absorbed by the participants did involve a shift in their roles and responsibilities. The care recipients' incorporation of these tasks back into their routine was often seen as assisting in their recovery and return to normal. Suggestions and encouragement were provided by the caregivers and were often specific to the care recipients' disposition. Additionally, some caregivers identified the challenges they experienced in providing such advice to their spouses.

**Seeking Help and Support**

The participants identified a wide variety of resources that they used when seeking help and support in the process of caregiving. These resources included people, both professionals and non-professionals, information packages including written and electronic materials, and recreational diversions. Many of the participants saw the family physician as an important resource for follow-up care. Others described the role that nurses had in providing support, stressing the need for follow-up care by a nurse after discharge home. One participant whose spouse required dressing changes by the home care nurse expressed his appreciation of the support provided when he wrote:

I believe it would be to good to have some help when leaving hospital and first day at home. .... I find these [home nurse] visits are necessary for patient and also for myself as I feel everything is OK.

Another participant gave recognition to the support and information she had received from the “research” nurse who had been a part of the study team for the rapid recovery program,
while a third described how she had sought information about her husband’s chest soreness from the surgeon via her sister who worked as a nurse at the hospital where the surgery had been performed.

Family, friends, and neighbors were frequently identified as providing both help and support. Not surprisingly, friends and neighbors tended to play a larger role when family support was not so readily available either because of distances or other commitments. Most of the participants expressed that they had “good neighbors” who would be able to assist them if asked. One woman specifically noted that she planned to use paid help when it was needed. She explained:

I figured the house isn't that dirty but I haven't called anybody yet, I have a list of people that I can call, not friends or relatives, I had made quite a study of that before we ever got to this so that if I needed any help from anywhere I had all these papers and lists and things, ... so I knew all the places to phone so it’s kind of comforting to know, but I haven't used it yet but it’s there if we really get bad, I do have family but they’re, everybody works so by the time they get their own work done, it’s not easy to come in here.

Physical help frequently involved assistance with the garden and lifting or moving heavy items. A second participant, who because of her own health challenges had been unable to vacuum without severe pain, had asked a cleaning person to give her an estimate for help in the home but the care recipient refused to have someone come into the house to help out.

Psychological support was both offered to the care recipients and sought by the participants for themselves. Family members visits’ were identified as a support for the caregiver, as much as the care recipient as these visits offered a different focus for the caregiver. Additionally, just talking to another individual helped one participant realize that her experience was not unique.
I was talking to a girl there telling her this sad story and how could I escape and she said you know, I've just been down to [city] and my [relative] had a similar operation and I said it was my three weeks in hell, and so I, [the participant] thought okay this is normal, it's not unusual for people.

Another participant, who did not drive, specifically approached her neighbor to take her out as she was feeling very restricted by both the responsibilities she had taken on and having no time to herself. This participant saw this action as a way to help herself feel better.

Receiving information was also viewed by the participants as a support for their caregiving role. Participants made references to the information they had received about what to expect in terms of the at-home recovery process. They discussed how helpful the pamphlets and booklets had been in assisting themselves and the care recipients know what to expect and what was normal. One of the participants stressed that both she and the care recipient knew “what we can and can’t expect, it was very good.” Another participant asserted, “Well he said it [the incision] was very itchy which they said on this pamphlet, we've got a booklet that [said] he would get that.” A third participant noted how the information they received and sought for themselves via the internet helped them prepare for the experience. She explained:

I think we read all that and knew what we were going to face, we knew that we were going to have to, mind you my husband had made quite a study of this operation on the internet, as soon as he found out he was going to get it ... the more you learn boy the easier it is to face, so that's what we did to prepare ourselves.

Many of the participants who felt prepared indicated that they had had the opportunity to attend the preassessment clinic where a great deal of educational information had been supplied. One participant confirmed the importance of the preassessment clinic for the insights that were provided when he reported:
It was extremely helpful and informative and everybody went out of their way to make it clear .... It gave you quite an insight ... you weren’t at a loss or anything like that so that was extremely good.

In contrast, a participant whose spouse had been offered the opportunity to attend an information session pointed out that she believed because of the associated travel costs they had not attended. Consequently, she missed the opportunity to receive some of the important educational information.

I believe that there is, um, situations where a husband and wife or relative can go with the patient prior to surgery and be given a whole lot of instructions and I do not know whether we were asked, I was never asked to go, my husband apparently was asked and he didn't bother about it because it was going to cost us a motel room and so I never got that chance, perhaps it’s all there, I don't know, maybe I missed something.

The fact that a caregiver and care recipient lives outside of the city may be a limiting factor in their ability to obtain the information that they require.

Those participants who had not gone through the clinic identified that they had either not received any information or that the information and/or the learning environment had been unsatisfactory. As one participant explained, she and her spouse were shown a film just before discharge from the hospital, and at a time when their viewing was frequently interrupted by visitors arriving to see the other patient in the room. This participant elaborated:

I asked if any further instructions, she [the nurse] said there's a movie, has the patient seen it, I asked the patient, no, oh well I'll bring it into your room so she brought it into the room, we watched this movie from the beginning to end, meanwhile the room mate had a huge amount of visitors passing in front of us every time, this was extremely stressful for the patient, ... we finished the movie of instructions, in it were a whole lot of catalogues patients/spouses could buy but I noticed it was [another] hospital, I'm amazed that there were none in [that] hospital.
Those participants who felt they did not receive enough information expressed concerns about being uncertain about knowing what to expect, and not understanding what was normal. As one participant stressed, “The only thing [which] really annoys me is the fact that I was suddenly faced with all this, without the proper consideration, I wasn't prepared.”

Another questioned whether what she and her spouse were experiencing was typical, “I kept thinking I wonder if this is normal ... because when a patient gets home immediately they think oh, this isn't normal, this isn't normal, I didn't know what was normal.” A third participant explained her concerns in the following way:

There was drainage there and I didn't know what to expect, as to what would be normal and really he didn't either, um, so that was a concern. .... I would liked to have known whether or not these little twitches or whatever should have been a concern or just how bad a pain is before I should be concerned, I mean there was literature but it really wasn't explicit enough.

Having information that outlined the recovery process and what to expect helped to make the caregiver’s experience of caring for an early discharged cardiac surgery patient less stressful and anxiety producing. Specific information for the caregiving role, however, had to be extrapolated from instructions and information provided in relation to the patient.

Recreational diversions or significant events were identified by the secondary participants as turning points in the care recipient’s at-home recovery process. For one participant it was her spouse’s return to work which enabled her to see the progress he had made. For others it was trips away which were identified as making a difference not only for the care recipient but also for the caregiver.

Then the end of September just on the spur of the moment we went on a cruise leaving out of [City] through the Panama and it was a twenty-one day [cruise]and that seemed to make the difference in making him do things and get out and it certainly relieved a lot of the pressure for me.
We did get away for a few days at the end of September with his doctor's okay and everything and that was really good, it was a nice break for the both of us, we went to [City] and it was warm and sunny and we had an excellent time, ... we had time to relax away from home ... and it was a really good break for the both of us.

Interestingly, the primary participants talked about trips or special events that they were looking forward to at some future date. For example, one participant talked of various trips that they were planning in order to visit relatives, while another described steps that the family were making to celebrate a significant birthday that she would be celebrating. These events provided a focus for the future allowing the caregivers to look beyond the current at-home recovery process.

The data suggest that the participants used a variety of resources when seeking help and obtaining information. Physical and psychological help and support was requested from both professional and non professional personnel. Access to a family support network was dependent on both the location and the availability of the family members. Information about what to expect and what is normal was sought through verbal, written and in one case electronic formats. The data does, however, also suggest that attendance at the preassessment clinic was significant for those participants who had access to that resource in terms of decreasing their uncertainty and increasing their understanding of the at-home recovery process. Finally, for the majority of the participants future recreational events were identified as providing a positive focus for both the caregiver and the care recipient. These events were often indicative of the return to normal which was seen as an important outcome for the majority of the participants and their spouses.
Returning to Normal

During the analysis of data the participants were frequently noted to use the term “getting back to normal” when talking about the process of caregiving. Return to normal involved the care recipients taking back the roles and responsibilities that they had prior to their illness. It also comprised doing things, or at least having the option of doing things that were a part of the customary way of life for both the caregiver and the care recipient before the care recipients’ diagnosis and surgery. Although not directly identified as the goal of the process of caregiving, the participants certainly alluded to the idea that returning to normal was an important outcome for them. When asked what the return to normal involved, one participant stated, “he’s going back and doing things like he does the dishes now... because that’s what he used to do.” The return to normal often involved the resumption of key activities, “so once he could start doing that [cutting the lawn] it came in little bits and stages.” The resumption of previous routines including specific household activities such as gardening, and vacuuming, along with pastimes such as walking and going out in the car again were described by the participants as part of the return to normal. Returning to normal also meant having less uncertainty and focusing on more than the disease. One participant identified that for her it related to not having “that pressure [of uncertainty].” A second described getting back to normal in terms of the change in her spouse’s focus and her ability to do things for herself.

Just the fact that he wasn’t nearly as preoccupied with himself and there were other topics of conversation when somebody came in or whenever he went out. .... Yeah I immediately started doing my own thing again.
A return to normal was important for both the caregiver and the care recipient in that the care recipient was well enough to participate in his/her presurgical role, and the caregiver had greater freedom to be involved in activities that are important to him or her.

**The Impact of Caring for a Cardiac Surgery Patient Immediately Post-Discharge**

During the process of caregiving the participants identified how the caregiving experience influenced their lives. The impact was described as *stressful, placing them in a vulnerable position, and requiring them to put their life on hold*. It was only when directly questioned, during the follow-up interviews, that the participants identified what for them were the *rewards of the caregiving experience, and the recognition* they received for their caregiving role. All of the participants depicted the experience as being stressful and tiring.

Additionally, some of the participants felt vulnerable, particularly when they did not know what to expect, or what was normal in the care recipient’s at home recovery process.

Throughout this early recovery period at home all of the participants were required to make adjustments in their own lives in order to take on the caregiving role. Any rewards related to the caregiving experience, and recognition by the care recipients of the care provided by the caregiver, were only identified when the participants were directly questioned about these components by the researcher. In the following section, the impact of taking on the caregiving role will be considered in light of the participants’ experiences.

**Being Stressed and Tired**

Consistently all of the participants in the study identified that they found the experience of being the caregiver of an early discharged cardiac surgery patient stressful. Stress began long before the surgery. Thus, for some participants, the stress and resulting tiredness was
not just related to the at-home recovery experience but also included the whole of the
caregiving journey from their spouse’s diagnosis through to the recovery at home. Many of
the participants emphasized the anxiety of waiting for surgery, and expressed concerns about
the complications of surgery. One woman summed up the experience in the following way:

Well it’s very traumatic actually, you know, he was such a strong man and it was such a
shock that he should have a heart attack, you know, and well, well first of all I had the
problem here in the hospital in emergency and then of course he was taken by air to [city]
and that's where he had the four way by pass done.

The stress of the experience was most often described in terms of the physical strain. One
of the participants wrote, “Too much work for one person alone - exhausted by evening
eyeiday,” while another recorded, “Starting to feel better today - I was quite tired after the
first three days home.” The stress of the experience also resulted in the participants feeling
tired, and for some participants this exacerbated their own health problems. To illustrate, one
participant described her experience in this way:

The phone was ringing, I was really tired .... all these people who wanted to know how
he was doing, now he's come home, they said now they wanted to see how he was
making out and so it just went on and on so you know, that was a bit stressful, I didn't
know and my leg was getting really bad by then.

For some participants the experience also included mental strain. For one participant the
anxiety of the journey home was tremendous and she talked of how she “broke down” and
“collapsed” during the wait for transportation. This breakdown was also noted to be “not
good” for the care recipient to witness. Another participant related her tiredness to the stress
of trying to encourage her spouse to exercise and to start eating again. This participant
explained, “Well it [being tired as a caregiver] was tired of making meals for two and then,
you know, someone saying well, I don't like that and it’s not what I want and you know they
get very, very picky.” As another participant verified “I am very stressed really if I had to be truthful but that will go”, while others readily expressed how they were affected by the experience:

It was hard for me, I'm waiting for surgery on my neck and it really put a lot of pressure physically and mentally on me to have to do everything, so I would say the first couple of months were really, really hard on me physically and emotionally.

Furthermore, two of the secondary participants described being “ready for a rest” once the initial recovery process had been completed, while at the time of the second interview, several of the primary participants identified that they continued to feel tired.

To summarize, all of the participants found that the impact of the experience of caring for an early discharged cardiac surgery patient was that they felt stressed and tired. For many participants the stress was physical, while others identified both a physical and a mental strain. Some of the participants noted that their own health problems were exacerbated by the strain of caregiving. While some participants freely acknowledged how the experience had resulted in stressful feelings, others needed to be prompted to consider this component of caregiving. Additionally, many of the participants described the stress in relation to the whole caregiving journey and not just during the at-home recovery period.

A Sense of Vulnerability

Another impact for the caregivers was a sense of vulnerability. While the term “vulnerable” was not specifically used by any of the participants, many of the participants recounted situations which indicated that they felt inadequate and therefore open to criticism and/or some sort of psychological attack or hurt. These situations often involved the participant’s lack of knowledge concerning what to expect during the at-home recovery
process, or which of the care recipient’s physical or emotional responses they should consider normal. Some participants indicated that it was the separation from the hospital and the expertise of professional caregivers that led to feelings that could be interpreted as those of vulnerability. These participants commented:

I was a bit apprehensive about him coming home because you know you feel you're on your own but when there in the hospital you know everything is there for them and if anything goes wrong it's all there where once you get home it’s quite different, you think oh I'm on my own you know, now I hope everything goes okay.

The only one thing is you leave the hospital, the patient leaves the hospital and the surgeon, the medical team, the nursing team have done their job and then he's out, it's just like that, I think it's far too much of a cut, there definitely should be a follow up just to initiate any other programs in the community or you know help this [separation], ... it helps the patient a great deal if one [the caregiver] can do more.

Another participant also commented on how her lack of medical expertise caused her concern, “Well it made me anxious too because not being a medical person I don't know, I mean I can only guess what his pain is like and try to reassure him.”

Some participants speculated as to whether what was happening was part of the normal process of recovery or that of aging. These participants were vulnerable because they were uncertain about the care recipients’ complaints and concerns, and therefore could be open to criticism.

It's been difficult because I felt that if I was given some information prior to surgery or prior to him coming home I would have been able to deal with it much easier and better because I felt at a loss ... I didn’t know what to expect to be as to what would be normal .... Yeah just to talk to and saying, you know, this is happening, is this okay or should I be concerned so I was sort of, at times I felt I was kind of floundering.

This participant went on to note that for her the most challenging component of the caregiving experience was related to “not knowing”. During the second interview she confirmed:
I guess the not knowing of what I really should be doing or whether I could be doing things differently or better for him, he never complained that I wasn’t taking care of him adequately but there was always this question in my mind, was I?

Another participant found herself driving her spouse to the hospital with a variety of complaints every time the weekend came around. She described the situation as “bizarre” and when questioned about the effect of this experience on herself as the caregiver she stated, “Oh dear (laughs) it caused a lot of anxiety, you know, it was, um, I kept thinking I wonder if this is normal?” A male participant, whose wife experienced a minor stroke which affected her speech, expressed his vulnerability by explaining that he did not think the fact that his wife could not think of the right word was an uncommon occurrence with the aging process. He claimed:

But that’s part of the course, I can’t [think of words] either, nor can my friends and relations of a similar age, your fishing for a word and it doesn’t come, two hours later it comes quite clearly.

This participant went on to explain that if he had been aware that speech problems could be a sign of a stroke he would have been able to watch for such a situation. Once more this participant was vulnerable because he did not know what to expect or what was considered normal.

Other examples of the participants’ vulnerability were related to unexpected news or events that happened at various times throughout the whole recovery journey. One participant expressed her vulnerability in terms of being upset with the wait for surgery since her first husband had died after being admitted to hospital:

He [first husband] was taken into hospital and he sort of was getting on for about five days but then he took another massive heart attack so I know a little bit about it and that’s why I was worried when he [current husband] laid here for seven days waiting to be air lifted to [city] because I knew that sometimes they can take another heart attack.
Other participants received unexpected information when phoned by the surgeon on the day of surgery. One woman was distressed to hear that her spouse had been given details about his mortality and other complications that she was not aware of and noted how “hurt” she felt. The unexpected nature of this information caused her to feel vulnerable, not only because she felt left out in terms of being unaware of the risks of the surgery, but also because of the potential of being psychologically hurt should anything untoward happen to her spouse. Another participant was unaware of the critical first twenty four hours after surgery, and when she heard from the surgeon she expressed her vulnerability in the following way:

Now I never thought about anything like that so then I just became speechless and for me to become speechless I'm really stressed out because I can talk forever, so I said oh I'd never thought about that, and I thought well I'll never get through tonight waiting.

Another way in which the participants indicated their vulnerability related to the hurt, either overt or covert that was imposed by their spouses. For example, one participant noted that on several occasions her husband had been insulting. Others indicated that they “felt upset” and “experienced [feelings of] resentment” when they made suggestions to their spouse about changes in life style related to diet and exercise. These participants indicated that both the verbal and non verbal reaction of their spouses to their suggestions left them feeling vulnerable.

While the focus of the discussion has been on psychological vulnerability, several of the participants were also vulnerable to physical hurt in their caregiving role. To explicate, all the participants described how the caregiving role required them to take on additional physical activities which made them tired, and in some instances led to increased health challenges for
the caregivers themselves. This vulnerability is summarized by one participant who contended, “He needed my help and for a woman who is usually smaller and not as, I'm not very strong physically so yes, it was difficult for me, that was probably physically the most difficult part.” Yet another participant described how his physical limitations caused him concern about his abilities in his caregiving role. He identified his vulnerability when he stated, “I know that I have a limitation and if somebody was to fall or something like that then I’d have a hard job to get them up .... So there was that behind it all the time.”

Thus, while the participants did not speak directly about feelings of vulnerability, a variety of instances in their individual experiences could be interpreted as displaying their vulnerability. These instances occurred throughout the entire recovery process, and included both psychological and physical exposure to hurt and injury.

**Putting Life on Hold**

As caregivers the participants found that their own lives were disrupted throughout the entire recovery process. The disruptions most often occurred during the wait for surgery and during the at-home recovery process. Several of the participants talked about being afraid to leave the house in case that “all-important” phone call came to say that a bed was available at the hospital. Once the care recipient was admitted to hospital those caregivers who traveled to the hospital from out of town experienced greater disruptions than those who only had short distances to negotiate to visit the care recipient. Some of the participants talked of feeling confined in a strange city, while another got lost and had to walk a great distance to reach her destination. One participant also noted how the disruptions created by being away from his usual environment carried over on his return home. He wrote, “When [I] first came
home it was difficult to get back into [a] regular routine after having everything done for you; it’s quite a change.”

Many of the participants described how they had made changes in both day to day activities, and to future plans during their caregiving experience. For example, one participant who was employed outside the home, took vacation time and stayed home from work for the first eleven days of her spouse’s at-home recovery period. For another participant, the need to be available for someone around the clock reminded her of her caregiving experience with her mother. Another likened the disruptions to her life to having a young child to care for:

Oh there was no way to escape, you know, it was like you know, just having to go for a walk or anything it was, it was like having a two year old around and short of putting him to bed and saying well I’m going out for a walk now and you're fed and I know you're all right.

Many caregivers discussed how they stopped many of their activities for much of the first two months of the at-home recovery period. For example, their own exercise programs were often curtailed, they gave up visiting friends, and they spoke of canceling holidays that had been planned. One participant specifically stressed that “one has to get away from the situation”. This participant also wrote, “Spouse’s [ caregiver’s] time for work, recreation, family relationships and friends strongly curtailed.” While some participants did not specifically describe having their activities curtailed, one participant hinted at this by his statement that going for groceries “was a nice change”. Another participant summed up her situation, “Well I just didn't plan things, you know, normally I, I like to see what’s going on down, you know, the concerts and things like that and I just didn't plan anything at all.”
While the basic essentials of daily living were taken care of by the caregivers during the at-home recovery period, most of the participants identified that their own lives and interests were not only disrupted but also curtailed when they took on the caregiving role. Many of the participants were required to put their own lives and interests on hold at various times throughout the entire recovery process, and specifically for up to two months during the at-home recovery period.

Rewards and Recognition

The rewards of caregiving can be defined as those components in the caregiving experience which provided a positive focus for the participants and helped to give meaning to the situation. Additionally, recognition of the caregiver included the words and/or gestures provided by the care recipient to the caregiver in appreciation for the care that had been provided. During the initial interviews a few participants alluded to the rewards of the caregiving experience. One of these individuals indicated that the experience had taught him “to use the washing machine” and to acquire “one or two culinary arts”. Another participant referred to how the surgery “has refreshed” her husband so that he now had more energy. This participant also noted a number of positive outcomes from the surgery, including that her spouse “no longer snored” nor had “a pot belly”. Whereas these outcomes were not specifically described in relation to the rewards of caregiving, they did reflect the focus of the rewards discussed by other participants.

When asked, many participants identified that the care recipient’s successful recovery was the primary reward. The participants spoke about rewards in terms of their spouse’s expected return to better health. For some of the participants it was the day to day
improvement that provided the rewards. They made statements such as, “Mainly I think to see him getting better everyday,” and “He’d rush right back [from a walk] when he came home and say well I did this and I did that, boy it was wonderful.” For others the expected long term outlook was identified as the reward. Participants declared, “Oh well he’s going to live for another fifteen years,” and “Well it was to see him returning to normal, and also the knowledge that the bypass had done such wonders.” In contrast, one participant specifically noted her reward was her successful role in the recovery process. She explained:

I guess I feel I did a reasonable job at it, he did recover without any problems and if I had, you know, if I had seen any problems occurring naturally I would have asked for some kind of help, so yeah there was a fair amount of satisfaction that things did go okay.

Additional rewards were also described by some of the participants. One women felt her reward came from the fact that she had managed to plant and grow a garden despite all her caregiving responsibilities. Another participant saw her reward in a future trip abroad, and the fact that the children in the family saw “a bit of difference [in their father’s health] for the better.”

The care recipients’ recognition of the care that the caregivers provided was mentioned by a few of the participants during the initial interviews. For example, one participant described how on his first night at home, her spouse noting how stressed she was, had laid out her night clothes as a gesture of his appreciation. Another participant identified that her spouse had been required to care for her after she broke her arm and ankle. This participant explained that her husband took a week off work to care for her which “repaid [her] as I was very good to him.”
When questioned if the care recipients had shown any appreciation for the care provided by their caregiver during the recovery process, several of the participants identified that their spouse had verbally expressed his/her appreciation. In addition, some participants spoke of the gestures that demonstrated to them the care recipient’s appreciation of their caregiving. For example, one participant received flowers on a “fairly regular” basis, and another received roses for an anniversary which was unusual since she usually grew her own. This participant also identified a number of small gestures which she saw in terms of appreciation of her care. She reported:

Oh actually these little things, well of course as I say even those days he would get up and he would set the table for dinner, well when he started walking to the corner of course he would then remember to bring bread and check to see if there was milk. .... Oh the odd time he would look to see if there was some fruit or something I liked and he would bring it home.

Many of these participants shared what was interpreted to be a more mutually considerate relationship with their spouse.

In comparison, some of the other participants reported that their spouses had not expressed any words of appreciation, in fact as one participant explained she did not believe her husband had any idea about the extent or challenge of the caregiving process. This woman acknowledged “I don’t think he even realizes today how difficult he was; I’m sure he doesn’t.” For another participant an acquaintance suggested to the care recipient that he might want to show his appreciation by buying a rose. However, when this did not happen the caregiver explained the omission by saying “that’s him, you know” and concluded, “I guess I have to accept it so maybe it’s a good thing, maybe when it’s the opposite way you know, then you start to wonder.” Both of these participants had relationships with their
spouses which were interpreted as being less mutually satisfying in character. Finally, a male participant who was questioned about whether his spouse had expressed her appreciation of the care he had provided seemed surprised by the question and stated, “No, (laughs) I don’t think she has, I didn’t expect her to really, it’s just one of the things you did and that was it but, um, obviously she appreciates some of the things I’ve done.” Since this participant saw caregiving as an expected part of his role he was not looking for any specific gestures or words of appreciation from his spouse.

To conclude, any rewards provided by taking on the caregiving role were not explicitly identified as influencing the participant’s experience until directly addressed by the researcher. Moreover, rewards of the caregiving experience were not prominent in the descriptions of the secondary participants even though at the time of the interview they were no longer caught up in the day to day caregiving process. The rewards were most frequently expressed in connection to the care recipient’s return to health. In addition, appreciation of the caregiver by the care recipient was, in the majority of instances, associated with the kind of relationship that the dyad shared.

**Summary**

In this chapter, the study findings were presented and interpreted based on the descriptions of the experience of eight caregivers who were involved in caring for an early discharged cardiac surgery patient. A schematic representation of the caregiving experience as revealed in the findings is found in Figure 1. The caregiver is represented by the object on the right while the focus of his/her care, the care recipient, is depicted by the object on the left. The top portions of both objects identify factors that influenced the caregiving
Figure 1: Schematic Representation of the Experience of Caring for an Early Discharged Cardiac Surgery Patient

- - - - - links milestones in the caregiving journey to the experience of caregiving
experience. The central influencing factor was the caregiver's and the care recipient's interpersonal relationship which is presented as a bridge between the two. The object depicting the experience of caregiving incorporates both the process of caregiving and the influence of the experience on the caregiver, while the object depicting the care recipient incorporates his/her experience with the disease. The care recipient's experience with the disease was often equated with significant milestones in the caregiving journey, and these milestones are linked by broken lines to the experience of caregiving. Any of these milestones could be the point at which the caregiving role was initiated. At the base of the schematic, the goal of caregiving, i.e. a return to normal, is depicted for both the caregiver and the care recipient. This return to normal is shown to arise from the care recipient's return to health, which was also one of the rewards of the caregiving experience.

In general, the experience is molded by the caregiver's past participation as a caregiver, as well as the caregiver's and care recipient's outlook on life and their interpersonal relationship. Previous experience with caregiving, an optimistic outlook towards life, and the existence of a more mutually considerate relationship between the caregiver and the care recipient helped to support the caregivers during the recovery process.

From the participant's frame of reference the caregiving experience was not always perceived as just the at-home recovery period but incorporated a number of other significant milestones in the recovery journey. The participants usually described their experience as it related to the care recipient's encounter with the disease process, diagnosis, surgery, in-hospital recovery and the at-home recovery period. For the participants, the at-home recovery
period was just one component of the continuum of the experience of being a caregiver for an early discharged cardiac surgery patient.

The participants engaged in the process of caregiving which could be conceptualized as the course that accompanied the care recipients', and often as a consequence, the caregivers’ return to normal. This process involved the work of caregiving including, being vigilant and monitoring the care recipient’s recovery; implementing strategies and techniques to assist the recovery process, and taking on a role to provide care and seek help as required. The focus of the caregivers’ vigilance and monitoring centered around the care recipients’ diet and exercise, and usually continued long term. Meanwhile, the strategies and techniques implemented to keep things on track were in most instances temporary in nature. Finally, a variety of resources were used by the participants in order to obtain help and information, but significantly, those participants who attended the preassessment clinic were less uncertain, and had an increased understanding of what to expect during the at-home recovery period.

The process of caregiving impacted the lives of all the caregivers in that they found the experience stressful and tiring, most often from a physical stance but also in some instances from a psychological perspective. The strain of caregiving was often noted to exacerbate the caregivers own health problems. Additionally, the experience provided the caregivers with feelings of vulnerability, and required that they put their life on hold, at least during the first eight weeks. Not all aspects of the experience, however, were perceived as being negative. For some caregivers the care recipient’s expected return to health and his/her appreciation of the care received were a part of the rewards associated with caregiving.

A discussion of the findings will be presented in chapter five.
CHAPTER FIVE: DISCUSSION

The purpose of this study was to increase nursing knowledge regarding the experience of being an informal caregiver of a cardiac surgery patient who had been discharged early from hospital. A qualitative research method, specifically an interpretive description approach, was used as a review of the literature identified only a limited body of knowledge on the role of informal caregivers of early discharged cardiac surgery patients.

The findings of this study indicate that the experience of caregiving is molded by the caregiver’s past participation as a caregiver, as well as the caregiver’s and care recipient’s outlook on life and their interpersonal relationship. The experience incorporated the process of caregiving which was comprised of three activities: vigilance/monitoring of the care recipient’s recovery, using strategies and techniques to keep things on track, and seeking help and support. These activities were directed towards a return to normal, involving the resumption of previous routines. The encounter with caregiving affected all realms of the caregivers’ lives, and the caregivers experienced feelings of stress, vulnerability, and being constrained. Positive experiences of caregiving included the care recipient’s return to health, and his/her appreciation of the care received (see Figure 1).

In this chapter, selected findings of the study will be discussed. Although each of the previously identified themes is crucial to the understanding of the informal caregiver’s experience, the discussion will be limited to those significant areas requiring additional explanation. The components which warrant more in-depth discussion are those related to: the work, goal and uncertainty of the caregiving experience; the ability of the informal caregiver to provide care; spousal relationships, and gender differences in caregiving. These
selected findings will be discussed in light of the related literature. Throughout this discussion implications for nursing practice and further research will be drawn. Additionally, the research method used in this study will be discussed and a summary of the findings will be presented.

**Discussion of Findings**

The findings from this study help to reaffirm existing knowledge described in the research and anecdotal literature concerning both caregiving and recovery from cardiac surgery. It is important to note, however, that the focus of the existing caregiving literature is primarily related to describing caring for the elderly and chronically sick. In contrast, the findings from this study help to enrich our understanding of caring for individuals with more acute health challenges. The caregivers’ stories in this study offer a profile of the experience of being a caregiver of an early discharged heart surgery patient which was not previously depicted.

Review of the findings of this study and the literature that addresses recovery from cardiac surgery suggest that while there are important agreements in the data, there are also key points of divergence to be considered. In the following discussion, the findings from this study that focus on the work, the goal, and the uncertainty of caring for an early discharged cardiac surgery patient will be discussed in light of selected allied research.

**The Work of Caregiving**

The types of work that were found to be central to the process of caregiving in this study (see Figure 1) are very similar to those identified in the framework developed by Gilliss and Belza (1992) to identify caregivers’ recovery work after cardiac surgery. Although the
terminology is different the process that has been identified in this study incorporates components described in the Gilliss and Belza framework. The framework components include "dimensions," such as scheduled and unscheduled activities; "strategies," such as nagging or encouraging the care recipient; and "types of work" including physical, monitoring, comfort, or support work. In this study the dimensions of caregiving work were either spoken about specially or alluded to by the participants. Despite the fact the interviews took place early in the recovery process, none of the caregivers described their involvement in specialized skills, such as taking vital signs, which were activities described in the Gilliss and Belza study. The strategies used by the caregivers in this study often included what they called encouragement and what they thought the care recipients might claim was nagging.

While the types of work described by Gilliss and Belza (1992) are evident in the findings of this study, the extent to which the work was accomplished was often restricted by the caregivers' physical and mental capabilities. In addition, there are also similarities between what Gilliss and Belza identified as caregiver problems and what in this study is described as the impact of the caregiving experience. For example, the problems noted by Gilliss and Belza often centered on the caregivers' feelings of being overwhelmed and uncertain which could be link to the feelings of being stressed, tired, restricted and uninformed described by the caregivers in this study.

The findings of this study and the framework described by Gilliss and Belza (1992) offer insights into the work and experience of being a family caregiver to cardiac surgery patients but because the study questions, time frames and methodology are different, the findings are presented using different nomenclature and structure. Together these studies provide nurses
of cardiac surgery patients with an understanding of the experience and work of being an informal caregiver of cardiac surgery patients that in turn can inform them in their work. Whether or not the findings of this study or Gilliss and Belza’s framework can be extended to informal caregivers who are involved during the recovery of patients experiencing other types of surgery will only be determined through future research.

The Goal of Caregiving

Maintaining normalcy and normalizing are components of the recovery process that are most frequently referred to in the literature in relation to the care recipient (Morse & Johnson, 1991; Tack & Gilliss, 1990). Care recipients often feel that progress is being made in the recovery process and there is a return to normal when they resume activities they were involved with prior to their diagnosis and surgery (Tack & Gilliss). This study, however, suggests that maintaining normalcy and normalizing is also important for the caregiver. The caregivers alluded to the idea that a return to normal was the goal of their caregiving experience (see Figure 1). The resumption of previous routines by both the care recipient and the caregiver were usually noted to be indicative of a return to normal. Thus, as the care recipient was well enough to start participating in presurgical activities, so the caregiver identified that he/she felt free to return to interests and activities of significance in his/her own life such as an exercise program.

The care recipient’s participation in normalizing events had implications for the caregivers in that they could now begin activities that addressed their own health needs. This step was significant since the caregivers were no longer required to put their own lives on hold. Consequently, the caregivers began to focus on their own welfare, and started to
overcome some of the physical and mental strain of their caregiving role. Thus, maintaining
normalcy by the care recipient reclaiming previous roles (Morse & Johnson, 1991), and
normalizing are important for the caregiver as well as the care recipient. A further
understanding of the rationale which leads caregivers to put many key aspects of their own
lives, such as exercise programs, on hold may provide valuable clues as to how nurses can
assist the caregivers find some balance. Hence, there is a need to seek ways to help the
caregivers address their own physical and mental health while they provide care for another.

There is also a contrast between the caregivers’ central goal of returning to normal in this
study, and the caregivers’ goals identified in the Gilliss and Belza (1992) framework. These
authors reported that the caregivers’ priority goal in the first week of the at-home recovery
was focused towards managing the illness. Although much of the caregivers’ experiences in
this study incorporated the work of managing the illness during the first week of the at-home
recovery, a return to normal was frequently alluded to as the goal of their caregiving. The
caregivers in this study focused on more long term outcomes which were not reported in the
Gilliss and Belza study. Clearly, this issue warrants further investigation.

Uncertainty

The caregivers in this study identified that having information that outlined the recovery
process and what to expect, helped to make their experience of caring for an early discharged
cardiac surgery patient less stressful and anxiety producing. The information helped to
reduce the uncertainty that surrounded the care recipients’ recovery. Redeker (1992) found a
strong relationship between uncertainty and avoidance coping, and what she referred to as
“wishful-thinking coping” (p. 49) for patients who had undergone cardiac surgery. The
findings in this present study suggest that the uncertainty experienced by the caregivers also influenced how they felt and dealt with the work of caregiving. Caregivers who did not receive enough information expressed concerns about not knowing what to expect, and not understanding what was normal. These caregivers often became either over or under vigilant in their caregiving roles.

Davis (1990) examined uncertainty as a concept in both recovering individuals and their family caregivers. She questioned if the family caregivers' stress was related more to coping with future uncertainties rather than uncertainties about the care recipient's past illness. The experience of the caregivers in the present study did not offer any support to this claim. The stress for the caregivers in this study seemed to be related to their uncertainty about knowing what to expect during their spouses' recovery from surgery, and not future uncertainties about their spouses' health. These caregivers did not discuss future uncertainties and identified that a focus on the care recipient's return to health was the primary reward associated with the caregiving experience.

The findings of this study also indicate that for some of the caregivers, information concerning the recovery process was not consistently available, and/or the learning environment was unsatisfactory. While other studies have identified that informal caregivers require information to help prepare them in providing at-home recovery care (Artinian, 1993; Bull & Jervis, 1997; Newton & Killien, 1988), and there are research findings that identify what and how the information should be provided (Cuppes, 1991; Newton & Killien, 1988; Wu, 1995), the findings from this study suggest that the needs of caregivers are not always met. This finding is not unforeseen in that researchers such as Mishel (1981) have observed
that while information seeking is a key activity which can lead to a reduction in uncertainty, there are often barriers within the health care environment to obtaining this information.

In this study most of the caregivers who felt prepared and knew what to expect indicated that they had attended the preassessment clinic where educational information had been supplied. Attendance at the preassessment clinic helped to reduce the uncertainty of the recovery process for these caregivers, however, for caregivers who lived some distance from the hospital, attendance at the clinic was not an option. It would seem reasonable to devote future research to understanding how attendance at the preassessment clinic helped to reduce uncertainty about the recovery process, and if there are other ways in which to provide this support to caregivers unable to attend the clinic.

One possible explanation for the focus that the caregivers in this study gave to their learning needs could be associated with Newton and Killien’s (1988) finding that the spouse’s learning needs occur earlier than those of the patient, often within the first week of the patient’s discharge. Since this study was conducted very early during the at-home recovery period the learning needs of the spouse caregivers may have been particularly evident. This finding points to the need for nurses of cardiac surgery patients to target and include the identified informal caregiver in teaching about recovery prior to the patient’s discharge.

**Uncertainty and early discharge.**

It remains unclear if early discharge exacerbates the uncertainty of patients and caregivers. While decreased length of stay may have the advantage of reducing iatrogenic complications and in-hospital health care costs, there are also disadvantages such as missed
physical and psychological symptoms in the care recipient (Brooten et al., 1988). For some of the caregivers in this current study this was the circumstance, and a lack of understanding of what was happening during the recovery process resulted in them being less vigilant in their caregiving roles. Consequently, two of the care recipients were rehospitalized as a result of initially unrecognized complications. To address the caregiver's need for information and support, a mechanism such as a telephone link to an identified nurse within the hospital or the community might be a first step.

Early discharge has also been noted to have a negative influence on learning (Sparacino, 1997), and to leave “families unprepared to manage patients so early in the recovery process” (Stengrevics, 1997 p. 53). In this study, having information that outlined the recovery process helped to make the caregiver's experience less stressful and anxiety producing. As noted previously, however, not all the participants felt they received sufficient information, and one participant specifically noted how the rush of discharge affected both her and her spouse's viewing of the informational video. Since the influence of early discharge on the informal caregiver's learning and preparation is unknown, further research in this area may provide a more solid understanding of how early discharge impacts the preparation and support of these significant individuals.

In summary, based on the findings of this study related to the work of caregiving it can be argued that this research reaffirms what has previously been described. Further, the study findings also suggest that the importance of maintaining normalcy, and normalizing might be broadened to include the caregiver as well as the care recipient. Additionally, since the
findings of this study identified that having information can positively affect the caregivers’ experiences, any barriers that restrict access to such information should be investigated.

**Ability to be a Caregiver**

The caregivers of early discharged cardiac surgery patients identified how the caregiving experienced influenced their lives (see Figure 1). The following discussion will consider how the impact of the experience, the temporal aspects of the experience and the caregivers’ expectations shaped their ability to be a caregiver. The similarities and the differences between findings in this study and those reported in both the literature on caring for more chronically ill care recipients, and that related to recovery from cardiac surgery will also be highlighted.

**Ability to be a caregiver and the impact of caregiving.**

The caregivers of early discharged heart surgery patients faced a number of challenges which affected them mentally, and physically. Some of the caregivers had their own health concerns which limited their ability to be a caregiver. Additionally, many found that they experienced difficulties in providing support to their spouses because their spouses were reluctant to accept direction from a non professional caregiver. In some instances, the caregiver lacked the knowledge of how to complete certain routine household tasks, and more critically, to recognize changes in the care recipients’ health status. Regardless, all these caregivers were noted by the professional health care providers to be supportive of their partners during their in-hospital recovery, and therefore considered suited to take on the role of caregiver after discharge.
The findings of this study suggest that the presumption that the presence of an attentive spouse during hospitalization of the cardiac surgery patient is indicative of his/her ability to be a caregiver at home is not necessarily sound. Unfortunately in practice this is often the assumption, and with very little research available the consequences of this assumption have to date gone undocumented. To explicate, the caregivers in this study despite being considered suited to take on the caregiver role described experiencing both mental and physical strain which in many instances exacerbated their own health problems.

The literature addressing caregiving for the elderly and those with chronic illnesses recognizes the informal caregivers for the valuable contribution that they make to the lives of the care recipients (Brackley, 1994; Boland & Sims, 1996; Lindgren, 1993). Similarly, the findings from this study point to the vital role that informal caregivers of cardiac surgery patients play in the recovery process. Consequently, it is important to ensure the caregivers’ well-being, and to avoid having them become patients themselves. Gilliss (1989) cautions that by focusing only on the patient and ignoring the family, the nurse unknowingly may add to the disorganization that occurs for the family during early recovery from cardiac illness. Additionally, Artinian (1993) when researching spouses’ perceptions of readiness for discharge after cardiac surgery recommended that “assessing spouses’ perceptions about their own health may cue nurses to spouses’ needs for additional support” (p.86). Thus, having knowledge about the caregiver of a cardiac surgery patient may begin to help nurses to identify what assistance the caregiver may need in order to take on the role.

Gilliss, Roberts, Highley and Martinson (1989) note that “the nature of families and their members is so intertwined that both will be affected by nursing care” (p.71). Inasmuch as
there is a move to know the patient as more than just a case (Liaschenko, 1997), an expansion of this practice to knowing the family member identified as the informal caregiver as a ‘person’ could be an important step in appraising the caregiver’s ability to provide care. To know a patient as a person implies knowing how that individual is "situated in and engages in the world .... what it means for the individual to have a specific history and live a particular life" (Liaschenko, 1997, p.27). The significance of knowing the person in nursing practice is related to helping the individual embrace life after disease and injury so helping to maintain the substance of their lives (Liaschenko). While there are issues such as intrusiveness, increased complexity of practice, and political factors to knowing the person (Liaschenko), the findings from this study suggest that more intimate knowledge of the caregivers than as just a presence during hospitalization would be beneficial. Knowing the person could assist nurses in assessing how caring for an early discharged heart surgery patient might impact the informal caregiver. In this way, some of the negative actual and potential outcomes of the experience might be reduced or avoided.

Ability to be a caregiver and temporal aspects.

Cardiac surgery patients caregivers’ ability to provide care may also be affected by both the point at which they are required to take on a more in-depth caregiving role, and also the duration of that role. The initial recovery period is a time when the care recipient is most likely to experience health problems (Redecker & Brassard, 1996), and provides little time for the caregivers of early discharged heart patients to gradually gain appreciation for their responsibility and role. In contrast, long term caregiving has been described as a career in which the caregiver may go through a phase of becoming "somewhat adjusted to the role and
establish[ing] routines for handling illness situations (Lindgren, 1992, p.216). The idea that the frustrations of caregiving may lessen over time is also noted by Motenko (1989). Motenko, who explored caregiving for family members with Alzheimer's disease, stressed that even though over time the care recipient may need increased care and have more severe symptoms “it is the initial disruptions in life style, expectations and plans that are frustrating” (Motenko, p.170). In question for caregivers of cardiac surgery patients is whether it is the severity of the care recipients’ health problems during the initial at-home recovery period and/or the newness of the caregiving role which affects their ability to be a caregiver. It would seem reasonable to devote further research to an understanding of these two factors and their affect on the caregivers abilities to provide care during the initial recovery period.

While the differences described above may start to point to the disparity between caring for an acutely ill and a chronically ill person, it should be stressed that there are other factors to be considered. One significant circumstance would appear to be the expectation that there will be some degree of recovery for the heart surgery care recipient. The expectation that the care recipient will make a recovery influenced the caregivers’ outlook in this current study and Gaynor’s (1990) study. Additionally, the lack of a positive outlook for the caregivers of elderly or chronically ill family members has been forecast to increase the perception of burden and resulting burnout (Almberg, Graftrom, & Winblad, 1997). All of these factors may provide a useful direction from which to not only explore the differences between caring for an individual with a chronic condition and one with more acute health challenges, but also to understand the effect of caregiver expectations on the experience of caregiving.
Ability to be a caregiver and expectations.

Caregivers are motivated by a variety of factors when adopting and pursuing a caregiving role (Globerman, 1996; Guberman, Maheu & Maille, 1992; Motenko, 1989). While motivation is a complex phenomenon, the findings of this study indicate that the expectation that their spouse would return to better health and that there would be a return to normal, assisted the caregivers with their caregiving role. In this study many participants alluded to the idea that the goal of caregiving was a return to normal, and a primary reward was the care recipient’s successful recovery (see Figure 1). These two components provided a positive focus for the caregivers and helped to give meaning to the situation.

The caregivers’ expectations in this study are similar to those identified by Gaynor (1990). She discovered that for a portion of her sample of caregivers the stress of caregiving was found to be mediated by the expectation that the care recipient would recover, and that the caregiving responsibilities and tasks would come to an end. In Gaynor’s study this caregiver group were spousal caregivers of husbands who underwent minimally invasive surgery for removal of the prostate, and so were similar to the participants of this investigation in that they were involved with caring for individuals with more acute health challenges.

In much of the health literature, in which ideas concerning an individual’s expectations are discussed, the focus of the deliberation is most often in relation to disease prevention and health promotion (Faulkner, 1997; Fleury, 1992; Strecher, DeVellis, Becker & Rosenstock, 1986). Many of these authors refer to the research by Bandura (1977) whose social learning theory hypothesizes that behaviors are contingent upon outcome expectations, the
individual’s belief that a behavior will lead to a certain outcome, and efficacy expectations, the individual’s belief that they have the personal capability to engage in the behavior needed to produce the outcome. Bandura also proposes that in stressful situations that given the incentive and the skills, an individual’s efficacy expectations will determine the amount and sustainment of effort to handle the situation. The findings from this study depicted the caregivers’ outcome expectations, however, their efficacy expectations were not as evident. At question is whether the caregivers believed their actions would make a difference, and to what extent these expectations are predictive of the caregivers’ stamina for their caregiving role. Certainly, more research is warranted in this area if the role of expectations in relation to the caregivers’ ability to provide care is to be better understood.

Although the expectations that there will be a return to normal, and the care recipients’ health will improve, were a positive foci for the caregivers in the early recovery period, it is important to consider how realistic these expectations might be over the long term. Redeker (1992) acknowledges that “although CABS [coronary artery bypass surgery] is not presented as a cure for coronary artery disease, many may perceive it to be curative and have high expectations for improved quality of life, in terms of activity status and freedom from angina” (p.68). For the caregivers in this study these high expectations certainly existed even though the long term outlook was unknown. It remains undetermined whether all caregivers of early discharged heart patients are able to sustain these expectations over time.

At the same time, it has been argued that having heart disease that requires surgery constitutes a chronic condition with its associated uncertainties (Moore, 1994; Redeker, 1992). Consequently, the caregivers in this study may be faced with becoming long-term
caregivers of a chronically ill spouse. Caring for individuals with a chronic illness with little or no hope of any recovery has been described as requiring a spirit of heroism in the nurse (Lanara, 1991). This need for a spirit of heroism could be even greater in informal caregivers who are often more emotionally attached to the care recipient, and where the need to continue to care “with faith and hope, without despair” (Lanara, P.51) may present challenges of unknown proportions. Only through further investigation will a better understanding of the experience of being the informal caregiver of a heart surgery patient over time be revealed.

The caregivers expectations from this study are also noteworthy when contrasted with the literature that addressed caregiving for elderly and chronically ill individuals. Gaynor, (1990) emphasized that for long-term caregivers the expectation that their spouse’s health would improve was unrealistic. Additionally, the affect of caring for an elderly or chronically ill family member often resulted in feelings of stress and burden for the caregivers in terms of mental, physical and social factors (Baille, Norbeck, & Barnes, 1988: Barusch, 1988, Gaynor, 1990; Lindgren, 1993). These feelings are not expected to decrease with time. Consequently, long term caregiving is noted to increase the risk for the caregivers’ physical and psychological health. For the caregivers in this study, the expected recovery of the care recipient, and a return to normal early in the caregiving process were prominent positive foci not available for caregivers of chronically ill individuals. What remains unclear is to what extent these expectations may help to mediate some of the caregivers’ potential health problems. Further research in this area may provide a more solid understanding of the importance of such expectations.
Thus, the caregiver’s ability to provide care has a number of dimensions, and the presence of a family member during the in-hospital recovery period is not necessarily indicative of his/her ability to be a caregiver. The challenge for nurses is to know the caregiver as a person, and to recognize not only his/her physical and mental stresses but also his/her expectations and motivations to care. Additionally, the acuity of the care recipient during the initial at-home recovery period, and the lack of time available for the caregiver to become familiar with his/her role and responsibility may also influence his/her ability to be a caregiver.

The final components of the caregiving experience to be discussed are those which relate to spousal relationships and gender differences in caregiving. The spousal relationship is significant in that it was one of the primary factors which influenced the caregivers’ experience (see Figure 1), while the gender differences related to how the experience was described and perceived by the caregivers.

Spousal relationships

The spousal relationship was revealed as a component that influenced the caregiving experience. The findings of this study indicated that a mutually considerate relationship helped to support the caregivers in their role, while a less considerate relationship could thwart the caregivers’ efforts. While this study’s findings suggested that it is the spousal relationship that exists prior to surgery that influences the experience of the caregiver during the at-home recovery process, consideration should also be given to the affect that the stress of caregiving may have on the spousal relationship. In previous research conducted to understanding family caregivers’ work after cardiac surgery, Gilliss and Belza (1992)
reported that dyad’s relationship was negatively affected by the strain of the recovery work. These researchers noted that the relationship difficulties occurred as a result of the dyad’s inability to “smoothly coordinate their management of the work of recovery” (p. 46).

Artinian (1991) also reported how the stress of caretaking responsibilities for spouses of cardiac surgery patients negatively affected the marital relationship six weeks after discharge. Artinian did, however, caution that in her study the marital relationship that existed preoperatively was unknown and therefore her findings should be viewed with caution. Such a caution is also applicable to this study’s findings, and the question of whether the preexisting relationship or the stress of caretaking has the greatest impact on the caregiving experience therefore remains unknown.

Inasmuch as the findings of this study are focused on the caregiving experience during the first seven days after discharge, this time factor may have resulted in the caregivers describing particularly high levels of stress. This claim that mental and physical stress are greatest during the early days of the recovery period has been supported by Artinian (1991) who exposed how the mental and physical symptoms of stress in women caregivers of cardiac surgery patients were greatest during hospitalization and reduced over time during the recovery period. Hence, the level of stress for the caregivers in this study during the early days of the at-home recovery may also have served as a factor that negatively influenced the marital relationship.

Other studies that have examined the relationship between the caregiver and the care recipient as an aspect of the caregiving context, have involved the caregivers of chronically ill and mentally impaired patients (George & Gwyther, 1986; Monahan & Hooker, 1995;
Robinson, 1990). These studies focused on caregiver burden and well-being, and suggested that both the caregivers' perception of burden and their well-being are impacted by the dyad's relationship. Robinson specifically noted that previous positive relationships predicted less burden, where burden is defined as both the disruptions to the caregiver's life and the caregiver's reactions to the experience.

The current study, with informal caregivers of more acutely ill patients, also provides support for the claim that many caregivers encounter feelings of burden. The caregivers found the experience of caring for an early discharged cardiac surgery patient stressful and tiring, and were required to put their lives on hold. Since both the preexisting marital relationship and the burden of caregiving might have affected the caregiving experience, a study that examines the dyad's preexisting relationship and the influence of the recovery work on that relationship warrants further investigation. Additionally, research that considers the factors identified above in both spousal and non spousal caregivers' relationships could lead to an increased understanding of the experience of being an informal caregiver to an early discharged surgery patient.

While the spousal relationship was noted to be a pivotal factor in the caregivers' experiences, a more subtle finding related to some of the gender differences in the caregiving experience. The lack of prominence of gender differences in the overall representation of the findings was most likely because of the limited number of male caregivers available to describe their experiences. However, these differences do warrant discussion especially since the number of women undergoing heart surgery is increasing (Artinian & Duggan, 1995).
Additionally, not only do women’s recovery experiences from heart surgery differ from those of men, but male’s experiences of caregiving also contrast with those of females.

**Gender differences in caregiving**

The findings from this study suggest that the experiences of women as caregivers may differ from those of the men. The male participants were not only more reticent and objective when discussing their experiences of caregiving, but the male caregivers also emphasized that their wives either did not complain, or were eager to progress in the recovery process.

While much of the previous research concerning recovery from cardiac surgery has focused predominantly on men (King & Gortner, 1996), any research findings from more recent studies concerning functional and psychosocial outcomes in women are contradictory (Cronin, Logsdon & Moracle, 1997).

The expressed idea that the female care recipients in this study did not complain and were keen to progress in the recovery process is supported by previous research findings. Cronin, Logsdon and Moracle, (1997) found that following CABG surgery female patients “seemed to be coping well postoperatively, with little depression and tension” (p. 22). At the same time, King and Gortner (1996) found that women’s perceptions of their progress in the recovery process occurred before objective measures of their functioning abilities showed parallel advancement. These perceptions could account for this study’s findings that the female care recipients were keen to progress in the recovery process. To this end, discharge information for male caregivers of female care recipients should acknowledge that the recovery process for women is often different from that of men. The information should also
outline realistic expectations and experiences for both the female care recipient and the male caregiver.

Whereas, the difference in being a caregiver for a female spouse following cardiac surgery might be partially explained by the variations between men and women during the recovery process, any kind of caregiving experiences of men have also received little attention (Parsons, 1997). The research on male caregivers is not only limited but is also contradictory producing more questions than answers (Harris, 1993). Regardless, Parsons, in a recent study of male caregivers of family members with Alzheimer’s disease, concluded that the caregiving experience “had a major impact on the caregivers and was of great significance in reshaping the way these men viewed their experience of being in the world” (p.406). Further research in this area may provide a more solid understanding of the experiences of male caregivers, and specifically those of early discharged cardiac surgery patients.

In summary, selected findings have been discussed. This study’s findings related to the process of caregiving, confirm findings described in existing research related to a framework for caregiver work following cardiac surgery. The goal of caregiving in this study, however, contrasts with caregiver goals described in the same framework. Regardless, the findings do suggest that the goal of maintaining normalcy and normalizing might be broadened from the care recipient to include the caregiver.

The concept of uncertainty in these findings was associated with not having information about the recovery period. Possible barriers that prevented the caregivers from being
informed were discussed. These barriers included both a lack of an option for attending the preassessment clinic for out of town caregivers, and factors associated with early discharge.

The study findings also indicated that the presence of an attentive spouse during the patient’s hospitalization is not necessarily indicative of his/her ability to be a caregiver. The physical and mental affects of caregiving may restrict the caregiver from providing care and/or exacerbate the caregiver’s own health problems. Knowing the caregiver as a person is one suggestion for beginning to assess the caregiver’s ability to provide care.

Additionally, temporal aspect may modify the caregiver’s ability to provide care. For caregivers of cardiac surgery patients, the point at which the focus of the care increases is one where the acuity of the care recipient is often highest. The caregivers also had little or no time to become familiar with their new role and responsibilities. These components might make caring for a more acutely ill individual different from caring for a chronically ill person.

The influence of expectations on the caregivers’ ability to provide care was also considered in light of the existing research. While outcome expectations were evident in this study, the effect of efficacy expectations was less apparent. A question that remains to be addressed is the extent to which one or both of these expectations may influence the caregivers’ motivational ability to provide care. The possible unrealistic nature of the expectations identified in the study was also questioned, since the care recipients all had what has been described as a chronic condition with all its associated implications.

Finally, the discussion of the findings included consideration of whether it is the preexisting spousal relationship or the stress of the caregiving experience that affects the
caregivers' experience of caregiving. This factor remains ambiguous. The findings, however, do help to expand understanding of gender differences in caregiving in that the description and perceptions of the experience seemed to vary between male and female caregivers.

Thus, the study findings reaffirm components of what is already known about the caregiving experience. At the same time, the findings also help to expand knowledge about the experience of being a caregiver for an early discharged heart surgery patient.

Discussion of Research Method

In order to accomplish the objectives of this study an interpretive description approach was used as it provided a rigorous methodology that is specific to addressing nursing’s unique knowledge mandate. This approach provided direction for eliciting and analyzing the cardiac surgery patient caregiver’s perspective. Use of this method resulted in both a description of the experience and an interpretation of that experience, which is linked to existing nursing knowledge and practice. At the same time, knowledge of the experience is presented in a way that is general enough but does not negate the individual experience. The purpose of this section is to discuss the limitations of the findings.

Certain limitations to this study need to be taken into account as the findings are considered. The limitations of this study relate to the transferability and the credibility of the findings. While the goal of the study does not include generalizability of the findings, the fittingness outside the study situation is limited by the context of the study, and the homogeneity of the sample. The findings represent the experience of caring for an early discharged cardiac surgery patient from one specific hospital setting only. The volunteer nature of the sample further limits the generalizability of the study findings. Additionally, the
study is limited to describing the experiences of husband and wife dyads and, therefore, the findings are not transferable to other family or non-family members as caregivers.

Johnson (1997) makes a distinction in qualitative research between horizontal generalizability, which is considered in the above discussion, and vertical generalizability. While horizontal generalizability is concerned with the extent to which the findings can be applied across settings, vertical generalizability refers to how the findings help to enrich others' understanding of existing knowledge (Johnson). Vertical generalizability is achieved by linking study findings with the work of others, and in asking questions that will indicate how the findings advance knowledge related to concepts/theories that have been defined for use within the nursing discipline (Johnson). The interpretive description method used for this study permitted achievement of these criteria. In discussing the findings it was possible to move beyond a description of patterns within the caregiving experience, to an interpretation of the similarity and differences of those patterns in relation to the work of other researchers and scholars. Additionally, insights were suggested about specific concepts/theories within the nursing discipline, for example, uncertainty as a concept in reference to caregivers of early discharged cardiac surgery patients. Thus, while the findings from this study are limited in relation to horizontal generalizability, they do meet the criteria for vertical generalizability in that the findings help to add another layer to nursing's understanding of the experience of being a caregiver for an early discharged cardiac surgery patient.

An additional component related to generalizability concerns the question of whether the responsibility for determining the relevance and use of research findings rests solely with the researcher. Johnson (1997) argues that both the researcher and the consumers of the
research study findings have a responsibility in considering the use of the finding to inform practice. A key objective in qualitative research is to stimulate discussion among all potential users of the findings. Consequently, while this researcher has attempted to discuss the generalizability of the research findings, it also important for those individuals who are consumers of these findings to discuss the results, and consider their applicability within their own practice.

The homogeneity of the sample also presents a limitation in that there is an absence of younger aged participants as caregivers. Although consideration was given to this omission as the study progressed no individuals in this category volunteered to participate during the time frame of the study. A lack of time was often identified as one of the main deterrents as these younger individuals often had full time jobs and child rearing responsibilities. The voice of these younger aged individuals therefore remains unheard.

Furthermore, although several strategies were employed to accomplish the use of multiple methods to address the research question, the use of the semistructured diary was confined to just two of the participants. Additionally, there was finite use of collateral data sources such as "...a body of lay literature or other media information as well as nursing case reports and clinical papers..." (Thorne, Kirkham & MacDonald-Emes, 1997, p. 174). More extensive use of such data sources would have expanded the information base thereby strengthening the generation of practice knowledge. The use of multiple data sources was therefore repressed to some extent with the result that credibility of the findings may have been impacted. As with all qualitative studies, although this study offers an interpretation of the experiences of a
specific group of eight caregivers of early discharged cardiac surgery patients; the findings cannot be seen as representative of the experiences of all caregivers.

Finally, although the interpretive description method was advanced based on the claim that nurse researchers have been conducting research that uses similar principles without a sound theoretical foundation (S. Thorne personal communication, November 24, 1997), this researcher and her committee occasionally struggled with what the research report would encompass. In evaluating this and other qualitative research, however, it is important to focus the evaluation on specific criteria that include: epistemological integrity, representative credibility, analytic logic, and interpretive authority (Thorne, 1997).

By using an interpretive description method designed for developing nursing knowledge, this study sought to achieve epistemological integrity. Although some limitations were noted, there was also an attempt to use multiple data sources in order to address the criteria of representative credibility. Analytic logic was approached by providing an audit trail for another researcher to follow, and by using verbatim accounts from the participants in the study findings which permitted thick description. Finally, interpretive authority was achieved by completing second interviews with the participants. The second interviews allowed the participants to refute or confirm the evolving interpretation of being a caregiver for an early discharged cardiac surgery patient. As nurses become more familiar with the interpretive description method it will be interesting to see how its utility for developing nursing knowledge is embraced.
Summary

As family members/informal caregivers of post-surgical patients are, by necessity, taking on the caregiving role sooner without any specified reallocation of resources to support them, nurses need to understand their concerns, needs, struggles and rewards. The focus of this study was therefore to increase nursing knowledge regarding the experience of being an informal caregiver of a cardiac surgery patient who had been discharged early from hospital.

The findings from this study suggested that the experience was molded by the caregiver’s past participation as a caregiver, as well as the caregiver’s and the care recipient’s outlook on life and their interpersonal relationship. For the caregivers, the at-home recovery period was just one milestone in the overall experience which included the care recipient’s encounter with the disease process, diagnosis, surgery, in-hospital recovery, as well as the at-home recovery period.

The caregiver engaged in a process of caregiving which could be conceptualized as the course that accompanied the care recipient’s and often as a consequence the caregiver’s return to normal. The process of caregiving involved: being vigilant and monitoring the care recipient’s recovery; implementing strategies and techniques to assist the recovery process, and taking on a role to provide care and seek help as required.

This process of caregiving affected the lives of the caregivers in that they found the experience stressful and tiring. Additionally, the experience provided the caregivers with feelings of vulnerability, and required that they put their lives on hold. Not all aspects of the experience, however, were perceived as being negative. For some caregivers the care
recipient’s return to health and his/her appreciation of the care received were part of the rewards associated with caring for an early discharged cardiac surgery patient.

It is hoped that this preliminary study will form a basis for future research including a study which examines the difference between the experience of female and male caregivers. Other suggestions for inquiry include an examination of the impact of spousal relationships on the caregiving experience; the experience of male caregivers of more acutely ill care recipients; the influence of the preassessment clinic on the caregiver’s knowledge of the recovery process; and the role of expectations in affecting the caregiving experience and the caregivers’ ability to provide care.

The findings of this study also suggest ways in which nurses can intervene to help informal caregivers take on the role and responsibilities of being an informal caregiver of an early discharged cardiac surgery patient. This intervention is essential in order to maintain the health and well-being of the caregiver, and to help prevent the caregivers themselves from becoming patients. While direct intervention with the caregivers is an important first step, nurses also need to be proactive in recognizing the contribution made by informal caregivers to the health of individuals. As the early discharge of surgical patients increases, nurses are in a position to advocate for the caregivers with the policy makers so that the necessary resources and supports will be made available to them.
REFERENCES


APPENDIX A

Journal or Oral Diary Questions

The participants (informal caregivers) will be requested to write or comment on the following questions every two to three days during the first seven days after the cardiac surgery patient is discharged from the hospital.

1. How has the caregiving experience been for you today?
2. What most worries or concerns you?
3. How have you managed the day? (consider any changes in usual routines, time for work or recreation, relationship with other family/friends)
4. What are some of your successes?