Transitions in Caregiving: Rural Caregivers' Experience of Waiting for One's Family Member to be Admitted to a Personal Care Home

By

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ABSTRACT

The purpose of this study was to describe and understand the caregiver's experience of waiting for his/her family member to be admitted to a personal care home (PCH). An exploratory and descriptive mode of inquiry was the approach undertaken. Families are often faced with relocating an older family member to a nursing home. These caregivers experience a wide range of emotions during this period. This phenomenon is of interest to nurses as knowledge development of appropriate care and intervention strategies are a prerequisite in addressing caregiver needs. The goal of this study was to explore and describe the rural caregiver's experience of having his/her care-recipient wait for a PCH "bed offer" and complete the admission to PCH. Transition Theory guided this inquiry. Literature that described the events encountered by family caregivers as they planned for PCH admission and the post-admission of the care-recipient was presented. Ethical considerations and precautions were included in the discussion of the research method.

A qualitative method (person-centered interviewing) using a prospective design informed the topic of the caregiver's experience of waiting. Data were collected through a semi-structured interview guide over two time periods. Ten participants were recruited and interviewed for this prospective study. A total of eighteen interviews were completed. Interviews were conducted over two time periods. Time 1 was the "waiting for admission" interview and Time 2 was the "post-admission or post-decline" interview. Data analysis revealed three key areas. The first area described the caregiver's experience of waiting for a PCH bed offer. The second key area presented the caregiver's experience of receiving the bed offer and accompanying the care-recipient on

admission day. The third area presented the caregiver's anticipated experience of what the admission day would be like compared to the actual admission day experience. Recommendations for future research and innovations in nursing interventions are suggested.

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CHAPTER I

STATEMENT OF THE RESEARCH PURPOSE AND OBJECTIVES

Introduction

Older family members may need to be admitted to a personal care home (PCH) when the resources of their family caregivers have been exhausted. Earlier studies have identified that family caregivers (or carers) experience considerable distress and guilt during this major family life-change event (Brody, 1985; Dellasega, 1991; Dellasega & Mastrian, 1995; Johnson & Werner, 1982; King, Collin, Given & Vredevoogd, 1991; Nolan & Dellasega, 1999, 2000; Nolan, Walker, Nolan, Williams, Poland, Curran & Kent, 1996; Penrod & Dellasega, 1998; Tipton-Smith, 1995). Family caregivers have reported significant emotional turmoil, uncertainty, conflict and crisis escalation during this transition from home-based care to facility care of their older family member (Dellasega & Mastrian, 1995; Johnson, Morton & Knox, 1992; Nolan & Dellasega, 2000).

The wait for PCH admission is unpredictable in rural long term care (LTC) facilities in Manitoba. Family caregivers do not know when a bed will become available or be offered to their older family member. Family carers in rural settings anticipate and encounter additional challenges when their older family member is waiting for admission to PCH. Resources such as Home Care services may be unavailable or minimal (Cuellar & Butts, 1999). The nearest PCH can be many kilometers away from the home community resulting in considerable travel burden for family caregivers during the preparatory phase of admission (Kelly & Maclean, 1997). Little is known of the rural

family caregiver's experience of waiting for PCH admission for their older family member once the decision for placement has been made.

This study complements and extends past studies on family caregiver's experience of Personal Care Home admission for their older family member. Previous studies have focused almost exclusively on caregivers in urban settings (Brody & Schoonover, 1980; Brody, Kleban, Johnsen, Hoffman & Schoonover,1987; Dellasega & Mastrian, 1995; Nolan et al., 1996). Past research has used a retrospective approach when collecting data on the event (Kellett, 1999; Nolan & Dellasega, 2000; Rodgers, 1997). The experiences of rural family caregivers awaiting notification and admission of their older family member to a personal care home is virtually unknown. A qualitative approach was used to understand the family caregiver's perspective of this life-changing event. Transition theory as proposed by Meleis, Sawyer, Im, Messias, and Schumacher (2000) served as the conceptual framework for this study.

Background Information

Nurse Case Coordinators (Home Care Program) and Discharge Coordinator Nurses (Acute Care) spend many hours working with family caregivers in planning care for their older family member who may have cognitive and/or physical impairments. One aspect of the care plan is the family's decision to make application to a personal care home for the purpose of admission of their elder. Once an application is completed by the Nurse Case Coordinator and family physician, it is then ready to be presented to a panel (of experts) who carefully review the eligibility of the applicant. In Manitoba, if the applicant is eligible, then his/her's name is placed on the waiting list(s) of the PCH of choice. Most PCH facilities conduct a pre-admission visit and invite the caregivers and

elder for a tour. Caregivers and care-recipients remain waiting for a bed offer depending on when a vacancy is created. The arrival date of the bed offer is unknown due to the manner in which a vacancy occurs. An admission date is negotiated once a bed becomes available for the elder. Many caregivers accept the PCH bed offer. Infrequently, the best-laid plans disintegrate when the caregivers decline the offer of PCH admission for their older family member. Caregivers may venture that the elder family member is just not ready for a nursing home admission. Reasons or rationale for declining a bed offer are mostly unknown.

Nurse Case Coordinators in the Home Care Program have on many occasions commented on how difficult the waiting period is for some caregivers. The family caregivers express much uncertainty about their decision to have their family elder admitted to personal care home (PCH). At times, it seems the longer the wait, the more conflict and uncertainty is expressed. Caregivers are less likely to accept a PCH bed if the elder remains opposed to the admission. Nurse Case Coordinators have identified these concerns arising from clinical practice.

A case example serves to illuminate this concern. A Nurse Case Coordinator had made application for PCH admission on behalf of an elderly married couple. The main caregiver for this couple was their daughter who lived near them. The daughter chose a PCH with a long waiting list. The Nurse Case Coordinator found that planning care and collaborating with the main caregiver was replete with challenges. Later, the daughter asked that her parents' name be placed on the waiting list of a PCH, which was known to have a short waiting list. Two beds in the short-listed PCH became available at the same time and the couple could be admitted together. The PCH facility completed the

necessary documentation and the nursing staff developed new admission care plans for the couple. The pair were admitted and settled in their room. Within 24 hours the daughter changed her mind, arrived at the PCH and had both parents discharged. The daughter had both parents move in to her home after discharge. The Director of Nursing services of the PCH, the Nurse Case Coordinator (Home Care), and the PCH Waiting List Coordinator discussed this situation at great length. Concern was expressed about the nature of the daughter's dilemma and continuing uncertainty over her decision in regards to PCH admission for her parents. The nurses involved in this situation reflected on how difficult it must be for some caregivers to wait for their older family members to be admitted and then to encounter the admission day.

Significance of the Problem

Caregivers are often faced with having to relocate their older family member to personal care home (PCH) when their personal care and health needs exceed the caregiver's resources. Relocation to a PCH is often a stressful life event for family caregivers and elders (Dellasega & Nolan, 1997; Johnson, Morton & Knox, 1992). Family caregivers may experience or anticipate a crisis situation when admission day to PCH is inevitable.

Considerable nursing staff time is dedicated to collaboration with family caregivers and elders in the PCH application and admission process. An admission to PCH for a family elder becomes imminent once all the necessary documentation has been completed and a bed has been held. If formal Home Care is involved then these services will have a planned termination date to correspond with PCH admission time. Many admissions to PCH occur as a seamless transition from home or hospital to PCH (Courts,

Barba & Tesh, 2001). At other times, this anticipated transition event becomes difficult for caregivers (Zarit & Whitlatch, 1992). Some caregivers have experienced uncertainty and hesitation in continuing with plans of the PCH admission for the elder. At the last minute (or a few days prior to scheduled admission date), the family caregivers may decline the bed offer. The caregivers decide to continue with home-based care rather than institutional care. The hasty withdrawal of entry of an elder to a PCH causes delayed admissions of other elders who may be in desperate need of a PCH bed. Other effects of declined admission are:

1. scheduling difficulties in re-establishing home care services;
2. unproductive nursing staff time which has been focused at completing, presenting and updating the elder's personal care home application as well as preparing caregivers and elder for PCH admission;
3. nursing staff expressing feelings of uncertainty on how to collaborate with care-recipient and caregiver at time of bed decline and return or remaining in home;
4. caregivers feeling pressure to continue home-based care even though it may affect their own well-being; and
5. lengthy hospital/acute care stays result as alternatives to facility-based long term care service.

Nurse Case Coordinators need to be aware of family caregiver's perceptions of this event, validate feelings expressed, and provide support to families as they progress through this caregiving transition event. PCH nurses work with family caregivers during the nursing home admission process. Many times elders are admitted to PCH directly from acute care facilities. Acute care nurses may be

involved in planning the relocation event with families and elders. Nurses working in these varied practice areas are in a position to provide support and be sensitive to the needs of the family caregivers as part of the older family member's caregiving network.

Positive outcomes of nursing interventions would be evidenced by decreases in intensity of negative or distressing feelings experienced by caregivers, increase in knowledge on caregiver role changes, a reduced number of declined PCH bed offers by caregivers and caregivers feeling prepared to participate in the PCH admission event. Further knowledge development of this transition event will guide nurses in developing more appropriate interventions to meet the needs of caregivers and their elders.

Purpose

The purpose of this study was to explore and describe the experience of rural family caregivers during the waiting period and actual admission of their older family member to a personal care home. The family caregiver's experience was explored following the decision that admission to PCH was necessary to approximately two weeks after actual admission to PCH or withdrawal of application from PCH waiting list occurred.

Objectives

The objectives of this research were to:

1. Explore the experiences, views and feelings of rural family caregivers when their elder is waiting for notification of a PCH admission.
2. Describe the rural family caregiver's perceptions when faced with waiting for PCH admission for their elder.

3. Describe the rural family caregiver's views and feelings as they prepare their elder for the admission day or process.
4. Describe the rural family caregiver's feelings and concerns during and shortly after the admission process.
5. Develop and identify recommendations for future nursing practice and research in family caregiver and elder transition events related to anticipated relocation to personal care home.

Problem Statement

The problem statement framed in an inquiry form is: What is the rural family caregiver's experience of the waiting period and actual admission event of their care-recipient to a personal care home?

Research Questions

The following research questions regarding the waiting period and admission event will be addressed:

1. What is the nature of the experience of waiting for notification of actual admission to PCH of one's care-recipient?
2. What is the nature of the experience of the rural family caregiver when they plan and are faced with preparing one's care-recipient for the actual admission (to PCH) day?
3. What is the experience like for rural caregivers when accompanying and assisting the care-recipient during the day of admission to PCH?
4. What is the nature of the feelings and concerns rural caregivers have upon leaving one's care-recipient and departing from the PCH on day of admission?

Parameters of this Study

The study was conducted in the rural and town regions of a Rural Regional Health Authority (RRHA) of Manitoba. The geographic borders were the same as those covered by the RRHA. Please refer to the Rural Regional Health Authorities (RRHA) map of Manitoba in Appendix A, page 195, for a visual location of the RRHAs within the Province of Manitoba.

The PCH that the older family member made application to or was admitted to was one located in Manitoba. PCHs selected by family participants had a waiting time of approximately three to six months duration.

Definitions

The following is a list of definitions and clarification of abbreviations used in the body of this document.

Acute Care Facility – this term refers to hospitals that provide acute care services. Care-recipients may be admitted to a hospital for acute care services until they become medically stable. Once stable, the care-recipient is discharged from acute care status and may remain in hospital pending admission to PCH.

Caregivers or Carers or Participants– refers to the identified caregiver (participant) for the care-recipient; can be spouse, adult children, niece, nephew, grandchildren or other individual identified as involved caregiver to care recipient; role can be one of direct and/or indirect care provision.

Care-recipient or Older Family Member or Elder – this term refers to the care recipient or family member who has applied and has been accepted on a waiting list for a Personal Care Home; it also refers to the individual receiving care from the caregiver.

Discharge Coordinator (DC) – Hospital discharge coordinator nurse responsible for discharge planning from the acute care facility.

Home Care Coordinator (HCC) – Nurse or Social Worker responsible for carrying out the professional tasks and responsibilities of the Manitoba Home Care Program.

Home Care Services – this term identifies formal services (public and private) that are provided in the older family member's home, this includes services such as home care aide or support worker, and/or direct nursing services.

RRHA – Rural Regional Health Authority located in Manitoba.

Long Term Care (LTC) facility – this term refers to and includes Personal Care Home Services and Chronic Care facilities or Extended Care. The facility is designated to provide services that encompass a lengthy need for nursing services. Long Term Care is viewed as part of the continuum of care services for elders.

Panel – Committee of health professionals who review applications/assessments for personal care home eligibility, this committee meets on a regular basis; this term also refers to the actual process (paneling) of determining eligibility for PCH.

Personal Care Home (PCH) or Nursing Home – this term refers to and includes nursing home services that are provided in a Long Term Care (LTC) facility. The PCH is staffed with Registered Nurses, Licensed Practical Nurses and Nurses Aides.

Summary of Chapter I

Chapter I presented the rationale for further research on the experience of caregiver's who are waiting for an admission to PCH of their care-recipient. Nurses often come in contact with caregivers at some point during this time period. At the time of the PCH bed offer families either accept, postpone, or decline the tentative PCH admission. The purpose of this study was to explore and describe the experience of waiting for a PCH bed offer and the admission day experience. Of particular interest, this study examined the experience of rural caregivers.

CHAPTER II

LITERATURE REVIEW

The literature review examines the guiding conceptual framework and transition events experienced by family caregivers during the pre-admission period and admission of their care-recipient to Personal Care Home (PCH). The conceptual framework that guided this study was Transition Theory. Literature describing four aspects of the caregiving experience of waiting for a "bed offer" and PCH admission was reviewed. The four aspects were: (1) factors influencing family decision to apply for PCH (2) waiting for notification of an available PCH bed (3) planning for admission to PCH (4) caregiver's perception of the admission day and post-placement experience.

Conceptual Framework

Polit and Hungler (1999) recommend the development of nursing research within a conceptual or theoretical context. The theoretical perspective of this study was drawn from Meleis, Sawyer, Im, Messias, and Schumacher's (2000) Transition Theory. Transition was defined by Chick and Meleis (1986, Chinn, Eds.) as "... passage from one life phases, condition, or status to another, is a multiple concept embracing the elements of process, time span, and perception." (p.239). The structure of a transition surround three phases: entry, passage and exit. Completion of a transition usually occurs when a period of greater stability returns (Meleis & Trangenstein, 1994). The major concepts of Transition Theory are presented along with the relationships between components. Research that has used Transition Theory as a guiding conceptual framework or conceptual theme was incorporated into this discussion. The applicability of this framework for caregiver research is also introduced.

Four Main Concepts of Transition Theory

Transition Theory encompasses the following four major concepts: nature of transitions, transition conditions (facilitators and inhibitors), patterns of response and nursing therapeutics. Please refer to Appendix B, p.197, for a visual presentation of Transition Theory (Meleis et al., 2000). Well-being is the goal or desired outcome of transition. Transition Theory proposes that nurse-client encounters most often occur during periods of transition such as becoming a new parent or admission to a nursing home. These transition periods are characterized by periods of instability, vulnerability, uncertainty and fractured realities (Meleis & Trangenstein, 1994; Selder, 1995)). Pearlin (1992) and Lindgren (1993) identified the transition of caregiving by progression through the phases of the caregiving career. Family caregivers may encounter and experience many changes as they wait for their care-recipient to be admitted and settled into a PCH.

Nature of Transition

The major concept of Nature of Transition encompasses three components: types, patterns and properties of transitions. A combination of these components influences the transition conditions (facilitators and inhibitor of the transition) and nursing therapeutics.

Types. Meleis et al. (2000) described four types of transitions: developmental, situational, health/illness and organizational. These transitions can occur on the individual, dyadic, family or organizational level. The first type, ***developmental***, refers to individual (or dyad) experiences in stages of the lifecycle such as becoming a new parent, engaging in menopause or the experience of aging (Schumacher & Meleis, 1994). The second category, ***situational***, describes transitions that occur during role, professional and educational changes. Experiences which have been characterized as situational

transitions include family caregiving. The third category is the ***health/illness*** transition. This aspect includes the impact of health/illness events on clients such as weaning from a ventilator, diagnosis and progression of chronic lung disease. It may also include the experience of change such as in levels of care in the health system such as from hospital discharge to home care services (Schumacher & Meleis, 1994). The fourth type of transition is ***organizational***. Organizations can experience change on many levels such as leaders or management structure or philosophy.

Patterns. Six Patterns of transitions have been identified: single, multiple, sequential, simultaneous, related and unrelated. These patterns can be combined into three diametrical components. Understanding the nature of transitions involves recognizing patterns that may be present in an individual or families' experience. Meleis et al. (2000) propose that type of transition is often not discrete and that rather a combination may be present in an individual/family situation. The first of these diametrical patterns is a ***single*** or ***multiple transition*** event. Multiple transitions involve experiencing two or more transitions as opposed to engagement in just one type of transition. An individual may have the responsibility of caring for her elderly parents (situational transition) while experiencing menopause (developmental) and managing rheumatoid arthritis (health/illness).

The second pattern involves timing of transition occurrence such as ***simultaneous*** or ***sequential***. An example of a sequential pattern is one where a female spouse with a recent heart condition (health/illness transition) must now provide care to her husband who has a new diagnosis of Alzheimer disease (health/illness transition). A sequential pattern would involve recent completion of a transition and initiation of a new event.

The third diametrical pattern is ***related*** and ***unrelated*** transitions. In related transitions "… a major transition may encompass a number of discrete transitions" (Schumacher & Meleis, 1994, p.121) such as the caregiving career (major transition) and role change (smaller transition) once a care-recipient is admitted to PCH. Unrelated transitions, in contrast, would be experienced as quite separate entities such as coping with workplace restructuring (organizational) and managing caregiving to a family elder (situational).

Properties of transitions. Several essential properties of transitions have been proposed. These properties often interrelate in a complex process. Schumacher and Meleis (1994) specify that "These properties help to differentiate transitions from non-transitional change" (p.121). The five properties identified are: (1) awareness (2) engagement (3) change and difference (4) transition time span (5) critical points and events.

The first property is ***awareness*** of a transition experience. The individual recognizes and perceives that changes are occurring. Situations may arise where an individual is not aware of changes but it was Meleis et al.'s (2000) opinion that an individual could still be considered within a transition situation. Many times caregivers report awareness of the caregiving transition when they talk about their feelings or perceptions of their caregiving experience (Skaff & Pearlin, 1992).

The second property in nature of transitions is ***engagement***. "Engagement is defined as the degree to which a person demonstrates involvement in the processes inherent in the transition"(p.19, Meleis et al., 2000). Awareness of the transition is a precursor and requirement for engagement to occur. Engagement is demonstrated by

such tasks as assuming role changes, seeking out information on situation and making adjustments in one's daily routine. An example of engagement is when a spouse caregiver contacts the district Home Care staff for information on their service.

The third property is ***change and difference***. Dimensions of change relate to the nature, timing and perceived significance of events. Familial, social norms and expectations guide perception of change. Change may be experienced as disruptions in relationships, behaviors, roles and routines. The dimension of difference is more a perception of one's situation being different. This can be a feeling of difference or seeing things differently. Caregiving often involves role change, the most obvious is the parent-child dyad. Societal norms expect parents to care for their children. A role reversal ensues (difference) when adult children provide care (change) for their parents.

The fourth property identifies transition ***time span***. Time span refers to flow and movement over time. Transitions involve entry, passage and exit (Meleis & Trangenstein, 1994). The time span of caregiving has been well documented by Pearlin (1992) and Lindgren (1993). The caregiving career proposed by these researchers involves onset of residential (or hospital) care, progressing to in-home care (informal and/or formal) or placement in PCH and ending with bereavement.

The last transition property is ***critical points and events***. An identifiable marker or critical event may initiate a transition such as the abrupt onset of caregiving after a family member suffers a stroke. Critical periods are often associated with more active engagement and or awareness of transition.

Transition Conditions: Facilators and Inhibitors

Transition conditions provide the framework to understand factors that facilitate or hinder progress towards achieving a healthy transition outcome. Transition conditions consist of three significant components: (1) personal (2) community (3) society. The components work together to provide a context within which a transition occurs.

Personal. Personal conditions consist of the cumulative effect of four factors. The factors are (1) meanings (2) cultural beliefs and attitudes (3) socioeconomic status (4) preparation and knowledge. The first factor, ***meanings***, refers to the meaning a transition holds for an individual. Meanings may be neutral, positive or negative towards a transition event. An individual's appraisal of meaning is crucial. An individual may have great enjoyment in providing care to their spouse and thus experience positive meaning.

Cultural beliefs and attitudes play a role in personal conditions. Long held values that are guided by cultural beliefs and attitudes may be placed in conflict as the transition evolves. Many cultural beliefs encourage adult children to provide direct and indirect care to parents as they age. Stigma is often attached to having a parent admitted to a PCH. Caregivers experience much guilt, depression and other negative emotions as they progress through this phase of the caregiving transition (Johnson, Morton & Knox, 1992).

The third factor of ***socioeconomic status*** refers to the effect that low socioeconomic status exerts on a transition experience. In many cases, low socioeconomic status has been found to inhibit the progress towards a healthy outcome because individuals may not be able to purchase the required resources such as housing

or health services. Financial security may serve as a buffer to facilitating transition progression.

The last factor in personal conditions is ***preparation and knowledge***. Adequate anticipatory and ongoing preparation for transition promotes a more favorable outcome. Knowledge seeking and acquisition contributes to preparation in managing a transition event. Caregivers who have taken training in caregiving skills such as managing dementia related behavior have more positive transition outcomes (Farran, 2001). Lack of knowledge may contribute to inhibiting transition outcomes.

Community Conditions. The role and support of community resources may facilitate or inhibit transition outcome. Community resources are composed of informal and formal networks of support. Formal networks may be the availability of services such as home care, day hospital, respite, meals on wheels and adult day programs. Informal networks of support can be family, peers, co-workers, friends and neighbors. The combination of available formal and informal networks might ease the transition if support is viewed as helpful. Inhibitors to transition may occur when support networks are limited or insufficient, nonexistent and/or contradictory or not viewed as helpful.

Social Conditions. Meleis et al. (2000) states "Viewing a transitional event as stigmatized and with stereotyped meanings tends to interfere in the process of health transition"(p.23). The transition needs to be viewed within the context of the current societal conditions. Society expects family members to provide care to their older adult (Matthis, 1992). Many caregivers perceive a stigma attached to the act of placing the older family member in a PCH. Perception of stigma may hinder transition outcome for some family caregivers.

Patterns of Response

Patterns of response are factors that indicate a positive transition outcome. Meleis and Trangenstein (1994) described many indicators of successful transitions but focused on the three most significant; emotional well-being, mastery, and well-being of relationships. Additional positive indicators identified have been quality of life, adaptation, functional ability, self-actualization, expanding consciousness, personal transformation, purposeful and mobilized energy (Meleis & Trangenstein, 1994). Two types of indicators compose the patterns of response component, process and outcome indicators. Both types of indicators occur on a continuum of response. Process indicators occur over time during the transition experience. Outcome indicators may be demonstrated when a transition is complete or during a period of stability in the event which initiated the transition (Meleis et al., 2000).

Process Indicator. Process indicators are behaviors, expressed cognitions and/or feelings that signal movement in the direction of well-being or away from health and towards vulnerability and risk. These indicators allow for "… early assessment and intervention by nurses to facilitate healthy outcomes" (Meleis et al., 2000, p.24). The four process indicators are: (1) feeling connected (2) interacting (3) location and being situated (4) developing confidence and coping.

The first process indicator, ***feeling connected***, describes the need to feel and remain connected to personal contacts (social and kinship networks) and formal health care providers. Meleis et al., (2000) recognized that a significant indicator of positive transition experience was evidenced when individuals were able to establish a trusting relationship with health care professionals. Caregivers who were able to make new

contacts (such as a caregiver support group) utilize kinship networks and establish connections with formal supports (ie. Home Care Services) would be demonstrating the process indicator of feeling connected. If an individual, such as a caregiver, was not keeping up previous friendships and had little contact with family members, this behavior becomes an indicator of risk or vulnerability in the transition outcome.

The second process indicator is ***interacting***. Intra-dyadic interaction involves exploring the meaning of the transition experience and behaviors with individuals involved in the transition. Review and reflection on past and emerging relationships occurs through interaction. The quality of interaction can indicate a healthy or vulnerable outcome. A family caregiver may attempt to plan formal care services through a confrontational approach with their elder. The elder may decline or resist participation in prepatory planning. The dyadic interaction in this situation may be one of conflict. This critical dimension is one of the indicators that may affect the process of the caregiver's transition experience.

Location and being situated is the third process indicator. Location can refer to back and forth movement either actual or imaginary in the transition process. It may imply a unidirectional movement from one location to another. Being situated occurs when an individual is able to make comparisons of events or relationships that have transpired and explain or justify outcomes. Comparisons can be multidirectional during a transition. Caregivers often understand the new caregiving relationship (indirect care) once their family elder enters the PCH by comparing to previous relationship which was one of more direct care provision.

The fourth process indicator is ***developing confidence and coping.*** Meleis et al., (2000) proposes that developing confidence and coping will be manifested by the level of understanding of the different processes that occur in the transition, in the level of resource use, and in the development of strategies for managing. "The dimensions of developing and manifesting confidence are progressive from one point to the next in the transition trajectory"(Meleis et al., 2000, p.25). Participants demonstrate an understanding of critical and turning points in a transition. Coping styles are utilized to manage the experience. Caregivers who describe an understanding of the need for PCH admission for their elder and cope with this wisdom by positive appraisal of admission would be demonstrating a more positive response on this process indicator.

Outcome Indicators. Outcome indicators signal achieving a sense of stability or balance in one's life. If outcomes are considered prematurely they may be evidence of process indicators, if too late, these may be related to other life events. Assessment of transition completion must be flexible in order to accommodate the variety, nature and patterns of transition. There are two outcome indicators, mastery of new skills needed and development of a fluid yet integrative identity.

Mastery is the first outcome indicator. It refers to the development of skills and behaviors needed to manage transition events and outcomes. Skills develop overtime throughout the transition and individuals experience a sense of stability. The extent of mastery of new skills indicates the possibility of a healthy outcome. "The results of the family caregiving study suggest that mastery results from blending previously established skills with skills newly developed during the transition process" (Meleis et al., 2000, p.26). Caregivers have demonstrated mastery of many skills and behaviors such as

managing an agitated, cognitively impaired family elder or providing personal care for a parent (Swanson, Jensen, Specht, Johnson & Maas, 1997).

The second outcome indicator is ***fluid integrative identities***. Transition experiences stimulate the development of identify reformulation. The identity reformulation is fluid or dynamic rather than static. The individual's ability to accommodate change generated by the transition experience is incorporated into identity. Lindgren (1993) identifies this as part of the exit stage of the caregiver career when institutionalization of the care-recipient occurs. "The Exit Stage can be considered to be the caregivers' relinquishment of the dependent care role and claiming other definitions of themselves they are comfortable with" (Lindgren, 1993, p.218). When caregiving occurs as a result of sudden onset, as in the case of a parent suffering a CVA, the individual who is able to integrate this new identity demonstrates a positive response pattern.

Nursing Therapeutics

Nursing therapeutics that are applicable to transitions are promotive, preventive and interventive. Meleis and Trangenstein (1994) propose that "... the mission of nursing should be redefined in terms of facilitating and dealing with people who are undergoing transitions ..."(p.255). Transition theory provides three areas for nursing intervention.

The first approach is ***assessment*** of readiness and progress through transition. The second area is aimed at ***preparation*** for transition. Preparation often involves education such as needed skills in personal care provision tasks. The third focus of ***intervention*** is in collaborating with individuals to develop or create supportive

environments for transition. This approach may involve role supplementation, for example, such as the use of formal home care services to assist with elder personal care. Nursing therapeutics may be implemented at any point within the transition components.

Transition Theory and Past Research

Transition Theory was used as a context for studies on caregivers. Transitions in caregiving has guided past research, for example, the grounded theory study of Brown and Powell-Cope (1991). Brown and Powell-Cope (1991) utilized a grounded theory method as a research strategy to explore and describe the experience of AIDS and family caregiving. Uncertainty emerged as an important psychological problem of caregiving within the transition perspective. Brown and Powell-Cope (1991) identified that transitions involve moving between states of certainty and intervals of uncertainty. Viewing AIDS caregiving through a transition perspective promotes anticipatory interventions by professionals such as nurses.

Fraser (1999) conducted a longitudinal case study on a daughter (caregiver) with a sudden onset of the caregiving role when her mother experienced a stroke. Fraser (1999) was interested in viewing the transition of caregiving over time. Transition theory was effective for predicting processes that occur over time and nature of change. The care recipient's hospitalization for a stroke became the trigger event for the initiation of the caregiver's transition. The nature of changes experienced by the caregiver involved identity, roles, relationships and patterns of behavior (Fraser, 1999).

Kellett (1999) studied caregivers during the transition event of nursing home placement of a relative. Transition concepts were evident in the context of caregivers finding a legitimate reason for a family member's admission to a PCH (evidence of the

transition conditions of finding meanings). Kellett (1999) discovered that caregivers, who were inadequately supported by others, experienced great difficulty in accommodating changes. Transition theory predicts that support from society is one component of the transition conditions that can influence the pattern of response.

Transition Theory in Relation to This Study

Transition theory guides the exploration and understanding of the rural family caregiving experience in relation to the PCH admission event. A goal of Transition theory is that it will help to explain the factors that may influence transition outcomes. Transition theory proposes that meanings, cultural beliefs and attitudes influence the patterns of response to a transition. It was anticipated that caregivers who held strong values of the family member caregiver role (to care-recipient) had more difficulty accepting need for PCH admission and the relocation event. Transition theory indicates that individuals who experience multiple transitions with little family or community support may experience difficulties during a major transition. It was expected that caregivers who were experiencing multiple transitions (for example, starting a new job, becoming a new grandparent, starting retirement or caring for other family members) and who had conflictual and/or no family supports experienced more distress throughout the caregiving transition event of PCH admission. The distress may be evidenced by expressing concerns with PCH care option and/or expressions of distressing emotions such as anxiety, guilt, worry and sadness during the waiting period.

The Transition Theory developed by Meleis et al., (2000) provides a useful framework for understanding caregivers waiting for PCH admission for their family elder. Transition theory proposes that the nature of the transition influences transition

conditions. The transition conditions consist of factors that will inhibit or facilitate progress through the transition. Progress is evidenced by the patterns of response by an individual. These patterns of response indicate stability or signal the end of the transition. Well-being is the goal or desired outcome of transition. The process and outcome indicators provide evidence of a sense of stability and well-being. If the indicators are not demonstrated then it is thought that the individual may be at risk or vulnerable to a less than positive outcome. Nursing interventions can occur at multiple entry points in the transition experience.

Literature Review on the Experience of Waiting for and Admission to PCH

Four aspects of the caregiver's experience of the PCH placement of their care-recipient were considered pertinent to the literature review. The four aspects are: (1) factors influencing decision-making (2) waiting for notification of an available PCH bed (3) planning for admission (4) admission day experience.

Factors Influencing Decision-Making

After much consideration, caregivers and their older family member arrive at a decision to apply for personal care home admission. Research has established that the decision to institutionalize one's family elder was one of the most difficult decisions family caregivers had to make (Dellasega & Mastrian, 1995; Johnson, 1990; Liken, 2001). What influencing forces play a role in caregivers having to make the challenging decision to apply for personal care home admission for their older family member? Forces found to influence the decision-making related to seeking nursing home admission are caregiver, care receiver and environmental characteristics (McAuley & Travis, 1997; Morycz, 1985). Within these three broad categories there are many factors that influence

arriving at the decision to apply for PCH. Of interest here are the caregiver characteristics and their relation to decision-making for long term care. The following factors are discussed: (1) role of caregiver appraisal (2) decision context (3) caregiver age, health, relationship and resources (4) caregiving roles and values.

Role of Caregiver Appraisal

Caregiver characteristics that have been associated with decision-making for nursing home admission include a variety of factors. Caregiver appraisal has been used as a broader term to encompass concepts of burden, impact, mastery and other multi-dimensional aspects of caregiving (Farran, 2001). The factor most researched is caregiver burden. Caregiver burden prompts many caregivers into deciding to seek nursing home admission as a formal care option for their elder (Aneshensel, Pearlin & Schuler, 1993; Chenier, 1997; Deimling & Poulshock, 1985; Liken, 2001; McFall & Miller, 1992; Retsinas, 1991;).

Caregiver burden encompasses two components. The first, subjective burden, relates to the attitudes or emotional reactions caregivers have in response to the caregiving roles (Vrabec, 1997). The second, objective burden, relates to type of caregiver tasks such as help with ADL (activities of daily living) or IADLs (instrumental activities of daily living) and the extent of disruptions or changes in various aspects of the caregiver's usual routines (Hoffmann & Mitchell, 1998; Montgomery, Gonyea & Hooyman, 1985).

Within the dimension of subjective burden, studies have found that caregivers experience role captivity, role engulfment, strained and conflictual relationships with care recipients, feeling that one can no longer cope, caregiver exhaustion, plus a myriad of

psychological distress such as anger, tension and depression (Aneshensel et al., 1993; Cohen, Gold, Shulman, Wortley, McDonald & Wargon,1993; Hoffmann & Mitchell, 1998; Pruchno, Michaels & Postashnik, 1990; Skaff & Pearlin, 1992;). Noonan, Tennstedt and Rebelsky (1999) described subjective burden as "...the subjective sense of being overwhelmed and overloaded" (p.14) in their qualitative study of caregivers to physically impaired elders. Noonan et al. (1999) found that a combination of other roles or a multiplicity of roles was perceived as more burdensome rather than the caregiving role alone.

Skaff and Pearlin (1992) conducted a study that used structured interviews to examine role engulfment and the loss of self with 527 caregivers. This study used different measures of self-loss and role engulfment. Role engulfment was described as a situation where "...the caregiving role is the main or sole surviving context for self-evaluation" (Skaff & Pearlin, 1992, p.658). They found that female caregivers were more likely to experience role captivity than male caregivers and that employment offered some protection from caregiving role engulfment. The most powerful predictor of self-loss was the caregiving context of providing care to a care-recipient who demonstrated potentially dangerous or troublesome behavior. These were a few of the factors that created a stressful caregiving context and hastened application for nursing home.

The findings of Aneshensel, Pearlin and Schuler (1993) are consistent with those of Skaff and Pearlin's (1992). In their study of 555 caregivers, the factors of stress and role captivity related to institutionalizing a care-recipient with dementia. These researchers conducted a multiwave panel survey using three person-to-person interviews

over one year intervals. Aneshensel, Pearlin and Schuler (1993) found that the odds of institutionalization of the care-recipient were greater when caregivers experienced a sense of role captivity. Role captivity is described as a situation in which individuals are unwilling incumbents of unwanted social roles. A limitation of this study was the sample recruitment. The recruitment source for the research participants was a local Alzheimer's and Related Disorders Association. The researchers accessed a small segment of the caregiver population. These participants may have had higher motivation characteristics by the fact they had joined an association.

Objective burden experienced by caregivers has been reported as difficulties in making care arrangements, interrupted sleep, curtailing social and family contacts, decreased participation in recreational activities, having to help with provision of ADL and or IADL, and difficulty with having strangers coming into one's home to provide care to elder (Chenier, 1997; Fink & Picot, 1995; Gold et al., 1995). Fink and Picot (1995) performed a retrospective descriptive study with ten caregivers. These researchers described events that contributed to a placement decision. They found caregivers identified that care arrangement procurement with other service providers became an ordeal rather than a relief. Caregivers expressed concern about strangers coming into their home and the lack of consistency in service providers. Caregiver exhaustion, conflict with family and work roles were other factors. Fink and Picot's (1995) and Gold, Reis, Markiewicz and Andres' (1995) findings are consistent with Liken (2001). In their study of 213 family caregivers, Gold et al. (1995) identified caregiver exhaustion as the single most cited reason for ending home care and initiating alternative care options.

The appraisal of caregiver burden continues to exert a major influence in relation to decision-making for PCH admission. Researchers have investigated the combination of objective and subjective burden components as they relate to caregiver decisions.

Decision Context

Research has uncovered additional factors that compose the caregiver characteristics that are influential in decision-making for nursing home application. Caregivers have reported making the decision to apply during a time of crisis and feeling very rushed to make this decision (Cheek & Ballantyne, 2001; Dellasega & Mastrian, 1995; Reed & Morgan, 1999). Significant others have held a role in the PCH placement decision-making process. The perception of nursing homes as a resource in care provision was a factor in placement decisions.

A number of caregivers have found the placement decision had occurred during a time of crisis. The crisis may have been precipitated by hospitalization because of illness or death of main caregiver, lack of caregiving resources (formal/informal) or escalation of caregiver burden. Liken (2001) conducted a secondary analysis study which involved content analysis of twenty transcripts based on person-to-person family caregiver interviews and a focus group with the same caregivers. Caregivers perceived a placement crisis situation arose when the care-recipient experienced functional decline and behavior problems. A limitation to this study was that a major portion of the data were obtained by secondary analysis. Liken's (2001) finding is consistent with Dellasega and Mastrian's (1995) as well as Cheek and Ballantyne's (2001) research on caregivers. In their qualitative study of twenty-five caregivers, Cheek and Ballantyne (2001) concluded

that the decision to place the care-recipient in PCH "...is a stressful experience and should be viewed as a family crisis" (p.234).

External pressure to make a rushed decision was felt to be hospital and/or professional health care worker driven when the elder was hospitalized and discharge to home was no longer an option. Reed and Morgan (1999) performed an action research study with care-recipients, caregivers and acute care staff. Seventeen caregivers of hospitalized care-recipients were interviewed. These caregivers described having felt rushed by the acute care facility to accept nursing home placement as a care option and choosing an acceptable PCH. Cheek and Ballantyne's (2001) findings were consistent Reed and Morgan's (1999) findings. In their retrospective study of twenty-five family members of recently discharged care-recipients, Cheek and Ballantyne (2001) found that caregivers felt pressured from the acute care center and a grave sense of urgency to select a PCH. "The feeling of the acute settings being somewhat hostile to the family and the frail relative emerged in several interviews" (Cheek & Ballantyne, 2001, p.231). The descriptions documented in this study were robust for a qualitative study with representation from a sample of twenty-five caregivers.

Caregivers have felt the decision to apply to PCH was influenced by others such as physicians, social workers, nurses or friends (Johnson, Schwiebert & Rosenmann, 1994; Johnson & Warner, 1982; McAuley & Travis, 1997; Smallegan, 1981). Johnson and Warner (1982) conducted a study with fifty-five caregivers regarding guilt feelings surrounding placement. They discovered physicians' involvement in 76% of the decisions to opt for PCH services. This particular finding from Johnson and Warner's (1982) dated study has been supported with more recent findings from McAuley and

Travis (1997). These researchers conducted a telephone interview survey with 145 caregivers. McAuley and Travis (1997) found that caregivers identified health care workers, most notably physicians and nurses, as playing a critical role in the decision to seek nursing home placement for the care-recipient. A limitation to this study was the retrospective timing. The study may have been strengthened if the surveys were conducted closer to the time of decision and thus avoid reliance on memory recall.

The caregiver's views and attitude towards nursing home as a care option is one of many aspects of the decision context. Hagen (2001) conducted a qualitative study with five caregivers. Hagen (2001) stated "All caregivers felt that the more negative opinion one had of nursing homes, the more difficult it would be to even consider the decision to place a family member in one" (p.50). Linn and Gurel (1972) in their classic study with veterans and their caregivers had a contrary finding in that caregivers had a more favorable attitude to nursing home placement. Linn and Gurel (1972) had a large sample, but the findings were limited by a rather homogeneous sample (care-recipients were all veterans). Researchers have discerned that the caregiver's attitude towards nursing homes as a long term care option was one of many factors involved with the decision to seek admission.

Caregiver Age, Health, Relationship and Resources

Caregiver age, health and relationship to the care-recipient have been identified as factors associated with PCH decision-making. Older caregivers are more likely to choose PCH admission as a care option for their older family member (Chenier, 1997; Smallegan, 1985). Caregivers who reported poor health realized they were unable to physically care for their older family member (Aneshensel et al., 1993; Cohen et al.,

1993; Fink & Picot, 1995). Past studies have discovered that caregivers who experience conflicts and difficult relationships with the care recipient are more likely to make a decision in favor of nursing home admission (Fink & Picot, 1995; Gold, Reis, Markiewicz & Andres, 1995; Liken, 2001; Spruyette, Audenhove & Lammertyn, 2001).

Spruyette, Audenhove and Lammertyn (2001) performed an analysis using data collected from face-to-face interviews and surveys with 144 family caregivers. They found that the quality of the caregiver, care-recipient relationship was a factor in the decision to seek institutionalization in PCH. Relationships that were reported as being poor, having conflict and critique were related to a higher rate of institutionalization. Spruyett et al.'s (2001) findings are likely to be robust as they were based on a longitudinal study design and a sample size of 144 participants.

Spouses tend to provide in-home care longer and more often than do adult children (or other relatives) (Cohen et al., 1993). An exception to this finding was a study by McFall and Miller (1992) who found that elders cared for by adult children were no more likely to be admitted to PCH than elders cared for by spouses.

Caregiver use of formal services has also played a role in PCH decision-making. Research has revealed that caregivers who used formal services were more likely to seek PCH admission for the care-recipients (Johnson & Werver, 1982; Pruchno, Michaels & Potashnik, 1990; Smallegan, 1981).

Caregiving Roles and Values

Family values placed on in-home and PCH care options influence the decision to apply for nursing home (Dellasega & Nolan, 1997; McCullough, Wilson, Teasdale, Kolpakchi & Skelly, 1993; Nolan, Walker, Nolan, Williams, Poland, Curran & Kent,

1996). Family care of the aged is a value that persists through the generations (Brody, 1985). The commitment to the active caregiving role may weaken over time and the desire to institutionalize is expressed (Pruchno, Michaels & Potashnik, 1990).

Cantor's (1983) study described a familial value system which valued family member involvement in caregiving but this involvement often led caregivers to feel strain. Brody, Dempsey and Pruchno (1990) found, in their study of 75 sons and 256 daughters, that the daughter caregivers were socialized as nurturers and caregivers. Strain was experienced when a disparity occurred between expectations of themselves in the caregiving role and what they can actually manage. McCullough, Wilson, Teasdale, Kolpakchi and Skelly (1993) findings were consistent with Brody, Dempsey and Pruchno (1990). McCullough et al. (1993) conducted a qualitative study that used a purposive sampling strategy with 23 family caregivers (also included 26 elders and 13 professionals). McCullough et al. (1993) described values, beliefs and behaviors of caregivers, professionals and care-recipients when making decisions regarding long term care. Filial responsibility was identified by caregivers as a duty to care for parents. McCullough et al.'s (1993) study had many strengths, the sample accessed was diverse and large, the data were analyzed by the five investigators, the instruments were pretested and the methodology was explicity described.

Caregivers who hold the value that family members should provide in-home care to elders will experience more guilt and difficulty in making the decision that PCH care is needed. The decision is often postponed until a crisis forces the response to seek PCH admission. Caregivers who value the care that can be provided by a PCH will be more

willing and accepting of the decision to seek PCH admission for his/her family member (Deimling & Poulshock, 1985; Spruyette et al., 2001).

Certain aspects of the caregiving role may influence desire to seek nursing home admission. Caregivers may be faced with the challenge of knowing when to relinquish the caregiving role (Pruchno, et al., 1990). Pruchno et al. (1990) found in their longitudinal study of 315 caregivers that participants were more likely to exit the caregiver role when (1) there was a strong desire to insitutionalize and (2) a combination of unsatisfying relationship, personal hardships, needy care-recipients and knowledge of alternative resources. These researchers indicated that caregivers who no longer derived positive value from the caregiver role sought PCH admission (Pruchno, Michaels and Potashnik, 1990).

Summary of Factors Influencing Decision-Making

Many factors are involved with the decision-making regarding selection of long term care services for care-recipients. Considerable research has been conducted on these factors. A review of the most pertinent factors was presented. Caregiver burden or appraisal was a significant factor. The context of the PCH placement decision was relevant such as when the decision occurred under the climate of urgency. Caregiver variables played a role in the decision such as the nature of caregiver/care-recipient relationships. The role and values of the caregiver were the last factors reviewed.

Waiting For Notification of an Available PCH Bed

Research investigating the experience of caregivers as they await notification of their care-recipient's admission to PCH is limited. A plethora of research exists on the decision-making factors and post-admission phase, yet little research has been conducted

on the caregiver's experience of the waiting, preparation and anticipation events. Once the decision has been made to select nursing home admission as the long-term care option for elder care, the caregivers engage in the waiting phase of this transition. Caregivers must complete certain activities during the waiting period such as the search and selection of a desirable PCH, dispersal or storage of elder's personal belongings and making financial arrangements (Cheek & Ballantyne, 2001; McAuley, Travis & Safewright, 1997; McCracken, 1987; Travis & McAuley, 1998). The search and selection of a suitable PCH may occur with some degree of urgency. Research has discovered that this phase is often an emotional time for caregivers fraught with uncertainty, and caregivers revisit the placement decision (Nolan & Dellasega, 2000; Penrod & Dellasega, 1998; Ryan & Scullion, 2000). Two aspects of the waiting period are presented: (1) searching for the right personal care home (2) emotional aspects of the experience of waiting.

Searching for the Right Personal Care Home

The search and selection of a suitable PCH may occur under a climate of urgency. The search and selection process was found to be either expert driven, such as when a nurse or social worker encouraged caregivers to obtain suitable PCH placement, or caregiver driven, such as when family recognized this need for service (McAuley, Travis and Safewright, 1997). McAuley, Travis and Safewright (1997) conducted a qualitative study on the PCH search and selection process with 25 caregivers. These researchers found that the main criteria caregivers used in their selection process was the perception that the PCH had caring and concerned staff. Search and selection of a nursing home were often expert driven when hospitalization or acute illness of the care-recipient

required the need to pursue placement as a long term care option (McAuley et al., 1997). McCauley et al.'s (1997) study had many strengths. Even though the study was retrospective, the time frame was minimized between admission and the scheduled interview. The participants were recruited from a diverse geographic areas consisting of rural and urban residences with a sample size of twenty-five.

McCauley et al.'s (1997) findings on the time pressured nature of the PCH search and selection process were supported by those of Rodgers (1997), Penrod and Dellasega (1998) and Travis and McAuley (1998). Rodger's (1997) qualitative study of nine caregivers found the concern of selecting a PCH with quality care often occurred under a climate of urgency. The sense of urgency was intensified when a bed was offered and caregivers had only a few hours to respond. Travis and McAuley (1998) described time-pressured PCH searches occurred as a result of an acute care stay and the need to minimize the admission time. Cheek and Ballantyne (2001) found that carers felt pressured into making an "on the spot" decision to accept a PCH bed even though it may not be the first choice.

Families report an overall lack of information and preparation for engaging in the search and selection process (Nolan et al., 1996; Rodger, 1997; Travis & McAuley, 1998). Many tasks are involved in the search and selection of a PCH. Caregivers have reported that a guide or list of criteria would be beneficial for this task (McAuley et al., 1997; Nolan & Dellasega, 2000).

Rodgers (1997) found carers were unprepared for handling the care-recipient's financial matters during the preadmission to PCH. Information pertaining to managing the family elder's financial affairs such as selling of the home and disbursement of

possessions along with arranging for PCH payment would be beneficial for carers (Dellasega & Nolan, 1997).

Emotional Aspect of the Experience of Waiting

The waiting period has been characterized by caregivers as a time fraught with fluctuating human emotions and new tasks to accomplish. Research has found guilt and grief were some of the emotions often experienced during this transition. Caregivers were faced with handling the care-recipients financial and household matters in preparation for PCH admission. Caregivers reflected on the decision to seek PCH admission for their care-recipient during the preadmission time.

Caregivers have expressed a wide spectrum of emotions in response to the nursing home placement process. Rodgers (1997) referred to this as the "turmoil of placement". Ryan and Scullion (2000) conducted a qualitative study with ten caregivers in Northern Ireland exploring their thoughts and feelings about PCH admission of their older relative. These investigators found that caregivers involved in the nursing home placement process expressed feelings of guilt, a need to justify their decision, helplessness, loss and regret. Ryan and Scullion's (2000) findings were supported by Cheek and Ballantyne (2001). In their qualitative study of 25 family caregivers, Cheek and Ballantyne (2001) also found that caregivers reported feelings of guilt, stress and being overwhelmed with the placement process. Nolan et al.(1996) suggested that negative emotions are most likely to occur during this transition for caregivers, but hopefully these would be tempered with appropriate interventions.

Research has also discovered that caregivers have reported feeling relief in having one's older family member waiting for PCH admission (Ryan & Scullion, 2000; Cheek &

Ballantyne, 2001). Cheek and Ballantyne (2001) discovered that some caregivers expressed a sense of relief in knowing that a reasonable solution was available for long term care of the care-recipient. These findings were previously established in Kellett's (1999) qualitative study of 14 family carers. The caregivers in this study described feelings of sadness and relief that occurred simultaneously.

Caregivers invested considerable time reflecting and revisiting their decision to apply for PCH as they await notification of a bed offer (Penrod & Dellasega, 1998, Rodgers, 1997). Penrod and Dellasega (1998) conducted a qualitative study using a grounded theory method on making PCH placement decisions with ten caregivers. These researchers found that caregivers felt uncertain with the permanency of the decision and accepting the option of PCH admission.

One of the emotional aspects of the caregiver's decision making and persistence with the wait for a PCH admission concerns feeling "singular". Dellasega and Mastrian (1995) found that caregivers felt solely responsible for making the placement decision even though other family members may have been involved.

Carers experience ethical dilemnas and conflict with long held values as they await notification of a PCH bed. Cheek and Ballantyne (2001) identified that carers found themselves in an ethical dilemnna when they needed a PCH bed for their elder but in order to acquire this bed another caregiver's elder would have died (thus providing a vacant PCH bed). Families have values in regards to providing in-home or choosing PCH services. Nursing home admission is often viewed as a negative value and as a last resort (Ryan & Scullion, 2000; Rogers, 1997). Kellett (1999) found that caregivers often felt a sense of failure when they had to pursue PCH admission as a care option. Caregivers

need to view PCH admission not as a failure or violation of caregiving values but rather as " … an inevitable process on the continuum of care.." (Nolan & Dellasega, 2000).

Summary of Waiting for Notification of an Available PCH Bed

A dearth of research exists on the caregiver's experience of waiting for a PCH bed offer. Caregivers often feel pressured into selecting and accepting a PCH admission for their care-recipient. Caregivers have felt guilt, grief, turmoil, helplessness and at times regret during this waiting period. Limited research has been conducted on the associated factors relating to the caregivers experience of waiting for admission of their older family member to PCH. Rural caregivers have not been extensively represented or sampled in past research. Research is lacking on the PCH waiting experience for caregivers when the wait for a bed offer could be lengthy (and not occur under a climate of urgency). The direct study of caregiver's experience and perceptions of this waiting period is nearly nonexistent.

Planning for Admission

Minimal research has been conducted on the study of how caregivers plan and prepare for PCH admission. Studies have been conducted with care-recipients or PCH residents involved in facility to facility moves (Amenta, Weiner & Amenta, 1984; Dickinson, 1996; Johnson & Hlava, 1994). Few studies have been conducted with caregivers on the preparation for PCH admission of one's care-recipient. The caregiver's experience of planning and preparing the PCH admission for the care-recipient is relatively unknown.

Johnson, Morton and Knox (1992) identified that caregivers lacked knowledge and information on the nature and processes of PCH admission. These

researchers conducted a qualitative study with 22 caregivers on the events of PCH admission. Johnson et al. (1992) found that caregivers lacked preparation for the experience of PCH admission. These researchers acknowledged a need for nursing interventions with caregivers aimed at the preadmission period (Johnson, et al.,1992).

Tipton-Smith and Tanner (1994) conducted a quasi-experimental study with 30 caregivers on preparation for admission to PCH of their care-recipient. These researchers used an adult educational program to prepare adult children for the PCH admission of a parent. Tipton-Smith and Tanner (1994) found that their intervention was somewhat effective for reducing stress in the treatment group. These investigator's findings could be criticized on the basis that the sample was one of a nonprobability convenience , size was quite small (n = 15 in treatment group) and not much time had elapsed between the intervention and actual PCH admission. A strength of this research is that the investigators focused the attention on caregiver interventions that might assist in alleviating the difficulties encountered during this transition.

Kaisik and Ceslowitz (1996) conducted a quasi-experimental study with 34 seniors that compared the effects of a PCH tour and video tour on reducing anticipated stress concerning the life event of PCH admission. The older persons who viewed the video on choosing a PCH and attended a discussion on this event demonstrated reduced stress levels compared to the pre-test. Individuals who attended an on-site PCH tour experienced higher post-test scores on stress. Kaisik and Ceslowitz (1996) recommended a program of gradual exposure to PCH through a vicarious route (such as viewing videos and participating in discussions) as a more effective approach for preparing elders for PCH admission. These researchers also recommended including caregivers as part of the

vicarious approach to preparation. This study has some limitations that caution the generalization of findings. The limitations are a small convenience sample (n=51) and no control group.

Schneewind (1990) has noted that there are no rituals to acknowledge or prepare for relocation of the care-recipient to PCH. Nursing home admission should be considered as more of a normative component in the family life cycle. Further research is needed to explore this view.

Summary of Planning for Admission

Researchers have noted that caregivers need more information on the nature and processes of PCH admission. One intervention study was located which used an educational program to assist caregivers in preparing for PCH admission of their care-recipient. Several intervention studies have been conducted with care-recipients. This area of investigation has been minimally researched.

Admission Day and Post-placement Experience

Considerable research exists on the care-recipient's experience of nursing home admission yet the caregiver's perspective has been traditionally neglected as a research focus. Studies have examined the post-admission adaptation by caregivers but not the actual admission event as experienced (Brody, Dempsey & Pruchno, 1990; King, Collins, Given & Vredevoogd, 1991; Zarit & Whitlatch, 1992). Research on post-admission adaptation has provided a few clues as to the caregiver's admission experience.

Caregivers have indicated that the PCH admission period provoked a reanalysis of their decision to seek placement for the care-recipient (Johnson, 1990; Meacham & Brandriet, 1997; Nolan & Dellasega, 1999). Johnson (1990) conducted a qualitative

multiple case design study with 16 daughter caregivers. The daughter caregivers described how the actual admission of the care-recipient raised doubts that the right decision was made. These caregivers experienced moral conflicts and dilemmas as they questioned if the PCH admission was being true to one's parents (Johnson, 1990). Johnson's (1990) research had many strengths, each participant had three interviews, the sample size was robust for a qualitative design and a pilot study was conducted prior to implementation.

Meacham and Brandriet's (1997) findings are consistent with Johnson (1990). Meacham and Brandriet (1997) found that nursing home admission was a time when family carers relived and reanalyzed the decision to admit their elder. These researchers conducted a qualitative study with a convenience sample of ten caregivers. Meacham and Brandriet (1997) observed "Placement caused family members to relive and reanalyze the decision to assess if admission was, indeed, the appropriate decision" (p.65).

Research has discovered that the PCH admission was at times difficult for caregivers. Difficulties encountered were stress and a diversity of emotions (Gaugler, Zarit & Pearlin, 1999; Johnson, 1990; Kammer, 1994; King, Collins, Given & Vredevoogd, 1991). Caregivers experienced stress at the time of admission if the decision was not consensual or supported by others (Johnson & Werner, 1982; Kammer, 1994). Johnson and Werner (1982) found that feelings of guilt were reduced in caregivers who had more people involved in the placement decision. This aspect was enhanced when the care-recipient was in agreement to the PCH admission. This finding was further validated by Kammer (1994).

The PCH placement experience provokes a diversity of emotions. Caregivers have described feelings of guilt, ambivalence, sadness, grief, loss, concern, depression, overwhelmed and relief (Grant et al., 2002; Johnson, 1990; Kammer, 1994; King et al., 1991; Matthiesen, 1989; Meacham & Brandriet, 1997; Nolan & Dellasega, 1999). Nolan and Dellasega (1999) conducted a quantitative/qualitative study using formal structured interview instruments and open-ended questions. These researchers explored U.S. and U.K. caregivers' experiences before, during and after the PCH admission of the care-recipient. They found that caregivers experienced feelings of guilt, loss, regret and also a sense of relief. These findings are consistent with Meacham and Brandriet (1997). Meacham and Brandriet (1997) suggested that at times caregivers felt guilt, a sense of failure, sadness but also felt relief, acceptance and coping in response to the actual placement. Matthiesen (1989) states "Even for adult children, such placement is an emotionally stressful event" (p.11). The myriad of emotions experienced is unique to each caregiver but the expression of several similar core emotions continues to surface.

Gaugler, Zarit and Pearlin (1999) studied the variables of family conflict and socioemotional support (outside of the caregiving dyad) among caregivers who institutionalized their care-recipient. Wives and daughter caregivers reported high levels of socioemotional support during and after PCH placement. Even though women caregivers are expected to provide care within family they still received high levels of socioemotional support and reported little family conflict during placement transition. Husband caregivers experienced an increase in family conflict and lower levels of socioemotional support during the nursing home transition. Gaugler et al. (1999)

proposed that husbands may view PCH admission as a failure and may perceive criticism from other family members.

Caregivers have experienced beneficial effects after the PCH admission of the care-recipient. Grant et al. (2002) conducted a study that examined the health consequences of having one's care-recipient admitted to PCH. These researchers suggested "...that both placement and death of the demented relative can have beneficial effects on the mood of the caregiver, but that this effect can take up to 12 months to become evident" (Grant et al., 2002, p.483). The mood referred to was depression. These researchers proposed that caregivers may find psychological relief during the first twelve months of the post-placement time period.

On admission day, family caregivers are not sure of their caregiving role. Schneewind (1990) described how caregivers were unsure as to what should be done so they occupied themselves marking clothes and felt awkward at saying goodbye to family member. There is no ritual to mark admission to nursing home thus family members have no guidelines on what caregiving activities should be performed (Schneewind, 1990). Spouses experience role changes following PCH admission of their care-recipient. Ade-Riddler and Kaplan (1993), in their literature review of spouse roles and PCH placement, described how wives were unsure of their role after institutionalization of their spouse. New roles were added such as visitor whereas other roles were deleted such as care-provider for physical tasks. Ade-Riddler and Kaplan (1993) suggested that with conflicting role expectations of caregivers, tension may arise and in time affect the caregiver's relationships with PCH staff. Further research is needed on this aspect of role change.

Pearlin (1992) and Lindgren (1993) described the post-placement experience of caregivers as a time for relief from the 24-hour responsibility for the care-recipient. "The exit stage can be considered to be the caregiver's relinquishment of the dependent care role and claiming other definitions of themselves they are comfortable with" (Lindgren, 1993, p.218). In Pearlin's (1992) article on "The careers of caregivers" he refers to the dynamic and evolving demands of caregiving and the well-being of the caregiver throughout the stages of the caregiving career. Pearlin (1992) refers to Zarit and Whitlatch's (1992) research and states "...certain components of well-being are particularly sensitive to and benefit from institutionalization" (p.647). Research has indicated that some caregivers have experienced enhanced well-being after the PCH admission of their care-recipient.

Summary of Admission Day Experience

Research on the caregiver's direct experience of the PCH admission day could not be located. Post-admission research has identified aspects of the caregiver's experience. Caregivers reviewed their original decision to seek placement after admission occurred. The post-admission period provided an opportunity for role changes, examining family conflict and support, gradual relief from depression and experiencing a myriad of emotions as times passes from the original admission day.

Limitations of Research

Many studies have been conducted with caregivers of elders with dementia, but few studies have focused on caregivers of physically frail elders. Studies conducted are often retrospective and caregivers are asked to recall experiences weeks or months after admission to PCH has occurred. Prospective studies would involve contact with

caregivers prior to admission. Caregiver participants have been traditionally recruited from PCH's family contact lists of newly admitted residents. Perhaps researchers have difficulty accessing participants during the waiting period as these caregivers are unknown if they have not sought assistance from professionals or are not registered in caregiver organizations. Home Care programs offer a potential resource for recruiting study participants (caregiver). Home Care services in the United States and in many provinces of Canada must be purchased therefore only more affluent caregivers would be registered with this program. This group of caregivers would represent a certain segment and the difficulty remains in obtaining a varied sample of caregivers.

The settings of most caregiver studies are urban rather than rural. The participant samples recruited are often well educated, have a secure economic status (can afford to pay for private nursing home stays), and often highly motivated (recruited from support groups). Many studies on caregivers have been conducted in the U.S., U.K. and Australia, few have been located that are Canadian.

Considerable research was conducted on the decision to seek nursing home admission and the post-placement experience. Research that has directly studied the waiting for a PCH bed offer and the admission day experience were not located. A gap in research exists on these particular aspects of the caregiver's experience with PCH admission of the care-recipient. Further research would expand the body of knowledge on these events and perceptions of caregiving.

Justification for Caregiver Study

Caregiver prospective studies are valued for minimizing time passed between the event experienced and the process of recall and description. In respect of past research,

this study will inform the topic of inquiry by conducting a prospective study. A prospective study will gather data closer to the admission event as the caregiving transition evolves. Older family members are often receiving Home Care services as they wait for PCH admission. Participants were recruited from a government insured community based Home Care program (no fee for services). Potential caregiver participants were recruited from the Home Care program as they waited for their family member to be admitted to PCH.

Study participants were recruited from differing economic and educational backgrounds as the Home Care program is a universal program in the Province of Manitoba. It is beneficial to recruit study participants from varied economic and educational backgrounds. Caregivers with higher education and economic status have been well represented in caregiver research, whereas, caregivers of lower socioeconomic status have been under-represented. One aim of this study was to give voice to the caregiver's experience regardless of economic or educational status.

Urban dwelling caregivers have also been well represented in past research. Researchers encounter more challenges when trying to recruit rural residing caregivers as study participants. In this study, caregivers who were living in rural municipalities of the RRHA were recruited into the study. The perspective of rural caregivers will enrich the caregiving literature.

Summary of Chapter II

Chapter II focussed on the conceptual framework and the literature review that undergirded this study. The conceptual framework was Transition Theory. The literature review presented four aspects of the caregiver's experience of waiting for admission to

PCH of their care-recipient. The first aspect discussed was factors pertinent to the decision to seek PCH admission as a care option. The second aspect was the caregiver's experience of waiting for notice of PCH "bed offer". The third aspect was the caregiver's experience of planning for the future admission to PCH of the care-recipient. The last aspect discussed was the caregiver's perception of the admission day and post-placement experiences. The limitations of past research were identified, for example, many studies conducted were retrospective and urban centered. The justification for this study was presented. There is a need for further research on the rural caregiver's experience of waiting for a PCH "bed offer" and admission of the care-recipient.

CHAPTER III

METHODOLOGY

In Chapter III I present the methodology used for this study. The research design, population selected, sample size, setting, and data collection methods are described. Criteria for establishing trustworthiness are discussed and the approach to data analysis are also presented. Ethical considerations are considered. A brief summary concludes this chapter.

Methodology and Method

A qualitative approach explored the caregiver's experience of waiting for one's care-recipient to be admitted to Personal Care Home (PCH). Person-centered interviewing served as the method. A prospective time frame was utilized.

Qualitative research methodology is useful when little is known about an area of interest such as the caregiver's experience. Qualitative methodology provides an exploratory and descriptive mode of inquiry for this minimally researched topic. "Exploratory studies are undertaken when a new area or topic is being investigated, and qualitative methods are especially useful for exploring the full nature of a little-understood phenomenon" (Polit & Hungler, 1999, p.18). The descriptive mode provides rich detail on "... what is happening in some setting or with a particular group of subjects, so that the point of view of the subjects can be understood" (Artinian, 1988, p.138). Research focusing on the rural caregiver's experience of waiting for and the actual admission of one's elder to PCH could not be located. The purpose of this study was to explore and describe the experience of rural family caregivers during the waiting

and admission events of the caregiving transition. A qualitative approach was well suited to achieve this purpose.

Person-centered interviewing was the method chosen for this qualitative study. "Researchers often choose qualitative interviews over ethnographic methods when their topics of interest do not center on particular settings but their concern is with establishing common patterns or themes between particular types of respondents" (Warren, 2002, p.85). Person-centered interviewing is one mode of qualitative interviewing. This method of inquiry was the route participants traveled to tell their story of the waiting experience and to share their perspectives of reality. The goal of this method was to understand patterns pertaining to the caregiver's experience of waiting for a PCH bed offer for his/her's care-recipient. These patterns, including categories and themes were derived from the interview data.

Person-centered interviewing considers the participant as both informant and respondent (Levy & Hollan, 1998). The informant aspect provides rich description on the phenomenon of interest, whereby the interviewee was the "expert witness" for description (Levy & Hollan, 1998). An example of this occurred when the participant became the informant as he/she described the manner in which a PCH bed offer was extended. The second aspect, participant as respondent, explored the experience of the phenomenon of interest. The participant became the respondent as she/he relayed their perceptions and feelings surrounding one's experiences, for example, the emotional response to receiving a PCH bed offer. "Person-centered interviewing moves back and forth between the informant and the respondent modes" (Levy & Hollan, 1998, p.336). The strength of person-centered interviewing is the ability to generate knowledge on a

relatively new topic or little described phenomenon. Caregiver's experience of waiting for a PCH bed offer was unknown. Person-centered interviewing generated data on the caregiver's experience.

A prospective time frame was selected for gathering data by qualitative interviewing. Participants were interviewed as they waited for the official notice of PCH bed availability and after the care-recipient was admitted.

Ethical Considerations

Ethical approval was received from the Education/Nursing Research Ethics Board (ENREB), University of Manitoba and the RRHA Internal Ethical Review Board. A certificate was received from ENREB. Please refer to Appendix J, page 219, for a copy of the certificate. The topic of study was of a sensitive nature therefore ethical considerations were carefully outlined. The ethical principles of autonomy, beneficence and justice guided the ethical considerations of this study.

Autonomy (Respect for Human Dignity)

Participants were advised and informed of their voluntary right to participate in this study without risk of penalty. Participants were advised on how to withdraw from the study as well. Please refer to Informed Consent document in Appendix K, page 222. Consent was obtained in writing at the beginning of the study. Ongoing consent was obtained verbally at the beginning of each interview and at any time during interview as circumstance change or unexpected events occurred (Kavanaugh & Ayres, 1998).

The process of sample recruitment took into consideration the potential participant's right to decline without any knowledge by researcher of this decision. The first point of contact was the Home Care Coordinator or Discharge Coordinator (please

refer to section on Sample Recruitment and Access). I had no knowledge of which caregivers received an invitation to participate in the study. Consenting participants were asked by the HCC or Discharge Coordinator for permission to refer their name and phone number to the researcher.

I was in a potential position of power in light of my employment with the RRHA as a Continuing Care Case Coordinator/Regional Access Coordinator. Strategies ensured that participants remained free from coercion. This involved removing me from any clinical involvement with participants. The RRHA Program Manager (Home Care) provided all Home Care services to research participants that would normally have been provided by me in my clinical role. This practice ensured that no impact on Home Care services resulted from participation in the study.

Beneficence

The risks and benefits of this research were explained to participants. Qualitative research can involve in-depth exploration into personal or sensitive areas (Polit & Hungler, 1999). "Assessing respondent distress during a sensitive research interview is complex and challenging but important to undertake to avoid harm" (Kavanaugh & Ayers, 1998). Participants' behaviors and expressions were continuously assessed during the entire study. This emotional information was documented in field notes along with behavior before and after interview. Several strategies were employed to minimize harm to participants during the interview process. Process consent was obtained throughout the study. I remained vigilant in anticipating signs of distress. I provided appropriate support during signs of a distressing period, this involved taking a break from interviewing, ending the interview, changing to a more neutral topic, validating feelings

and/or behaviors and offering appropriate referrals such as pastoral or community mental health worker. I provided a debriefing at the end of each interview. A follow-up telephone contact was made if I felt concerned about participant's level of comfort during an interview.

Justice

Confidentiality and the right to privacy were maintained. Participants were informed of their right of confidentiality and privacy as well as how this was protected. The recruiting agents (HCCs and Discharge Planner) were not informed of who agreed or declined to participate in research. This process protected the participant from any influence on services. The participant was informed that any information provided was grouped with others in the findings of the research. This practice assisted in providing anonymity. Data (audio-tapes and field notes) were stored in a locked filing cabinet in researcher's home. Data will be stored for seven years followed by disposal as confidential waste. Disposal of confidential documents was and will be performed by a mechanized paper shredder. Participants received an ID number to maintain anonymity. Codes and pseudonyms were used to identify transcript data, this provided participants with anonymity.

Sample Recruitment and Access

A nonprobability purposive sample of rural caregivers was used. The sample size is established, along with the criteria for sample selection. The process of participant access and recruitment are also described.

Sample Size

A nonprobability purposive sample of rural residing caregivers was used. Morse (1986) states "The purpose of selecting nonprobability samples is to facilitate understanding, for description, and to elicit meaning" (p.184). Participants were selected because they were able to describe their caregiving experience during the waiting and admission period. A sample size of ten participants was selected. Each participant was interviewed at least once during the waiting period. Six participants were interviewed once after their care-recipient was admitted to or declined the PCH bed. A total of 18 interviews were conducted. The goal of sampling was to obtain informational adequacy that was provided by the anticipated number of interviews with participants (Morse, 2000). Figure 1 presents the interview sequence and numbers.

Figure 1

Interviews

Time 1	**Time 2**
Waiting for PCH Admission	Care-recipient Admitted to PCH
n = 10 interviews (2 participants interviewed twice n = 2)	n = 4 post-admission interviews n = 2 post-declined PCH bed offer interviews n = 4 Time 1 participants not interviewed (no bed offer received)
Range of Wait for a PCH bed offer	Range of days post-admission/decline interview: 1 week to 3 weeks

Criteria for Sample Selection

Criteria for sample selection guided the recruitment and selection process of eligible participants. The following criteria directed sample selection of prospective caregivers:

- Participants were identified as the significant and/or main caregiver to a care-recipient (can be identified by the care-recipient, other family members or professionals involved with family)
- Spoke and understood English
- Resided in a Rural Regional Health Authority (RRHA) region or were providing care to a care-recipient who resided in a RRHA
- Comprehended and provided verbal and/or written consent
- Their care-recipient was panelled for Personal Care Home (PCH) and was on a nursing home waiting list, and the waiting list was approximately four months or less
- Were over 18 years of age

The participants had the capacity to describe and relay their caregiving experiences.

Participant Access

Participant access was sought through a Rural Regional Health Authority (RRHA). A letter of introduction, brief study description and request of permission to access RRHA caregivers was sent to the RRHA's Vice President of Planning and Regional Development. Please refer to Appendix C, page 199, for a copy of this letter. RRHA granted permission to access RRHA care-recipients and caregivers for study.

Please refer to Appendix D, page 202, for a copy of the e-mail granting permission to access participants (dated February 11, 2003).

Sample Recruitment

The assistance of Home Care Coordinators (HCC) and one Hospital Discharge Coordinator Nurse were solicited to aid in sample recruitment. The HCCs and the Discharge Coordinator submit applications for PCH to the Home Care Panel for acceptance. This group of nurses (and three social workers) were in frequent contact with caregivers and care-recipients, thus they were in a position to approach potential participants.

I met with all HCCs and the Discharge Coordinator at a Home Care meeting and reviewed the purpose of the study, as well as the recruitment and participant eligibility processes. The HCCs and Discharge Coordinator were given a letter of introduction on the study. Please refer to Appendix E, page 204, for a copy of this letter. The HCCs and Discharge Coordinator were also provided with a copy of the script that was used to recruit participants. Please refer to Appendix F, page 207, for a copy of the script. The implementation of the script (Invitation to Caregivers to Participate in a Nursing Study) was reviewed with the HCCs and Discharge Coordinator. HCCs and the Discharge Coordinator were asked to extend the invitation to all caregivers who met the eligibility criteria. A follow-up phone call was made to each HCCs and Discharge Coordinator to answer any further questions.

The invitation to participate was extended by the HCCs or Discharge Coordinator via telephone contact only. A telephone contact was the setting chosen to extend the invitation so as to minimize any sense of prospective participants feeling obliged to enter

into the study. The script was read over the phone and potential participants were asked if they were interested. If they answered yes, then their names and telephone numbers were forwarded to the researcher. If no, caregivers were advised by the HCCs or Discharge Coordinator that the contact was confidential and no one would have knowledge of the outcome of the invitation.

I was only given the names and phone numbers of potential participants after they had discussed their acceptance or interest with the HCCs or the Discharge Coordinator. This practice protected the identity of individuals who were approached and declined to participate as I had no knowledge that he/she declined the invitation to participate. The HCCs or the Discharge Coordinator telephoned me with the name and phone number of the consenting participant. The HCCs and Discharge Coordinator were thanked and notified to cease recruiting once ten participants were enrolled in the study.

The second invitation to participate in the study was extended directly by the researcher once the name and phone number of a potential participant were received. The potential participant was contacted by telephone. A Researcher's Script of Invitation to Participate in Study was developed. Please refer to Appendix G, page 209, for a copy of the script. I read the script to the potential participant. If the caregiver agreed to participate then a time was scheduled to review the consent form and conduct the interview. If caregivers declined to participate, they were thanked for their time. Caregivers were advised that their response was confidential and that no one would be informed of the outcome.

I received a total of thirteen potential participants' names and telephone numbers from the recruiters. Twelve of the potential participants who were contacted agreed to

participate in the study. Two of the participants were ineligible as their care-recipients died prior to the first scheduled interview. One potential participant declined to participate after the purpose of the study was further described. The potential participant informed the researcher that he/she thought the study was on a different topic than the one presented.

Data Collection Methods

Data were collected using a semi-structured interview format. Data collection occurred over two time frames. Fieldnotes were also maintained. The interview setting was either in the participant's home or an interview room in the local RRHA facility. Interviews were tape-recorded and transcribed verbatim.

Semi-structured Interview

Data were collected using a semi-structured interview technique over two time periods. The semi-structured interview was composed of both close-ended questions and open-ended inquiries. Basic demographic information was obtained for a description of the sample. Open-ended questions gave voice to the caregiver's experience. Interviews were tape recorded and transcribed verbatim.

The interview guide was based on the literature, personal clinical experiences, discussions with peers (Home Care Coordinators), Home Care Supervisors and Thesis Committee Members. Person-centered interviewing enabled the researcher to arrange questions to facilitate dialogue (participant as informant) and progressed onto discovery of participant's more sensitive experience (participant as respondent). The interview guide was developed with a laddered approach, arranging questions as to participants'

level of comfort (Price, 2002). Please refer to Appendix H, page 211, for a copy of the Interview Guide.

Interview Time Period

The semi-structured interview format was administered over two time periods. Please refer to Appendix I, page 217, for the Time Line of Events and the Data Collection Periods. Time 1 refers to the "Waiting For admission" interview. The Time 1 interview was scheduled and conducted during the PCH "waiting for a bed offer" period. Time 2 refers to the "Post-admission or Post Decline" interview. The Time 2 interview was scheduled and conducted after the care-recipient was admitted to PCH or after the caregiver (participant) had declined the PCH bed offer.

A brief description of the Manitoba Panelling and Placement Process (for PCH) follows and provides more detail on the study time line (Appendix I, page 217). In Manitoba, caregivers and care-recipients apply for an admission to a chosen PCH. A Home Care Coordinator (HCC) or Access Coordinator of the Manitoba Home Care Program assists these individuals in completing an application/assessment (PCH A/A) form for PCH. The HCC or Access Coordinator presents the PCH A/A to the Regional Health Authority's Home Care Panel. The Panel usually consists of a Home Care Program Manager, Social Worker and a Physician. Once Panel accepts a PCH A/A it is then eligible for admission and the applicant's name is placed on their chosen PCH waiting list(s). The PCH A/A is forwarded to the PCH depending on each Regional Health Authority's criteria for order on wait lists (most use chronological order of date of Panel). Once the PCH A/A is received at the PCH, contact may be made with caregivers or care-recipients to notify them of receipt of the PCH A/A (this depends on each

individual PCH practice). In time, the PCH contacts the caregiver or care-recipient and notifies them that a bed is available. The care-recipient or caregiver has the option to accept or decline a PCH bed.

The interview guide was divided into three data collection sections. The first section of the interview guide consisted of questions pertaining to caregiver demographics. The second section consisted of open-ended questions on the Time 1 experience of waiting for PCH admission. The third section was composed of open-ended questions on the Time 2 experience of post-admission or declining PCH bed.

The length of interview time varied from 30 to 90 minutes. Participants were interviewed at Time 1 or as they were waiting to receive a bed offer from the PCH. Two participants were interviewed twice during Time 1 as the interview could not be completed in one sitting. Six participants were interviewed at Time 2, this interview occurred approximately 1 to 3 weeks post PCH admission of the care-recipient or after the PCH bed offer was declined. Point of clarification – the Time 2 interview occurred after the PCH bed offer was made and an outcome had been achieved.

Data Organization

All eighteen in-person interviews were tape-recorded with permission from the participants. Interviews were transcribed verbatim by the researcher. Each interview was assigned a code to denote a Time 1 or Time 2 Interview. Table 1, page 70, presents the legend of codes. Notes on participant and researcher non-verbal behavior were documented directly on the transcripts. Fieldnotes were documented after the interviews. Fieldnotes reflected research observations, interview contexts, description of body language, and impressions or perspectives on the interview. Colored file folders were

used to organize and store data. Red folders contained methodological documentation; blue folders contained analytic, personal response, fieldnotes, data reconstructions; green folders contained data reductions; yellow folders contained raw data such as transcribed interviews.

Research Setting

Interview times and places were arranged with caregivers. Settings that were convenient to the caregiver were chosen. Six participants were interviewed in an RRHA facility interview room. RRHA facilities that were in close proximity or convenient to the participants' residence were selected. Four participants chose to be interviewed in their own homes. The interviews were conducted in either the kitchen or living room of the participant's home.

Accessing the research setting most convenient to the participant involved considerable automobile travel by the researcher. The research setting was situated within a large geographical rural area. The researcher traveled to the participant's choice of interview sites. A return trip to conduct an interview ranged from 26 kms. to 480 kms. The researcher traveled approximately 5,412 kilometres to conduct all eighteen interviews.

Methodological Rigor

Past literature has indicated that trustworthiness of qualitative research has been demonstrated with the use of various techniques or guidelines. Sandelowski (1993) cautions researchers that "... rigor is less about adherence to the letter of rules and procedures than it is about fidelity to the spirit of qualitative work." (p.2). Sandelowski (1993) advises researchers to use care when relying on rules or guidelines for establishing

trustworthiness "Trustworthiness becomes a matter of persuasion whereby the scientist is viewed as having made those practices visible and, therefore, auditable; it is less a matter of claiming to be right about a phenomenon than of having practiced good science." (p.2). Ceci, Limacher and McLeod (2002) add more support to Sandelowski's (1993) perspective when they suggest that the problem may not be with the rules of establishing trustworthiness but rather the "particular" applications of the rules.

Krefting (1991) proposed that the trustworthiness of qualitative research could be evaluated with Guba and Lincoln's (1989) conceptual model. Establishing methodological rigor with this model uses four aspects of trustworthiness: (a) truth value or credibility (b) transferability (c) dependability (4) confirmability (Krefting, 1991). This study incorporated these four aspects of trustworthiness of research. The practice of these strategies was guided by Sandelowski (1993) and Ceci, Limacher and McLeod's (2002) encouragement on establishing trustworthiness within the spirit of qualitative research.

Truth Value or Credibility

Credibility of research refers to the fit between the constructed realities of the respondents and the reconstruction attributed by the researcher (Guba & Lincoln, 1989). One strategy for ensuring truth value in the study was prolonged engagement at the site of inquiry. I engaged in general conversation with participants before and after each interview. Time was dedicated to establishing a comfortable setting for participants. This practice facilitated rapport with participants. Peer review and debriefing was employed by meeting periodically with thesis committee members and discussing findings, impressions and reviewing audit notes. Negative cases or cases that seemed out

of "sync" with others were reviewed, documented in analytic notes and discussed with peers.

The technique of progressive subjectivism was attempted by recording in the personal response documentation. Prior to each interviews a self query was made as to any "a priori constuctions" followed by a documented reflection post-interview.

Participants were given the opportunity for feedback at the end of each interview in Time 1 and Time 2. Sandelowski (1993) recommends that researchers must account for differences in findings if the participant wishes to change his/her rendition of shared experiences. "As noted previously, the stories that members tell in interviews are themselves constantly changing" (Sandelowski, 1993, p. 5). At the end of each interview I summarized with the respondent the key experiences shared to inquire if "I got it right" (Guba & Lincoln, 1989). At the beginning of the Time 2 Interview I reviewed a summary of what was discussed in the last interview held with the participant.

Transferability

The burden of proof of transferability is up to the receiver to acknowledge (Krefting, 1991). An adequate description of the processes used by the researcher facilitated transferability. Thick and detailed descriptions were documented. Descriptions of time, place, context of interview, physical behaviors, methodological decisions and impressions were documented in appropriate file folders.

Dependability

Dependability refers to the stability of data over time and tracking of changes and shifts in constructions (Guba & Lincoln, 1989). A dependability audit system recommended by Rodgers and Cowles (1993) was employed by keeping four types of

documentation files. Each type of documentation encompassed a distinct category: (1) contextual documentation (descriptions of settings, activities during interview, behaviors, etc.) (2) methodological documentation (3) analytic documentation (4) personal response documentation (reflections, perceptions, a priori thoughts, etc.).

Confirmability

Confirmability assures that the data, interpretations and outcomes are rooted in contexts and person (respondent) apart from the investigator (Guba & Lincoln, 1989). Use of direct quotes and referencing notes were employed. Krefting (1991) recommends six categories of data for confirmability (1) raw data – field notes, use of audio-recorder (2) data reduction (hypothesis) (3) data reconstruction (4) process notes which includes design strategies (5) intentions and dispositions of researcher (6) instrument development (pilot forms, interview question development). The aforementioned categories of data were documented according to topic and kept in file folders. The Thesis Chairperson was asked to serve as an auditor with the commencement of the study.

Data Analysis

The style of data analysis selected to guide this study was thematic content analysis. Burnard's (1991) stage-by-stage method of data analysis served as the general framework for data analysis. Burnard (1991) describes an approach that uses fourteen stages for data analysis. Interviews were recorded, transcribed, read and coded. Categories and themes were developed. This method was well suited to a novice researcher as it offered structure to the practice of data analysis.

A computer-based data management system (Microsoft Word '98) was used to transcribe audio-tapes verbatim. A manual data management system of colored file folders was used to manage and organize all data (transcripts, analytic notes, etc.). Yellow file folders were used to store all raw data – transcripts. Envelope style multi-colored file folders were used to store all categories that corresponded to one theme. An example, a large purple file folder contained all the categories that belonged to Theme II: Emotional Roller Coaster of Waiting. Notes and impressions at the end of each interview were kept in a file folder. Descriptions of nonverbal components such as body language, gestures and settings were noted and recorded on the transcript.

Key Areas of Analysis

The data were organized into three key areas for analysis. Burnard's (1991) stage-by-stage method of data analysis was applied to each key area. The first key area was composed of transcripts from the Interview 1 time period. This key area consisted of a total of twelve interview transcripts. The second key area was comprised of transcripts from the Interview 2 time period (post-admission or declined PCH bed). Six transcripts pertained to the second key area. The third key area explored the Time 1 and the corresponding Time 2 interviews (same participant). A total of thirteen transcripts were reviewed in relation to the third key area. Six of the ten caregivers participated in the Time 1 and Time 2 period interviews. One of the six participants had two sittings for the Time 1 Interview (this accounts for the uneven number of interviews in the third key area). The transcripts from these participant interviews were placed under the third key area for analysis.

Data Analysis Stages

Sandelowski (1995) suggests that the beginning of data analysis occurs at the "... earliest stages of analysis where researchers look at their data in order to discern what to look for in their data" (p. 371). The memos and documented post-interview impressions evolved into the first stage of analysis (Burnard, 1991). The documented memos and notes were kept in a file folder. Two forms were utilized to assist in data analysis and data management. These forms were the general memo form and the transcribed interview review and summary form (Miles & Huberman, 1994).

The second stage of analysis involved typing the transcripts and reading the entire transcript. Notes were made on impressions as transcripts were typed. Transcripts were read in their entirety and line by line many times. Notes were made after reading the completed transcript. The notes were entered in a "Transcribed Interview Review and Summary Form". Transcripts were read individually as a whole and this practice enabled the researcher to become immersed in the data. The researcher must get a sense of each interview before attempting cross interview comparisons (Sandelowski, 1995).

The third stage of analysis involved open coding. Transcripts were read and then codes were written in the right hand side of the transcript margin. Codes were generated through paraphrasing key sections with a few words. Codes identified similar phrases, patterns and commonalties within the data (Berg, 2001). Categories consisted of the grouping of similar constructs, these constructs were contained in the codes. Categories were generated and documented directly on the transcript and later transferred onto a documented memo form. At this point in data analysis the committee chairperson was consulted to review progress on codes and category development.

Grouping categories under higher-order headings comprised the fourth stage of analysis. Broader categories were developed and documented on a general memo form. The fifth stage involved reviewing and re-working the list of categories and higher-order headings. Stage six involved consultation with a colleague or peer for review of the progress of data analysis and category generation. The Thesis Chairperson was presented with the transcripts and notes on analysis including categories for review.

Transcripts were re-read to determine if adjustments or changes to categories and subheadings were required (stage seven). The transcripts were worked through with the use of colored highlighters. Colored highlighters were used to circle quotes that corresponded with the categories. In stage nine the color coded sections were cut out of the transcript and placed in a file folder of the same theme. The next step involved organizing the color coded sections in each folder. The contents of each folder contained a theme and the supporting categories. The color coded sections of each category were taped onto long streams of computer paper. The data in any of the categories were kept intact and reviewed in this manner. Category data were filed under the corresponding theme file folder.

Time Ordered Data Matrix

Data analysis on the third key area was performed in the same manner as above. A time ordered matrix display was developed to assist with the process of data analysis. The coded sections of the transcripts were entered in time sequence (before and after admission/declined bed). This visual device aided in category and theme development. Figure 2 (page 67) presents an example of the matrix that was utilized.

Figure 2

Anticipated Versus Actual Response To PCH Admission

Individual Code	Time 1 Interview Anticipated Response to Admission	Time 2 Interview Actual Response to Admission
CG* 100		
CR* 100		
CG 200		
CR 200		

* CG represents Caregiver and CR represents Care-recipient.

The writing up process began once all the data were organized in categories and under the corresponding theme. Interview quotes were used to link data examples in each category.

Summary of Chapter III

A qualitative approach, prospective in nature, served to explore the caregiver's experience of waiting. The focus of study was caregivers whose care-recipient was waiting for and admission to personal care home. Person-centered interviewing served as the method for this qualitative study. Data were collected with a semi-structured interview guide. The design was prospective with interviews scheduled at two data collection time periods. The research setting was in the participant's home or a health

facility interview room. The establishment of trustworthiness for qualitative research was described. The process of data analysis selected was Burnard's (1991) stage-by-stage method. Data were organized into key areas for analysis. Ethical considerations were described. Ethical approval was received from the Education/Nursing Research Ethics Board (ENREB), University of Manitoba and the RRHA Internal Ethical Review Board.

CHAPTER IV

FINDINGS

> You're getting the freedom you've been wanting uh to live your life, and it's now to debrief yourself from that....and do what you always wanted to do all along....but because of the vulnerability of the aged parent you still have that concern ...for their care uh.....you still feel that you have to ....continue to be a caregiver in a lesser way possibly...(Ann-C,1754-1759).

Introduction

In Chapter IV I present the qualitative analysis of eighteen interviews. Three key thematic areas describe the participants' experience of waiting for a Personal Care Home (PCH) admission for their family member. These include (1) Waiting for Notice of an Available Bed (or "the bed offer") at the PCH (2) The Admission Day Experience (3) Anticipated versus Actual Admission Experience. Table 5, page 77, illustrates the key areas and themes arising from the data analysis.

Description of the Participants

Ten caregiver participants were recruited and participated in this study. The caregiver participants are referred to as either caregivers or participants throughout this chapter. The coding of transcripts, number of interviews, and pseudonym legend are presented to ensure clarity of the findings. Demographic data describe the caregivers and care-recipients. The data include items such as caregivers' age, gender, relationship to care-recipient, employment status, length of time waiting, receipt of bed offer, and onset and length of caregiving. Care-recipient demographic data include age, gender, location and general diagnosis.

Interview and Transcript Codes

All ten caregivers were interviewed at least once as they waited for the PCH bed offer. Two caregivers were interviewed twice during the waiting period as the interview guide could not be completed in one sitting. The first interview for all the caregivers was coded as the "A" interview. For the two caregivers who received a second sitting of the "waiting" interview, the first interview was coded as "A" and the second sitting had a code of "B". Table 1 lists the transcripts number, codes, pseudonyms, number of interviews and relationship to care-recipient.

Table 1

Transcript Codes, Pseudonyms and Interview Number

Transcript Code	**Pseudonym**	**Time 1 Interview Code**	**Time 1 – 2nd Sitting Code**	**Time 2 – Interview Code**	**Relationship to Care-recipient**
100	Ann	Ann [A]	Ann [B]	Ann [C]	Daughter
200	Oli	Oli [A]	N/A*	Oli [C]	Husband
300	Bob	Bob [A]	N/A	Bob [C]	Son
400	Dan	Dan [A]	N/A	N/A	Nephew
500	Eve	Eve [A]	N/A	Eve [C]	Daughter
700	Jim	Jim [A]	N/A	N/A	Brother
800	Jan	Jan [A]	N/A	N/A	Daughter
110	Sam	Sam [A]	Sam [B]	N/A	Son-in-Law
900	Art	Art [A]	N/A	Art [C]	Husband
210	Sue	Sue [A]	N/A	Sue [C]	Daughter
Total Number of Interviews n=18		**n=10**	**n=2**	**n=6**	***N/A refers to not applicable.**

Six caregivers were interviewed after their care-recipient was admitted to a PCH (post-admission interview) or if the caregiver declined the bed offer. These interviews were coded as "C". One caregiver was unavailable for the post-admission interview after numerous attempts by the researcher to schedule an interview and the participant did not return calls. Three caregivers remained waiting for a PCH bed offer at end of the eight month data collection time frame. Pseudonyms were assigned to caregivers, care-recipients, family members and involved professionals to protect their identities.

In summary, twelve (n=12) "waiting for admission interviews" were conducted and six (n=6) post-admission (or declined bed offer) interviews were completed for a combined total of eighteen (n=18) interviews. All interviews were transcribed verbatim by the researcher.

Caregiver Demographic Data

The ten caregivers who participated in this study had a mean age of 62 years, a median age of 61 years and an age range of 43 to 89 years. Six of the caregivers were male and four were female. Four caregivers were daughters. Two caregivers were spouses (husbands), one was a son, a nephew, a brother, and a son-in-law. Three caregivers were employed full-time, four caregivers were retired, one caregiver was employed part-time, one caregiver was semi-retired and one caregiver was a full-time caregiver at home.

Four caregivers had a sudden onset of assuming caregiving tasks and role whereas six caregivers reported a gradual onset. Eight caregivers had been providing care to their care-recipient for more than one year and two caregivers had been providing care for

three to six months duration. At the time of the first interview, four caregivers had been waiting longer than 4 months for a PCH bed offer, four caregivers were waiting 2 to 4 months and two caregivers were waiting from one week to less than 2 months for notice. Table 2 presents a summary of caregiver demographics.

Table 2

Caregiver Demographics

Age	Age Range = 43 – 89 years Mean Age = 62 years Median Age = 61 years Age in years: 89,74,69,69,63,59,53,52,49 and 43
Gender	Males = 6 Females = 4
Employment	Retired = 4 Full-time = 3 Part-time = 1 Semi-retired = 1 Other = 1
Onset of Caregiving	Gradual = 6 Sudden = 4
Duration of Caregiving	> 1 year = 8 3 to 6 months = 2
Length of Wait for PCH Bed Offer	> 4 months = 4 2 – 4 months = 4 1 week to <2 months = 2
Outcome of Bed Offer (n=6)	Accepted = 4 Declined = 2

At the conclusion of data collection, six caregivers received a PCH bed offer, four caregivers accepted the PCH bed and had the care-recipient admitted to PCH. Of the four caregivers who accepted the bed, two were male spouses and two were daughters. The remaining two caregivers declined the PCH bed offer, one declined during the bed offer time frame and one caregiver declined the PCH on admission day. Of the two who declined the PCH bed, both caregivers were adult children (a daughter and a son). The

two caregivers who declined the PCH admission were providing care to their cognitively impaired parent (one mother and one father). Both adult children caregivers encountered opposition to persisting with the PCH admission, the opposition was from the parent. Both parents were cognitively impaired but each could express opposition to a PCH admission. The adult children were not willing to contravene the care-recipient's request. Table 4, page 76, presents a summary of caregivers and the PCH bed offer outcome.

Care-recipient Demographics

Nine care-recipients were female and one care-recipient was male. This finding is consistent with population statistics that identifies more females live longer than males (Centre on Aging, Fact Book on Aging, 1996). The ten care-recipients had an average age of 83.5 years, a median age of 83 years and an age range of 71 to 99 years. Six care-recipients had a major diagnosis of cognitive impairment, three experienced a combination of physical and cognitive impairments, and one care-recipient was living with a serious physical impairment. At the time of study, four care-recipients were living in their own suites in an Elderly Persons Housing Unit (EPH), three were living with the caregiver (in the caregiver's home), one care-recipient was in hospital, one was in a PCH respite admission and one lived in her own house. Table 3, page 74, provides a summary of the care-recipient's demographics.

Table 3

Care-recipient Demographics

Age	Age Range = 71 to 99 years Mean Age = 83.5 years Median Age = 83 years Age in Years: 71,75,78,81,83,83,87,89,89 and 99
Gender	Males = 1 Females = 9
Medical Diagnosis	Cognitive = 6 Combined cognitive & physical = 3 Physical = 1
Current Location or Residence	Community – Elderly Persons Housing = 4 Caregiver's Home = 3 Community – Own Home = 1 Hospital = 1 Respite Bed (in PCH) = 1

Demographic Summary

The caregiver sample shared both similarities and differences. There were differences in relationship as 40% of the caregivers were daughters, 20% were spouses and 20% were other. Interestingly 60% of the caregivers were male and 40% were female. The caregiver sample varied in age and relationship. The age difference in caregivers was notable as the youngest caregiver was 43 and the oldest caregiver was 89 years (difference of 46 years). The two spouse caregivers were older males and had accepted alternative arrangements for the physical care of their wives as they waited for notice of a PCH bed. The remaining caregivers were able to provide or arrange for the provision of the physical tasks of caregiving in the care-recipient's home.

The main similarity shared was the caregiver role. The majority of the caregivers were providing care to cognitively impaired care-recipients and had been waiting for

some time (80% > 2 months) for a PCH bed offer. The caregiver demographic variables could not be linked to any particular aspect of the qualitative findings.

The care-recipients were more similar in age characteristic, the youngest care-recipient was 71 years and oldest was 99 (difference of 28 years). The care recipients were mostly older women with cognitive impairment.

Table 4

PCH Bed Offer Outcome

Pseudonym	Relationship to Care-recipient	Care-recipient Impairment	Outcome
Ann	Daughter	Cognitive & physical	***Accepted*** PCH bed offer.
Oli	Husband	Cognitive	***Accepted*** PCH bed offer.
Bob	Son	Cognitive & physical	***Declined*** PCH bed offer.
Dan	Nephew	Cognitive	Not available for outcome interview.
Eve	Daughter	Cognitive & physical	***Accepted*** PCH bed offer.
Jim	Brother	Physical	No bed offer received at end of data collection period.
Jan	Daughter	Cognitive	No bed offer received at end of data collection period.
Sam	Son-in-law	Cognitive	No bed offer received at end of data collection period.
Art	Husband	Cognitive	***Accepted*** PCH bed offer.
Sue	Daughter	Cognitive	***Declined*** PCH bed offer.
			n = 4 accepted PCH bed offer n = 2 declined PCH bed offer n = 3 remained waiting for offer n = 1 not available for Time 2 interview.

Table 5

Key Areas and Themes

KEY THEMATIC AREAS OF ANALYSIS		
KEY AREA I: **Experience of Waiting**	**KEY AREA II:** **Admission Day Experience**	**KEY AREA III:** **Anticipated versus Actual Admission Experience**
Theme I: Reviewing One's Decision to Apply	Theme I: The Bed Offer is Made: FeelingYes/Saying Yes	Theme I: Anticipating Difficulties
Theme II: Emotional Roller-coaster of Waiting	Theme II: Passing of the Torch: New Caregivers, New Location	Theme II: Mismatched Expectations
Theme III: Worry, Worry and More Worries	Theme III: Moral Support From Family Members	
Theme IV: Dreading or Welcoming the Anticipated Bed Offer		
Theme V: Preparing for an Unknown Admission Day		

Key Thematic Area I: Experience of Waiting

The first area concerned the participant's experience of waiting for notice of an available bed at the Personal Care Home (PCH). Five themes emerged and accounted for this experience. These themes include: (1) Reviewing one's decision to apply for PCH (2) The emotional roller-coaster of waiting (3) Worry, worry and more worries (4) Dreading or welcoming the anticipated bed offer (5) Preparing for an unknown admission day.

Theme I. Reviewing One's Decision to Apply for PCH

The caregiver spends considerable time reviewing his or her decision to apply for PCH admission for the care-recipient. The waiting period is often lengthy and this time provides frequent opportunity to mull over this significant decision. Caregivers take this decision seriously and respect the importance that it holds in both their and the care-recipient's life paths. Four categories support the theme of *Reviewing One's Decision to Apply for PCH.* The four categories are: (1) rationalizing the decision to apply for PCH (2) feeling solely responsible for making this difficult decision (3) reviewing the timing of the decision – too soon or too late? (4) family support versus family conflict regarding PCH decision.

Rationalizing The Decision To Apply For PCH

The first category involved rationalizing one's decision to apply to PCH for the care-recipient. Caregiver participants needed to rationalize this important decision as they continued to wait for a PCH bed offer. The waiting period can be lengthy and this provides caregiver participants time to justify the decision to seek PCH placement. Many different factors support the reasoning that PCH is a viable option for care provision.

One factor described caregivers who perceived that they were encouraged by health professionals to apply for PCH. Caregivers were thus advised that PCH was the only option for long term care provision. At times this advice was perceived as straight forward.

> I was told by other people I should do that…(Art-A,487-488)

> I didn't you know, at the time when Helga [wife] was in the hospital, in October, and she was released from her stroke, you know, they told me, social worker, physiotherapist, and what is the other therapist…(Art-A,492-495)

> The physiotherapist they were all there in the room, they were talking to me you know, and they suggested Sunnybrook Hospital, there is an interim facility until she gets placed into a permanent home…(Art-A,499-502).

A feature of justifying one's decision is reviewing and accepting how difficult it was to arrive at this decision. Caregiver participants often described what a hard decision it was to make even when others were encouraging them to continue with the decision.

> I guess in part it was through talking with other people and then Marg [wife] working here. We knew people to talk with and stuff and and they kept telling us like do it now don't wait, do it now and that was probably the hardest decision that we have ever had to make in our lives because we said we would look after her as long as we possibly could… (Sam-A,27-32).

In another scenario a caregiver participant related discussions she had with the care-recipient on future plans for care provision. Even though pre-planning with the care-recipient occurred the final decision to persist with PCH admission remained difficult.

> So Mom and I talked about it and sometimes the kids have to over-rule for what's best for them because they were living in un..and home care was saying they were living in an unsafe environment and like you can't do that and she said you know she always said she never wanted to live with one of her children and that we were always to make a decision and and place her even if she said even if I go kicking and screaming….you know…and that's not me, remember that's not me…so we had talked about it in context of my aunt and uncle …and I always

> thought that would make this whole thing way easier…umm…[laughs – hesitant, nervous type laugh]…
>
> Interviewer: It doesn't?
>
> Participant: No… (Jan-A,267-281)

When rationalizing and reviewing the decision to apply for PCH caregiver participants experienced considerable ambivalence over their decision. The unpredictable nature of a cognitively impaired care-recipient added to this ambivalence. Caregiver participants reviewed their decision to determine if they had made the "right" decision. Caregivers could more easily justify their decision if the care-recipient experienced a physical decline, but a cognitive decline was more difficult to reason.

> It was really it was really really a tough time a really um because if it was a physical thing for me, I think, it would be easier saying because I know there's it's either going to stay the same or get worse, you know like I mean at some point you know sorta the prognosis for physical, but but ….um with a cognitive impairment like that you have no idea day to day…you know, well actually hour to hour [laughs]…what it is that that is linked to… (Jan-A,181-188).

Caregiver participants considered the importance of keeping the care-recipient safe when rationalizing their decision to persist with the PCH application and waiting process. In circumstances where the care-recipient was cognitively impaired, value was placed on safety as being paramount to the plans of PCH care provision.

> Yeah you try and balance your decisions and then everything goes okay you can get away with it but sometimes I realize that something could happen but I'm I'm but we both realized that us we're in a situation where something could happen and if something did happen maybe we would feel guilty about that or I don't know you know if my mother put the house on fire and they burned uh….(Bob-A,1360-1366)

As part of the process of continuing with the placement decision, caregiver participants recognized that they reached their capacity of providing long term care to the

care-recipient. Caregiver participants described reaching a point where their ability to cope affected the quality of life of both care-recipient and caregiver.

> They all go in there....and that sort of you know "Did I do the right thing" Yeah and totally questioning and sometimes you know...[pause] I I am quite sure I did the right thing because ...um...it's dumb but some of the things that I never thought would be hard in this situation are hard the the ....lack of social skills and the fact that you couldn't do nothing about that at a a table...uh uh just get to you and I you know I I'm pretty even tempered but I snap and then I think yeah okay this is better cause then she'll get upset cause I'm upset and you know [laughs – nervous teeter] self-fulfilling philosophy..you know thing but um it so then I think well yeah then then it's better for all of us cause I can calm down a little ....and and she you know when I see her when I'm with her there will be quality time.... (Jan-A,337-350)

A contributing factor that appeared to affect the caregiving capacity was limitations of available formal support services, for example Home Care Services. Caregiver resources and the formal system gradually became inadequate to maintain the care-recipient at home. Caregivers felt that there were no options left for continued care in the care-recipient's home setting.

> No I mean there really isn't I mean when they get to that age and all this you want them to have some quality of life and uh so and you know they can't have it at home and uh you know so that the nursing home is about the only option like I am self-employed and I have a lot of customers...and uh they have uh you know these are more wealthy people and they have home care 24 hours a day well of course uh in that case my parents wouldn't be able to afford that eh to have somebody come in 24 hours a day like uh private company so so this is about the only option (Bob-A,388-396).

Part of rationalizing the decision to continue with waiting for PCH admission involved recognizing that a nursing home was indeed an acceptable care option. Caregivers viewed PCH admission for the recipient as a new residence or new home setting. Caregivers perceived that they would continue their relationship and person-to-person contact with the care-recipient.

> ...and like it's just a different address for her to go to and all this and a different home and uh and uh I mean a lot of people are very happy there you know so... (Bob-A,1167-1169).
>
> It will be like [nervous laugh] it will be a stressful day but I guess uh I don't know whether uh and then depending again how my Mother's reaction is I mean I don't think me myself personally if I take my mother down there I know I'm not putting my mother away in an institution where I can't never see her again I'll be able to go and visit her there I mean it's just like going to uh uh to her home it just means we'll be going there the family to visit her there we'll be going there on the weekends and whatever you want...
>
> Interviewer: right...
>
> Participant: and we can take her out we can take her to a restaurant and all this so I don't think it will affect us Rita [wife] and I personally it will just seem... (Bob-A,1240-1251).

Caregivers dedicated time to reviewing their decision to seek nursing home admission on behalf of the care-recipient. It was not a decision taken lightly as caregivers carefully rationalized and reflected on this decision. Different factors influenced the reasoning that supports the decision for admission. Some of these aspects were the role of professionals as they encouraged caregivers to apply for PCH placement, the difficult and emotional nature of the decision, care-recipient's safety, reaching one's capacity for caregiving, and nursing home as an acceptable option for long term care.

Feeling Solely Responsible For Making This Difficult Decision

Caregivers felt solely responsible for making the difficult decision about placement in a PCH. This was often reported as a solitary decision which is constantly reviewed during the waiting period for a bed offer. Caregivers felt that they were "the" individual responsible for deciding to apply to PCH and continuing with the wait of a PCH bed offer for the care-recipient. Caregivers identified the need for imminent PCH admission for the care-recipient, however, they viewed themselves as responsible to

make this decision. One caregiver in particular expressed the wish or desire for someone else to make this decision.

> Cause mostly, now just you know talking talking to Kate and Donna actually [Home Care Coordinators] came to part of it um…and and just offered not advice but some things to think about it and that was the nicest was….well I wanted somebody else to make the decision [nervous laugh, serious facial expression or strained facial expression when making this comment] um….
>
> Interviewer: you did eh…..
>
> Participant: Yeah, I really really inside thought like I want somebody to say to me you know…this is the ….right…thing …to do…(Jan-A, 219-233).

One of the caregivers expressed a practical outlook in making the solitary decision that PCH admission was needed. The necessity of the decision was recognized and acted upon.

> Well well it didn't really bother me you know, it's just a part of process of life and all this and you have to go through that and if it's no big and I wasn't depressed or anything like that I mean I felt it just had to be done and you know and we were going to go through with it and I knew way along in making the application wasn't going to do much of anything for quite a while so anyways we were going to run into problems later on…(Bob-A, 278-284).

Even though caregivers sought advice or confirmation from others that this was the right decision, this support did not always alleviate the responsibility of making the solitary decision. One caregiver invited family members to make the decision of PCH application. After consulting with family members the caregiver was still left with the ultimate responsibility of the decision.

> My brother has…my one brother um that lives in Melfort has definitely said you that…he feels that is the right thing to do …and um…my sister says the decision is up to me um…uh….and my other brother who has been most involved in caregiving um says it's up to you too but in a different man…you know like he…more of just says whatever [shrugs her shoulders] and Gary says you you are the only one that can sit in that place and make that decision now and…you make it and we are right there with you…um…but sometimes lots of times I still don't know if it's….the right…. (Jan-A,237-246).

Once the decision was made and acted upon, caregivers accepted the responsibility this incurred. One concern in particular appeared to add to the overwhelming factor of making such an important unilateral decision. A few of the caregivers in the study had not informed the care-recipients that their application had been paneled, accepted and placed on a PCH wait list. The caregivers were unsure when to approach the care-recipient with this information. The reason most often given for not sharing the decision was that the care-recipient was cognitively impaired and this information might upset them. As one caregiver explained:

> And that's part of the waiting now is thinking like Mom has no idea I've done this...um...because, um...to me if I told her she would forget...um or she would be upset and what portions of it she did remember for that period of time if she happened to be upset she would be up...so I would just make her upset if she is going to be upset about it I will make her upset when things are going to happen, because she doesn't have the memory...(Jan-A,285-292).

Many of the caregivers experienced an overwhelming sense of responsibility for this very serious decision. Even though others provided advice and confirmation, this still did not ease the caregiver's sense of solitude in making the decision.

Reviewing The Timing Of This Decision – Too Soon or Too Late?

The third category of reviewing and revisiting the decision to apply and wait for a PCH admission involved questioning the timing of the decision. Caregivers frequently wondered if they made the decision too soon or too late. Caregivers would review the timing of their decision based on the day-to-day health status of the care-recipient, preventing a crisis situation in care provision and the consequences of declining a PCH bed offer.

Many caregivers questioned whether the care-recipient's health status would match the need on the actual admission date. Some caregivers expressed hope that the PCH bed offer would come when the care-recipient really needed this care option because of failing health.

> Well uh I don't know if whether it is comforting to know that she might go in there this summer. Like we keep on looking at this situation okay uh it's it's is it deteriorating? If it deteriorates to the point where it is getting so bad than it won't be that hard to put her in, you know. But if she is still okay and uh then of course uh it will be harder then it's going to be harder so uh it's almost crazy to think "oh I hope my mother is going to be at the point where uh she is ready when they call that she is going to be ready for…that she has to be ready for the home" and you know, you kind of would like her to be better but then you know if she is going to be better then we will pretty well have trouble getting her in the home you know, so…it gives you mixed emotions and all that like like you sometimes wonder is she going to be ready when they call, is she going to be ready for it like the longer you wait you know the situation don't improve and it deteriorates so uh by the time we get the call she might be more than ready or she might really have to go.. (Bob-A,1486-1502).

One caregiver did feel a sense of relief in knowing that the decision was made even if it involved taking a risk that the health status of the care-recipient might not exactly match the need for placement.

> Yea, it was sort of a prepatory thing….like, um, I could have said, no we can wait, and I could have waited until it got really bad, but I am the kind of person who is prepared kind of thing, so it was a relief, I knew it was coming, it is sort of a relief to know that she is going to get the care when the time comes. (Ann-A,89-93)

Preventing a crisis in care provision to the care-recipient was important to some of the caregivers. One caregiver expressed concern that she did not want a crisis to occur and therefore she felt committed to follow through with the decision to wait for a PCH bed offer.

> But I could wait longer to have her paneled till I felt more sure and then think about placing her somewhere else for a period of time [interim] you know that that they wouldn't leave me in a crisis …um…and uh…so just weighing all those

> things against the fact that you're wondering [laughs] if...you know...so then so then I just finally you know we talked my husband and I and we said well um...we can give her more of a life being here [PCH] even if it's too soon...or sooner than we thought we would place her in PCH if we place her...(Jan-A,196-204)

Fear of declining a PCH bed factored into reviewing the decision to continue the wait for a bed offer. Several caregivers expressed the concern that declining a PCH bed offer would start a new and lengthy wait for PCH when a more urgent need could arise in the interim. Caregivers worried that if the care-recipient's cognitive and/or health status was stable at the time the bed offer was made, they might decline the offer. Caregivers, however, were aware that there would be consequences to declining the PCH bed. The perceived consequences were that the care-recipient's name would be removed from the waiting list of the first choice PCH (often these had long waiting lists) and the care-recipient would have to take a less desirable nursing home if a crisis in health or care provision occurred.

> Yeah because we uh you know uh we didn't know for sure if she would be able to carry on in her home and all this and um and and we knew that the waiting period would be a long long time so especially in Silver Home [PCH] uh so we figured well we would apply and a you know we are looking at the situation where I think her name is getting closer to the top and uh and now she seems not too bad right now....but uh but then we are thinking we don't want to turn it down then you are going to go to the bottom of the list or you're maybe you're going to be scratched off and uh you know (Bob-A,124-132)

Caregivers frequently questioned the timing of their decision to apply and wait for a PCH bed. One caregiver spoke to this with clarity and sensitivity:

> So then the big decision you know Kate [Home Care Coordinator] talked to me lots and lots about was...like when you know now that I had the physical [medical examination of care-recipient] like when did I want her to go to panel.....um...and that was ***a huge***[emphasized] and that was such a hard decision and and some of that is still that rollercoaster thing, did I go too soon, did I not go soon enough.....um....because you can't know the progression of of ....of anything. (Jan-A,158-164).

Family Support Versus Family Conflict Regarding PCH Decision

The last category of reviewing one's decision to apply for PCH involved caregivers exploring the role of other family members in this decision. Caregivers appraised the past and/or ongoing family support or differing of opinions when thinking about the decision to panel and continue with the PCH wait.

Caregivers appreciated support demonstrated by other family members. Support was often conveyed by agreeing and cooperating with the decision to panel and wait for a bed offer.

> My sisters are very cooperative like there is no problem. There is no problem with my sisters they are sort of agreeing with the whole thing and uh they know what he is like and all this you know so…..and they you know they keep on saying you know uh I've been really understanding trying to do my best and all this, because they know they don't have the patience uh to put up with all that bullshit sometimes (laughs)….you know.
>
> Interviewer: yeah, so you're actually all working together like your…
>
> Participant: Yeah, we're all trying to and you know and like… (Bob-A,1113-1124).

One caregiver valued a key family member who was more influential with the care-recipient. The caregiver was a younger brother providing care to an elderly sister. The prominent family member, an older brother, became an ally when discussing with care-recipient the need to apply for PCH and continue with the wait.

> Well, I think she's doing the right thing….
>
> Interviewer: um hum…
>
> Participant: Yeah and my older brother does too, he he's been saying to me like we discuss it sometimes that she should really be down on this side [participant is referring to PCH as sister lives in attached EPH] this is where she should be, and more than likely he has said to her the same thing, which is make her agree she

> thinks, he says it was for her to do the best thing for her to do she would probably do it, and that would be another answer for up above here……
>
> Interviewer: yeah like the two of you if you….
>
> Participant: yeah like well yeah, if he said she would it's like this it's like that
>
> Interviewer: she values his opinion…..
>
> Participant: oh yeah, yeah….(Jim-A, 207-221).

Family conflict or disagreements surfaced during the planning and ongoing decision making process. Caregivers considered the nature of the conflict when thinking about the care-recipient waiting for a bed offer. Family discord, at times, had the potential to create more tension for the caregiver.

> I wanted her to go into a home in Winnipeg cause that's where my son lives…[takes a deep breath/sigh] so it wasn't my decision to have her here, but I'm not unhappy with Linden Place (local EPH)…you know, but it was Dave [brother] and Denise [sister-in-law] that did that….um because Denise. [sister-in-law] is Bruce's [husband] sister there is a close family relationship you know, and we're we're involved in all of the decisions…and my sister Terry was married at nineteen and moved away…and most of the time she has lived in the States….she doesn't understand the system always and she's um….well I'll have to confess, last summer at one point she phoned and was telling me everything I should be doing for mother and this and that and everything and I literally blew just terribly on the phone and hung up on her. (Eve-A,146-160.

One caregiver predicted that the strained family relationships would actually improve or resolve once her father was admitted to PCH. The care-recipient was living with the caregiver and one family member (a sister) would not visit the care-recipient in this setting.

> So the one that I have a problem with, well I don't think I have a problem with but she has a problem with me, doesn't matter which way you look at it, but like she's welcome to come here and see my Dad, she will not, she won't even phone me…since we went to the nursing home together, I mean we've done everything together and I was really shocked when all at once she turned on me like that that she will not come out ***here*** [emphasized]…so that's another reason why my Dad

> wants to leave here....I think because he uh this way...he doesn't see her very often, he doesn't see his grand-children very often from her her family.....
>
> Inteviewer: okay....
>
> Participant: so that's another reason why I think once he's in a neutral place ....
>
> Interviewer: yes....
>
> Participant: things will pick up for him. (Sue-A,506-517)

Theme I. Summary

The four categories composing the Theme of Revisiting One's Decision to Apply for Personal Care Home have relevance for the caregivers. Waiting for a bed offer permits time for caregivers to second-guess and question the decisions for the care-recipient's future care provision. Revisiting these decisions may create more questions for caregivers. The first category described how caregivers felt the need to justify their important decision in making an application to PCH for their care-recipient. The second category presented the singularity that caregivers felt in persisting with the wait for a PCH bed offer. The third category presents how caregivers reviewed the timing of their decision to apply for PCH and if timing matched appropriateness of need for admission. The last category discussed how caregivers valued positive family support while waiting for an offer.

Theme II. The Emotional Roller-Coaster of Waiting

> Yeah, just you know those stupid feelings that um you know you would feel really good and really bad all at the same time but that really good that she is comfortable where she is and really bad cause cause those times then you know she has no idea who you are....cause sometimes I try to fool myself....you know...(Jan-A,676-680).

Caregivers described a range of emotions that occurred in different or similar contexts. Caregivers felt as if they were on the ride of their life and would gladly welcome the occasional break from it. Many emotions were recounted but, of all these, guilt seemed the most prevalent. Logic was used to battle guilt. The emotional struggle was far from over as admission day loomed in the future. Five categories were developed from the data and accounted for the second theme. These included: (1) The ups, the downs (2) The prevalence of guilt (3) Feeling relief (4) Anticipating a loved one's mortality (5) Oh the pressure! The stress continues.

The Ups, The Downs

The first category represents caregivers' descriptions of a waiting period fraught with mixed feelings and emotional swings. Caregivers had difficulty at times naming the emotions they experienced, yet they quite clearly indicated they felt mixed emotions.

> Yeah, it's not like a drastic thing, so it's a ....don't mind me I do this [wipes some tears from her eyes] menopausal stuff...[laughs] (Ann-A,255-256)

> Yeah, get really emotional but you are not really emotional...(Ann-A,261).

> I really don't know I think I've said basically everything that I could think of, it's uh with mixed feelings that you wait and although I know once he's in there ...it's just this initial ...step that's really gonna be a big problem (Sue-A,1237-1240).

One caregiver expressed a contrary emotional aspect of his experience of waiting for a bed offer. The caregiver was minimal in his emotional experiences around placement.

> Interviewer: Some caregivers experience a lot of different emotions while this waiting period is going on, has this happened to you?
>
> Participant: I'm not a very emotional person really…
>
> Interviewer: Oh yeah….
>
> Participant: Nothing too extreme…just ….common stuff…
>
> Interviewer: Oh yeah….day to day?….
>
> Participant: Yeah… (Oli-A,110-121)

The context of the emotional sways was well described by caregivers. One of the situations that evoked emotional responses from caregivers occurred when facing some of the difficult decisions in planning care for one's care-recipient. One caregiver relayed his experience.

> Yeah whether she should be going there you know you know and then we kind of wonder whether uh uh she would be more comfortable in her own home then she would be in the uh nursing home…Yeah uh I sort of you guess….mixed feelings about it like you know it's ah ah my Mother, always said we'll see what happens [laughs] and well anyway uh well of course you know well uh we all know what's going to happen and all this…(Bob-A,1509-1519).

Caregivers often linked the emotional roller-coaster ride to the relationship with one's care-recipient. If the care-recipient was happy or was experiencing a more settled time then the caregiver expressed a sense of contentment for the moment.

> Well, it it is just like you feel like you're on a roller-coaster I guess that's the best way I could explain it because you're ukhh you know you're so happy that she's back like calm again and and more at ease inside of herself and and your homelife is more comfortable but then you're always on edge and you're second guessing what she's saying and doing…so it's just….(Jan-A,141-146).

Caregivers recognized the fragile health status of the care-recipient; this most often involved cognitive frailty. One aspect of this frailty pertained to the care-recipient as having good and bad days while they waited for a PCH bed offer. One caregiver recounts having to listen to his sister-in-law cry on the phone over the cognitive deterioration of the care-recipient. The care-recipient was living in the same home with the caregiver. The caregiver was aware of the many changes in the cognitive status of the care-recipient. The caregiver described his emotional perspective through this experience.

> She wouldn't accept the fact that Grandma wasn't well, to this day and has not handled that....at all...and and so she phones her up, talks to her on the phone and then phones us about an hour later, and she's crying on the phone, like what's going on you know, it doesn't sound good. And there's some days when she has bad days, but tomorrow morning she'll wake up and be the exact opposite, so like we're on a bit of a roller-coaster ride, and we're happy with it like, we don't have a problem with it...so...just accept the fact that this is the way Grandma's gonna be, and she will not be better I mean that just does not get better...(Sam-A,509-518).

A few caregivers described the turmoil experienced when providing care to a care-recipient who did not recognize the caregiver. Five of the caregivers lived in the same home with the care-recipient during the wait period. All five of these care-recipients were cognitively impaired. Four of these care-recipients were often unable to recognize the identity of the caregiver. Caregivers struggled emotionally with the reality of this caregiving condition.

> Um as opposed to the sometimes you feel imposed upon, put upon, you know she would certainly do it for me but ....you run that whole gamut, yea this is the right thing to the fact that you know then like sometimes she will say oh thank you for things, but some every once in a while you know about 90% of the time, Mom does not know who I am, I'm a significant person but I'm not necessarily her daughter....but 10% of the times she does and and those 10% of the time and she'll say stuff and um then you think but why do those things bug me...so it is a huge rollercoaster [emphasized]....(Jan-A,354-362)

> And they are total up like I mean there's like little room for middle of the road [laughs] it it's huge swings…(Jan-A,367-368).

The last quote quite aptly describes the emotional roller-coaster caregivers find themselves riding. Many events and situations trigger the emotional swings. Caregivers were able to share some of these, for example, the day to day relationship with the care-recipient.

The Prevalence Of Guilt

One of the most prevalent feelings identified and expressed by the caregivers was guilt. Caregivers experienced guilt when they recognized they could no longer continue indefinitely with their duty to physically care for the care-recipient. Guilt also surfaced in a different context. A few of the caregivers described wishing for a vacancy in the chosen PCH and then feeling guilty in the knowledge of how the vacancy was created.

One caregiver described his feeling of guilt when he recognized he could no longer care for his cognitively impaired spouse. This caregiver had tried his best to provide care and keep the care-recipient in the home. The caregiver was exhausted, yet he felt that it was his duty to provide ongoing care.

> So I was still run-down, so that was finally the reason that even uh Louise [Home Care Coordinator] she says and also the Home Care [Home Care Aides] you cannot do this, you cannot do this, you know, and I says I know and and I kind of …..had this guilt feeling….
>
> Interviewer. Yeah….
>
> Participant: about to send her away, you know you think no she won't (Art-A,211-219)
>
> Participant: She she belongs to here, you know, especially since we are married, we are married what 48 years, you know, so to you know….and and you have this this feeling you know, how can you do this, how can you send her, you know, but there was no other way…(Art-A,227-231).

Another caregiver recounted how she felt it was an expectation that the care-recipient should be cared for in the caregiver's own home. The caregiver expressed a sense of relief in that her home was not physically suitable for the care-recipient, yet she still reported feeling guilty.

> She was never was happy on the farm, like she doesn't like farm, and so uh in a sense I I have a I feel a certain amount of relief that I I'm uh I have an excuse, a good one for not totally caring for her…you know… for saying this takes a lot, whereas I'll take her home and look after her, I technically can't ….do it…
>
> Interviewer: Do you feel like that's sort of an obligation….expected of you or….?
>
> Participant: Well, you know as in talking to you that was just what what hit me, like how is this going to sound that I am saying this….that I feel this guilt….
>
> Interviewer: Yeah….
>
> Participant: because, ah if if the situation is that she can no longer be cared for there, am I finding an excuse for myself….but is it a good one or not doesn't matter, it's an excuse. (Eve-A,1161-1179).

Caregivers attempted to reconcile feelings of guilt. Two of the caregivers reported that they had received counseling in the past (related to other issues) and this counseling provided skills to manage some of the feelings of guilt. One caregiver described her approach to offset the effect of feeling guilt.

> You're in turn actually helping them you're not abandoning them cause you do probably get caught up in a guilt situation very easily.
>
> Interviewer: Yeah,….I think so yeah….
>
> Participant: You always have to keep reinforcing your thoughts and things, I'm not [emphasized] responsible but I do have an obligation to see that certain things are done to assist the elderly parents….
>
> Interviewer: And there's ways you do that….

> Participant: And there's ways you do that and there's no guilt with that because you've done what needed to be done kind of thing and you've given them a little bit of independence and um you've been a big help… (Ann-B,889-903).

Logic was also used to mitigate guilt. Caregivers recounted how they relied on logic to counteract the feeling of guilt. Caregivers would argue back and forth within themselves the reason a PCH admission was needed for the care-recipient. Caregivers recognized this was often a solitary debate based on the emotional struggle between guilt and reason.

> Yeah, well, like still like I said before I still have this feeling of guilt when I when I go today and see Helga [wife] today, I say "Frank [self], why did you do this?"
>
> Interviewer: Yeah…?
>
> Participant: but then comes my logic again and says you know you can't….
>
> Interviewer: Yeah….?
>
> Participant: It's just too much,….
>
> Interviewer: there's your feeling part and then there's ……
>
> Participant: Yeah….
>
> Interviewer: thinking part that is…..
>
> Participant: Yeah, exactly, exactly,[stated with emphasis] the feeling part says no, she should be at home, and thinking says no, no no no no listen, you know, it says…. (Art-A,553-572).

At times, caregivers were at a loss to explain the cause of the guilt feelings experienced. One caregiver responded to the query on the source of these feelings:

> Interviewer: Yeah, and where does that where does that pressure come from? Is that society or…….[laughs]….point to your head, yeah……
>
> Participant: [gestures and points hand to self] Oh yeah, I mean yes to a degree I think it is, like there is always….
>
> Interviewer: What makes us think that way…..

> Participant: Yeasss, [stated with emphasis] what does, you tell [stated with emphasis] me! (Eve-A, 1181-1189).

Another caregiver described what she felt was the source for guilt feelings during this caregiving experience. The caregiver attributed some of the origin of guilt to cultural expectation and role-modeling by her parents.

> Yeah, it is sort of ingrained that you know as a parent you look after your children and then the children look after the parent or or see to it that they're care is being looking after or tended to you know, I think it's a country kind of attitude that is expected and the European type of attitude is that the daughter is the caregiver and the sons are the ones that get the riches [laughs] (Ann-A,372-377).

> You know, they automatically assume the daughter is going to look after me, I mean, so it's cultural, it's small town community it's the upbringing it's....(Ann-A,381-383).

> You're very easily convinced , you're actually brainwashed into thinking because that is how you grew up you know Mom and Dad looked after their parents, so it's expected of you whatever.... (Ann-A,387-389).

The second aspect of guilt surfaced when caregivers wished for a PCH bed offer. Caregivers recognized that for a PCH bed offer to be made someone in the PCH had to die. Caregivers expressed making the link of wishing for a bed offer to an involuntary wishing for someone to pass away. Feelings resembling guilt were described in response to desiring or needing a PCH bed for one's care-recipient.

> So, when you hear you know of a death within the facility you know that that you're one step closer which is where we're headed...and once you're headed down that road I want to keep it going and yet feel like isn't that awful that you're almost happy that somebody [whispers] died...and then....
>
> Interviewer: and then it's the circumstances....
>
> Participant: Circumstances, but you know it's like, I guess so everything just being off kilter...you know everything sorta...the dorkiest things throw you off kilter...[laughs]..(Jan-A,1095-1105).

Guilt was augmented given the rural context. Living in rural Manitoba posed a unique consequence in the wish for a PCH bed vacancy. Caregivers who reside in smaller rural areas know many of the local people. This would include knowing the identity of many of the local PCH residents. One caregiver in particular articulated this unique situation and what it meant for rural caregivers.

> So that's the hardest thing or the worst in the waiting period…is that…that…and then I think and then I think like you know I know people here in Rivendale Home [PCH] and I think….like what if they die [whispers the word die]…and that's why Mom has to go like…uhhhh [nervous type giggle]…you know….
>
> Interviewer: Yeah…so you you've got yeah, this conflict…this conflict…..?
>
> Participant: Yes, you know and that's small that's living in a small town and and… (Jan-A,1120-1129).

The caregivers revealed guilt as an emotion transitionally experienced throughout the wait for a PCH bed offer. Caregivers described how they managed these feelings by using logic and rationalization. Rural caregivers were often faced with knowing the person who has vacated a PCH bed and this realization was another source of guilt for some of them.

Feeling Relief

> It was a relief, cause it kind of took the responsibility off me, um, knowing that we are that much closer to getting the care that she needs, so it was, actually I was anxiously awaiting for the time (Ann-A, 16-18).

A sense of relief was often felt in knowing that one's care-recipient was on a waiting list for a chosen PCH. Sentiments of relief were described vividly. Caregivers reported a sense of comfort once the decision was made to apply for PCH admission and to continue with the wait for a PCH bed offer. Caregivers voiced feeling relief on three levels: (1) relief that the PCH application and wait status is complete (2) relief in having

help with caregiving responsibilities (3) relief in knowing that one's care-recipient will be safe.

Caregivers expressed that it was important to have the care-recipient's name on a PCH wait list. The knowledge that one's care-recipient had been paneled, accepted by panel and had their name placed on a chosen PCH wait list, provided the caregivers with a sense of comfort. One caregiver relayed his feeling of relief in knowing that his aunt was on a PCH wait list.

> Uh well I guess it's a it's more or less a relief to get her on a list. I think that's the biggest thing because you know it's gonna be a matter of time just before so I think that's a big big step to get her get her on a list and you know....you know, not being on a list has been a concern because you know you're not lined up to go in so....(Dan-A,165-169)

Caregivers voiced relief that some of the responsibility of caregiving would be diminished. One caregiver related her feeling of relief by knowing that there was an alternative care option for her father. The metaphor of an open door refers to a PCH admission for her care-recipient.

> Wellll, I feel like ummmm, I'm not left alone with a situation that I I really can't cope with at the end, I know that there is something at the end...
>
> Interviewer: that's right....
>
> Participant: You know, I know that right now I I I'm going to give him all the things that I can give him, with my sister's here and my sister-in-law will be coming soon, so I'm trying to give him uh a nice time in-between but I I it's a good feeling, that when things get worse that there is an open door ...you know" (Sue-A,256-266).

Caregivers valued a safe and caring environment for his or her care-recipient. A source of comfort for participants was the knowledge that a chosen nursing home would provide the care required by one's care-recipient. A son, who was the main caregiver to

his elderly parents, poignantly described his feeling of relief while anticipating a PCH bed offer.

> Yeah, yeah so you know once she goes into a nursing home uh it will be a relief for us uh that we know uh she has better care there then she is getting right now, Yeah cause you know because we don't know, like everything on the surface seems to be okay, uh my Dad tells me everything is going okay, but then we hear different stories sometimes from the home care workers and....yeah,yeah. (Bob-A,1320-1325).

Anticipating a Loved One's Mortality

> It will be hard, you know, it it will still be hard because it's added another step down the road...(Eve-A,711-712).

The fourth category describes the caregiver's perception that the waiting period and the admission to the nursing home represents the end of the life-cycle for one's care-recipient. A few of the caregivers relayed feelings of sadness and anticipatory grief as they talked about waiting for a PCH bed offer. Caregivers described having to reason with or console the care-recipient in the realization that PCH admission represented the end of one's life journey.

Many caregivers referred to the waiting period and admission to PCH as the end stage or "last stop on the road" for the care-recipient. Caregivers realized the connection between nursing home admission and the approaching death of one's care-recipient.

> That's how I look at it, that's the end stage, from that part you can just get down, I mean he'll never come out of again....
>
> Interviewer: Yeah.....
>
> Participant: Unless of course somebody holds pulls you up at the, thing is it's a nursing home means a state of mind and body, and once you're there you've reached a certain point in your life...
>
> Interviewer: right....

Participant: and there's no reversing it…you know…(Sue-A,606-617).

Not only had the caregiver created this association, the care-recipient voiced the same or similar sentiment. Caregivers were aware that the care-recipient held the perception of PCH admission as symbolizing the end of their life journey. One caregiver described this same realization during two separate interviews.

> There is advantages, but you know let's face it, I'm not her, okay, and and they associate the long term care [meaning PCH] as the last stop on the road. (Ann-A,217-218).

> I'm not my Mother so I don't know I'm sure that she must have some mixed feelings you know that the time is coming you need that service, but it's sort of the last stop on the road type of thing so (Ann-B,59-62).

Caregivers expressed feelings of sadness and fright as they described anticipating the mortality of the care-recipient. One caregiver had taken her father on a tour of a chosen PCH. As they were touring the nursing home the caregiver felt frightened at the prospect of her father deteriorating to the same stage as the residents she had just seen.

> If they had said for this was interim if they had said for the interim we're gonna put him there where there was people who still "normal" quote unquote normal, just a bit handicapped and older I think that that wouldn't have been a problem. I could've seen him find a few friends where he could actually talk with at his level. But upstairs….that was frightening that was like his…end [softened voice] at that stage. (Sue-A,90-96).

A husband caregiver expressed sadness at the passing of residents from the local nursing home where he volunteered. He anticipated that his wife would follow the same journey once admitted to PCH.

> Well….I've been a volunteer at the Greatview Lodge [PCH]for about 8 years I guess….And I see the all the ….patients there gradually disappearing and stuff like that. (Oli-A,162-164).

> And they are sort of family to me….

> Interviewer: Yeah, yeah…

> Participant: They get to be sort of a family....Sad to see them go gradually....And I can see some of the residents just about....my wife will be later on in a year or two...
>
> Interviewer: um hum...yeah, you must think about that....
>
> Participant: Yeah... (Oli-A,173-183).

The wait for a bed offer permitted a caregiver to reflect on her mother's mortality. The daughter expressed sadness and grief as she anticipated this event of her mother's life cycle.

> The inevitable that will happen. My Mom, she says she's prepared, she says if she knew she was going to die tomorrow she would be already, okay, so that's what's she telling me when the time comes that I guess it's just that part of it um [starts getting teary eyed – dabs at eyes]...
>
> Interviewer: Yeah, it's kinda....
>
> Participant: umm [pauses to wipe eyes]...
>
> Interviewer: it's okay, here [passes some tissues to participant]...
>
> Participant: that I would have to be the one there...[referring to Mother's passing]...
>
> Interviewer: at that point....
>
> Participant: at that point. (Ann-B, 204-221).

Caregivers were faced with having to console the care-recipient in regards to anticipating death as a future resident of a nursing home. One caregiver, however, captured the essence of this experience with humor and sensibility.

> Like my Dad figures you know he said to me uh uh I don't like the idea of going to a nursing home because everybody dies there. I said well Dad uh uh you know that's not true. But in a sense it is true I says people do go there and they are very elderly and it is sort of the last stop and uh I says sure a lot of people do end up dying in a nursing home but I says...(Bob-A,1177-1182).

> Yeah, so anyways I said you know you know they're not going there they don't kill them there. They just happened to get old and uh you know they can't take care of themselves and of course uh and uh they realize themselves we can't stay here forever and all this. Uh uh and it's happening and they see that all their friends are dying...(Bob-A,1187-1192).

Caregivers were cognizant of the fragile health and mortality of the care-recipients. PCH admission symbolized the last phase of the life cycle.

Oh The Pressure! The Stress Continues

The stress of caregiving continued as caregivers waited for a bed offer. Caregivers described feeling frustrated with being on call twenty-four hours a day. Rural caregivers who lived in separate residences then the care-recipient experienced unique challenges to caregiving. One caregiver described the time commitment involved in providing care to an elderly aunt who lived twenty miles away. The caregiver expressed feeling frustrated that he had to take time away from his family and employment in order to perform his caregiving role. Travelling time was substantial in relation to the caregiving role.

> Um but I I just feel for these like I know for 4 weeks now for Monday mornings we've been I've been driving to Wynyard [town 20 miles north]. We've taken the van [handi-van] to Inisfeld [town 20 miles southeast], get the blood done for half an hour and run back to Wynyard [town] and then I run home here...so basically my morning is gone....it's not a big deal but you know when you can be making some money somewhere else (Dan-A,921-926).

Caregivers had to tend with driving great distances to provide care to a family member who lived far from the caregivers' residences or home towns. The drive was onerous when the roads were icy or snow packed and exhausting if the caregiver was tired given other commitments and events. A daughter caregiver (lived on a farm) had driven many miles to care for her elderly mother who lived in a larger rural centre. She described the drive.

> Yeah, you know that three-quarter of an hour to an hour fifteen in the winter, you know, especially that ***that*** [emphasized] drive…
>
> Interviewer: How far is it from your Mom's …place to your place?
>
> Participant: I'd say about fifty miles…
>
> Interviewer: Yeah…
>
> Participant: Maybe a little less, maybe about forty-five I'm not sure, something like that…
>
> Interviewer: Yeah, so it's it's a long drive….
>
> Participant: It's you know, uh it's not quite an hour if everything works fine.
>
> Interviewer: Yeah and the roads are good…
>
> Participant: Yeah, that's about ten miles on the gravel, so….[laughs] (Eve-A,556-574)
>
> To have ***three*** [emphasized] miles on gravel I have to go ***way*** [emphasized] around so I don't do that, although that's kind of an option….(Eve-A,578-580).

Several caregivers described having to drop everything and run. The rural caregivers used the term "run" or "fly off" to describe getting into their cars and driving many miles.

> Because I used to get a call at the office that she is very very sick you know, you got to come home, so you know, my superiors would say okay, you can take three days off and fly off to Foam Lake and I'd get there and everybody in the building would have the flu including me but it ain't Mom [laughs] okay. (Ann-A,291-296).

Some caregivers were frustrated or upset when they were on call most of the time. Caregivers felt they were on call for the care-recipient and at times for Home Care. Caregivers interpreted being on call as fielding phone calls about the care-recipient's concerns or travelling to the care-recipient's home when needed.

> Yeah, yeah I get upset you know, lots of time when I'm on call….

> Interviewer: When you're on call....
>
> Participant: hang up the phone and I think I'm not gonna phone there the old b.i.t.c.h. any more urrrr....you know she's miserable as sin, urrrr....come on now she's your sister, urrrr....[laughs] that causes trouble at home you know, we get arguing, back and forth about it between him and I [partner at home]. (Jim-A, 483-491).

Theme II. Summary

The second theme, *The Emotional Roller-Coaster of Waiting*, recounted the topsy-turvey emotional spin cycle that caregivers described. Caregivers described a wide spectrum of emotions that they experienced while waiting for a PCH bed offer for the care-recipient. Caregivers referred to the emotions as a roller-coaster ride, sometimes they felt bad and sometimes they felt good at the same time. Other feelings that surfaced were guilt, relief, and frustration with continued caregiving. Feelings of fear and sadness when thinking of one's care-recipient possibly dying were also voiced by caregivers.

Theme III: Worry, Worry and More Worries

> But uh....I just worry about meals, I worry about uh you know falling, I worry about uh uh you know not getting looked at that closely...because Home Care they're not nurses...(Dan-A,1066-1068).

The third theme, *Worry, Worry and More Worries*, depicted the many concerns and worries which caregiver participants voiced during the waiting period. Caregivers frequently referred to concerns and worries throughout the interviews as they recounted the wait for a PCH bed offer. The focus of the caregivers' uneasiness was the well-being of the care-recipient. Four categories supported the theme of *Worry, Worry and More Worries*. The four categories were: (1) Is she/he eating enough? (2) What if he/she gets hurt? (3) Concern about the care-recipient's vulnerability (4) Concerns about future care in the nursing home.

Is She/He Eating Enough?

The nutritional intake of the care-recipient was of concern to the caregivers. Caregivers worried that care-recipients had not eaten adequate amounts of food. Care-recipients who were on therapeutic diets and had consumed the wrong types of food was of concern to the participants. Safe storage of food was an issue in relation to cognitively impaired care-recipients. A nephew caregiver lived far from his aunt and he could not be present for most of her mealtimes. He expressed great concern on the adequacy of her food intake.

> Well uh meals is one concern that she is getting eating enough, she was very very thin and uh I don't know if Home Care is enough, they don't force her to eat. (Dan-A,86-88).

> Yeah a worry of that yup and the eating thing too I was concerned about she got her one meal at noon but it was the supper hour breakfast hour I wasn't even sure

> if she was even getting enough. So um there is nothing really structured there as you are kind of on your own so that is the problem....
>
> Interviewer: and Home Care is a supplement...
>
> Participant: Yeah, yeah so you worry about things like that (Dan-A,97-105).

Several of the care-recipients were on therapeutic diets. Caregivers expressed concern over the appropriateness of food consumed. Caregivers worried that the care-recipient had eaten foods that were contraindicated on the therapeutic diet and suffered further ill effects. One caregiver described how his cognitively impaired care-recipient raided the fridge and hid food frequently. The caregiver worried that his mother-in-law had consumed food contraindicated on her low-gluten diet.

> So you you take it as far as you can, you try what you can and when you realize it doesn't work quite to certain degree but it it causes her to binge eat afterwards...so there's no managing it, then she eats stuff that maybe she shouldn't eat, cause she's on this special diet, cause she's glucose [sic – actually referring to low-gluten diet]....uh like she can't eat any flour anything with wheat in it and stuff, but she'll reach into the fridge and grab anything and eat it, and it might be something that she shouldn't so then she gets ill from it....(Sam-B,1545-1552).

Caregivers worried that care-recipients consumed tainted or improperly stored food. This was especially an issue with cognitively impaired care-recipients who lived some distance from the caregivers. Daily physical contact with the care-recipient was not possible and the caregiver was unable to check the quality and location of stored food. A son caregiver describes his experience of finding decaying meat in his parent's kitchen cupboards.

> We have to throw things out because she puts meat in the cupboard and hides things eh? Like you know she saves little pieces of meat and she puts in containers and all this and you know...
>
> Interviewer: and you have to check that...

> Participant: Yeah, so you never know what the heck is going on and cause you know the summer there Rita [wife] and went down there and Rita [wife] says "O my God it smells in this house" [emphasized] and uh....Yeah....so anyways we found...
>
> Interviewer: It was meat?
>
> Participant: Yeah it was meat in the cupboard. (Bob-A,650-666).

The quality and quantity of the care-recipient's nutritional intake remained a concern to caregivers.

What If He/She Gets Hurt?

> Um, because, you are always wondering if you are not there what is going to happen, there is no family, I'm the only family member (Ann-A,27-29).

Caregivers frequently worried about the safety of the care-recipients as they waited for a PCH bed offer. Major safety concerns centered on the risk of falls and wandering. Caregivers described secondary safety matters such as one's care-recipient being, alone in their home, at risk of house fires and able to drive a vehicle.

Several caregivers expressed concern that the care-recipient had fallen in the past or had been at-risk of falls. Caregivers who lived apart from their care-recipient fretted that the care-recipient had fallen and no one was in the home to lend assistance. Caregivers described being worried that injuries occurred as a result of these falls. Caregivers were apprehensive regarding the care-recipient being at risk for falls.

> Yeah, because I mean the last fall she stayed on the floor I don't know how long, all she bruised was her hand but then until they came and picked her up in the morning, you know, she couldn't get up....you know, so that that's a constant worry I have about her being there is. (Eve-A,729-733).

Caregivers worried about care-recipients who were cognitively impaired and wandered. Several care-recipients demonstrated wandering behavior. Caregivers

worried that the care-recipients would wander outside and either incur an injury or become lost.

> My father walks out the door and he'll be standing a a few feet away and he'll say to me....How so I get back in, you know, or how even in the house, like he'll be standing at the basement steps he basically be looking right at the door where his room is and he'll say "How do I get to my room?" ...you know... (Sue-A,281-285).
>
> Then we have like we fenced in our back yard and stuff last year, more deterrant kind of things, you know a fence that's this high [shows with hand gesture height of fence] but then our worry was you know her going outdoors so then we would have to keep all the doors locked and you know so it's just like....
>
> Interviewer: the worrying?....
>
> Participant: yea, you know...like constantly so when you were trying to do some other things (Jan-A,89-99).

Secondary safety issues were a matter of concern to caregivers. Caregivers wondered if care-recipients had safely performed daily activities of living. Several caregivers lived a considerable distance from the care-recipient. Day to day overall safety of the care-recipient worried caregivers when they were unable to perform daily on site checks.

> Because if it's stressful now you kind of wonder every day what's going on down there. You can't be you know if I phone and uh if everything sounds okay but you don't know what's going really on eh cause you uh.....(Bob-A,1269-1272).
>
> Oh yeah, well that makes you worry because you sometimes wonder in your mind uh you know are they really safe you know are they doing things okay and all this I think you would have an uh if anything would happen like you know. (Bob-A,1329-1332).

Caregivers worried that care-recipients were at risk for fires in their homes. Risk of fire was typically associated with unsafe cooking. Caregivers were faced with the

decision of having the care-recipient's stove disconnected or not and then worried about the consequences of this action.

> We've been told that sometimes the kettle has been on sometimes an element has been on and all this so you know uh uh so and uh and I guess that can happen in any household, can happen here too. I mean uh we can do that too and I know that where my Mom and Dad are I mean leaving an element on is not an actual fire hazard (Bob-A,2893-2898).

> Yeah, Yeah, but they would smell that if something would start burning I would think but, then you never know, so I mean you know you can't take you can't make everything so safe that there is no danger at all I mean you know…

> Interviewer: there's risk….

> Participant: There's a certain risk involved I mean. (Bob-A,2907-2914).

Another secondary source for concern to one caregiver was that his care-recipient drove a car. The caregiver fretted over his elderly father who continued to drive his vehicle to Dafoe. The elderly care-recipient lived in a small rural town and drove to Dafoe on a somewhat regular basis.

> Or Or a car accident like right now with just him driving, he seems to be uh driving good but you know anybody can have a car accident, now of course if my Dad ends up having a car accident now I should have or even my sister will probably say "Well Bob [self] you should have taken his driver's license away" you know or you should have done something…you should have done something. And that kind of worries me sometimes, because I know then again every time they come into Dafoe I kind of wonder is he uh…(Bob-A,1370-1380).

> So that worries me about him driving and the responsibility like uh (Bob-A,1406-1407).

Caregivers worried about the overall safety of the care recipient. The concerns expressed were most acute when caregivers acknowledged they were not able to be on site with his/her care-recipient.

Concern About The Care-recipient's Vulnerability

> But then I see her there, she is so helpless, she can't she cannot express her feelings, her thoughts, nothing…you know. (Art-A,240-241)

Caregivers expressed feelings of worry and sadness as they recognized the vulnerability of their care-recipients. Care-recipients with cognitive deficits were perceived by caregivers as the most helpless. Several caregivers used the analogy of a child as they referred to their care-recipients' vulnerability.

> And and she was scared right out of her tree…you know, scared more than than angry, she was just scared like a little kid would be scared…and and so you know, you give her a hug and you say Pat [care-recipient] it's okay we know that it is and that's why you're living with us so that we can help you out and whenever you get feeling this way…that's the very first time she ever came to me…she always goes through Marg [wife]..(Sam-B,1989-1995).

Caregivers felt sad with the realization that their loved ones were vulnerable. One caregiver relayed a past experience he had as the caregiver to his cognitively impaired mother-in-law. His care-recipient realized she was losing her memory and cognitions. The realization of these losses had frightened her and the caregiver perceived his mother-in-law's vulnerability at this stage of her illness. The care-recipient turned to her son-in-law for support. He expressed an overwhelming sense of concern and loss on how he dealt with this situation.

> Yeah…and and then there's times when when she is just man, it uh …it makes you almost want to cry…one day just last week actually she powered downstairs "Bruce [self]" Marg [wife] was out somewheres, I don't know where, she said "Can I come down and talk to you?" (Sam-B,1967-1971)

> You can see her, Yeah, it was …she was just very afraid….And and wanted to talk and and just get talked through it a little bit you know and ….(Sam-B,2017-2019).

> It just kinda calms her down and she's okay….but it it's gotta be hell for her like and then that's when I just feel so…you just feel so inept at what you're doing…not really helping (Sam-B,2032-2034).

Several caregivers used the term helpless as they described the vulnerability of the care-recipient. The helplessness was perceived to be a result of the cognitive impairment suffered by the care-recipient. One caregiver described how difficult it was as she had visualized her father slowly losing all his independent functioning.

> Then later on you know, you saw him helplessly standing there and those are the hard [emphasized] things like, the actual seeing how…how…he's degrading like when he when you see he can't he's eating off a plate where there's no food….(Sue-A,999-1002).

> Or drinking out of a cup where there's nothing in…you know, those things are hard… those are the things that are hard about waiting…then you wish they were right there where you could just say you know take him over and say gee, you know, he needs your help, you know….(Sue-A,1004-1010).

> And I think that the way he's uh falling apart though is a difficult thing….cause you feel sorry for him…you feel sorry and you just hope (emphasized) you just hope he doesn't realize it. (Sue-A,1016-1018).

Caregivers acknowledged the care-recipient's vulnerability and felt great concern over this loss. Caregivers struggled with how they coped with this change in the care-recipient's level of independence.

Concerns About Future Care In The Nursing Home

The last category of the theme *Worry, Worry and More Worries* was presented as concerns about future care in the nursing home. Several caregivers expressed concerns about the type of care the care-recipient would eventually receive in the PCH. The concerns described by caregivers included quality of meals, adequate staffing and the overall PCH environment.

Caregivers expressed concern about the quality of meals that would be served in PCH. Caregivers wondered if the amount of food and taste would be acceptable to the care-recipient.

> How is the food you know, like some nursing homes have the hospital food which I didn't like, because she was in October in the hospital and I saw that. (Art-A,428-430)
>
> You know, so I thought gee I don't want Helga [wife] to eat that that stuff her whole life…you know…(Art-A,448-449)

Several caregivers were concerned with the training of the PCH staff in relation to managing the care-recipient. One caregiver described the night-time ritual that she had with her mother and how she hoped future caregivers would perform the same routine. A husband caregiver expressed concern about how adequate PCH staff were trained.

> Well, Yeah, I had uh kinda concerned what would happen to her in the nursing home. Is it a good place for her, you know, I had to convince myself you know…
>
> Interviewer: what you had thought about before….
>
> Participant: …of before I that was when my concerns you know, how it would be if staff is well trained you know. (Art-A,410-428).

One caregiver shared his father's concern that regarded the PCH environment. The caregiver was the main caregiver for both his parents but only his mother was waiting for PCH placement. The family recalled a past experience of a friend who resided in a PCH and how this had given concern for future placement of the care-recipient in PCH.

> Apparently she was really uh bad she was uh running up and down the hallways and you know trying to wipe walls and all that. So I guess they see some pretty horrible things there. So I don't want them to go there. But you know like uh…
>
> Interviewer: Yeah, I guess maybe that kind of thing worries them…you know…
>
> Participant: Yeah, Yeah…I guess he's concerned about her going to a place like that you know, and he's concerned about her getting good care..(Bob-A,153-161).

Theme III. Summary

The third theme, *Worry, Worry and More Worries* described the concerns and worries that participants expressed as they waited for a PCH bed offer. The waiting period provided caregivers with time to fret or worry about the continuing well-being and the future care of one's care-recipient. Caregivers focused on issues of adequate nutritional intake and fear of falls or other injuries for the care-recipient. Caregivers recognized the vulnerability of the care-recipient and how they were in need of comforting and protection. Several participants expressed concerns on adequacy of future care provision by the chosen Personal Care Home.

Theme IV. Dreading Or Welcoming The Anticipated Bed Offer

The fourth theme, *Dreading or Welcoming the Anticipated Bed Offer,* describes the caregivers' thoughts and feelings as they waited for the "phone call" or notification of the PCH bed offer for the care-recipient. The timing of the notification was a complete unknown and was unpredictable. The telephone call from the nursing home could come at any time in the future but most likely within a year or less of the PCH panel. Caregivers described a sense of dreading, welcoming and ambivalence or uncertainty when anticipating the PCH bed offer. The fourth theme, *Dreading or Welcoming the Anticipated Bed Offer,* is supported by three categories. The categories were: (1) Dreading the anticipated PCH bed offer (2) Welcoming the anticipated PCH bed offer (3) Ambivalence and uncertainty towards the anticipated PCH bed offer.

Dreading the Anticipated PCH Bed Offer

> Yeah, for sure....no question and uh neither one of us, Marg [wife] or I, looking forward to the day when we get that call saying "Okay there's a bed", you know, it won't be a happy day for sure...(Sam-A,66-68).

Caregivers voiced a sense of dread as they anticipated receiving the phone call from PCH announcing the bed offer. Caregivers described apprehension and at times actual fear at the prospect of receiving the phone call or contact from the chose PCH. One caregiver revealed his apprehension and dread as he thought about receiving the bed offer telephone call.

> Right now because since then uh we've noticed some bigger changes in in her Mother and uh our saying oh maybe it's time and so we're getting a little bit more prepared for when that phone call comes, however at the same time I'm not looking forward to it....that we know it's going to be hard... (Sam-A,696-700).

Several caregivers felt stressed when thinking about receiving the phone call of a bed offer from the PCH. One caregiver described that at times her stress was triggered by the ringing of the telephone. Sometimes when the phone rang at home or work the caregiver wondered if the telephone call was from the PCH calling with a bed offer. The caregiver described receiving phone calls at different times and thinking perhaps the call had something to do with a PCH bed offer.

> Um....[pause] a little weird because sometimes when somebody phones and they'll say this is so and so on the phone you'll think...is this you know.....
>
> Interviewer: Is this it?....
>
> Participant: Yeah...is this something [laughs] and uh you know and what name should I be thinking of [laughs] who should be phoning me...um and so then so then you think like should I be so when you think so right after that then I think of gee should I be doing like I feel like stalled out. Should I be doing something should I be....cause I know that once that call comes....(Jan-A,483-494).

Caregivers predicted that when the phone call from the PCH came they would come under stress. Stress evolved from thoughts of how to plan and carry out the actual physical move to PCH for care-recipient.

> You know we realize when the day comes I guess we are going to have a little bit of stress that day and all this and I guess I guess when we are given a definite date and then it will cause a little bit of...because all of a sudden uh, like it isn't reality yet. Right now because we know her day is coming but we don't know when and all this and uh you know and all of a sudden we are going to be given like just say August and all of a sudden we are going to have to make arrangements with that date and all this. And then we have to make plans accordingly you know and then I think then I think we will probably be a little bit more under stress and uh you know and uh coping with a a you know coming closer to the day...(Bob-A,1691-1701)

Caregivers explained why they felt a sense of dread on receiving the PCH bed offer telephone call. Several caregivers described reaching the point of now having to face the final decision of declining a bed offer or persisting with a PCH admission.

> Well I have to, I gone through a few different emotions, too. Um I'm afraid oh, if he's gonna have one of his moments where he's going to refuse…I mean…if he refuses, I'm afraid that I might get soft and keep him….(Sue-A,334-337).

> And if I if I keep him, then I'll be starting the whole thing all over again….you know…(Sue-A,341-342).

> And then there's the dread of when ….the…call….comes will I say yes and Marg [wife] say no or will I say no and will Marg say yes….and then what [emphasized] happens? (Sam-A,1147-1149).

> I'm afraid he's going to ….back down and want to…stay and I might say, "Okay, we'll give it another shot" [emphasized] you know, it also depends on how far, you know, like uh how far he's digressed, you know…(Sue-A,391-394).

Several caregivers described feeling fear as they anticipated receiving the "bed offer" telephone call from PCH.

> Cause I know that once the phone call comes….then I have limited period of time in which to to set things fully into action…Lumps in my my life you know like like little little almost fear in the pit of your stomach you know…(Jan-A,493-505)

Welcoming the Anticipated PCH Bed Offer

A few caregivers expressed the desire to receive the "bed offer" telephone call from the chosen PCH. Several caregivers welcomed the anticipated bed offer and perceived a timely need for placement of one's care-recipient. One caregiver explained how she looked forward to receiving a PCH bed offer when she knew her care-recipient desired PCH admission. The decision to seek PCH admission was supported by both the caregiver and care-recipient.

> No basically….Arwen [Home Care Coordinator] says it could possibly be July and both Mother and I are looking forward to this, she says that all the time, she says "When can I go" you know, you know uh and then…maybe it will never be…. "I'll never go" she says, I say "No, Mom, it's July" well you know something happens that it's August, she doesn't remember that well or whatever, we'll carry on, but personally I really hope it is July…(Eve-A,325-331).

Caregivers anticipated welcoming the "bed offer" telephone call when the timing of the need for admission was current or of an urgent nature. Several care-recipients were in need of imminent placement because of limitations in formal and informal supports. In these situations, caregivers welcomed the phone call that offered a PCH bed.

> There is [emphasized] a sense of urgency…you know, yeah…in in fact this is where where something comes in with Dave [brother], like he phoned Ituna or whatever or the head office, somebody named Tom does that…(Eve-A,351-354).

> For me, I'm looking forward to it, I'm I'm my Mom hasn't sort of raised any issues hasn't said she wasn't gonna go kinda thing, um.. We've had her medication changed recently so things are sorta improving a little with her (Ann-B,16-19).

On occasion, caregivers felt pressure from other family members to accelerate the process of receiving a bed offer. Caregivers described family members who felt the need for admission to PCH was important for the care-recipient and desired an imminent bed offer. One caregiver was the main caregiver for an elderly sister. The caregiver tentatively welcomed a PCH bed offer but felt his elderly brother desired the PCH admission for the care-recipient within a shorter time frame.

> Well it's got to come, and it's probably the sooner the better, but in my eyes, um being selfish as I am, I'm hoping it won't be a little while yet, maybe two or three months, that's the way I look at it…(Jim-A,281-283).

> No, no, no but my brother might be, I don't know I don't know what his, his situation is. He says she should be down on the other side [PCH] and of course his wife is saying the same thing so they may be just hoping like heck the phone call comes soon. (Jim-A,288-292).

One caregiver concurred with family members that a bed offer was welcomed but exerting pressure on the system was not required during the wait for notification of bed availability.

> Dave's [brother] argument just recently with me is there you know, he's saying there is there is a list but there's always exceptions to the case, like he's wanting me to aggressively try and have her placed sooner and um....I don't feel that I am going to do this not because I wouldn't like to see her placed, but she's getting ...you know she could have a lot more Home Care than she does....she's safe...she's not going to go outside in a snowbank...(Eve-A,370-377).

Caregivers welcomed the phone call announcing a PCH bed offer when the care-recipient concurred with these long term care plans.

Ambivalence and Uncertainty Towards the Anticipated PCH Bed Offer

Some caregivers expressed feelings of ambivalence and uncertainty as they contemplated receiving a bed offer. Caregivers were uncertain as to how they would respond to the notification of a PCH bed becoming available for one's care-recipient. One of the challenges encountered while waiting for a PCH bed offer was not knowing when the contact or invitation would be extended. The uncertainty that was experienced over the timing of the bed offer added to the ambivalence caregivers felt towards this process. One caregiver discussed the difficulty with not knowing when a bed offer would have occurred.

> That's what ....bothers me more than anything is just not knowing because you know if that call came tomorrow it would be ...uh....really tough to think about it....
>
> Interviewer: To think about it....
>
> Participant: It comes three months from now it might be the same thing or it might be a whole lot easier depending on how Pat [mother-in-law] is...
>
> Interviewer: that's right...
>
> Participant: So it's it's just ....it's the not knowing....it's uh uh....and at the same time we know that there's no one that can change that really....because that's just the way it is....you know unless there became buildings galore and we could get her a room tomorrow kind of thing and we all know that's not going to happen....so that's the only thing that would fix it...really for for people in our situation and and really it's just the not knowing.....(Sam-A,1099-1117).

Caregivers described the uncertainty they felt as they contemplated the timing of the bed offer. One caregiver relayed that depending on the current circumstances and the day a PCH bed offer was made she might accept or decline the offer.

> Whereas like I said before sometimes you wish the call would come right then and there when you see these bad days....
>
> Interviewer: Yeah, but on those days...you wish you did get the call that day?
>
> Participant: OH YES [emphasized], the yeah...uh sometimes you say "Oh no problem" you can cope with it, no problem, I mean then other days you say, "Oh no this I can't I can't I just can't" when when it comes with um him being maybe uh disgruntled...and then also mixed up you know. And then you get this real you just see him moping [whispers] you know, you just see him sitting there like uh so unhappy [emphasized] and you know, and doing things, strange things and you know that he's not. Then you wish that the call was there....the good days you want to shove it away and then I guess it's very normal....(Sue-A,1060-1075).

A sense of dread and need of a PCH bed offer occurred at the same time among participants. Caregivers recognized and accepted the need for long term care for the care-recipient. Caregivers described the coexistence of not wanting the PCH to call with notification of an available PCH bed, yet needing the support of a PCH admission for long term care of the care-recipient.

> In a sense I sometimes I thought, I hope they don't call at all....eh...cause I wanted her here [emphasized]. You know....but then on the other hand sometimes I thought you know I think that it's time that she gets somewhere....but then again this other that feeling was stronger than....
>
> Interviewer: the don't call the don't call feeling....or the....
>
> Participant: Yeah, yeah, the don't call feeling...you know....
>
> Interviewer: Yeah....

> Participant: There was a feeling, you know, like you said, it's a struggle between the feeling and the the your logic, you know, ….and the feeling was kinda stronger than the logic sometimes…(Art-A,608-622).

> Yeah, I still had this hope….it never happens….you know…(Art-A,635).

Caregivers experienced ambivalence and uncertainty as they waited for the arrival of the bed offer.

Theme IV. Summary

The fourth theme, *Dreading or Welcoming the Anticipated Bed Offer,* discussed the cognitions and feelings held by participants. Participants were at a loss to predict when a nursing home bed would be offered or become available for one's care-recipient. Caregivers described different responses to anticipating notification from the nursing home. Caregivers cited feeling a sense of dread as one more common response. Several caregivers eagerly welcomed the phone call or contact from PCH. Participants also expressed feelings of uncertainty or ambivalence regarding their future response once the bed offer was received.

Theme V: Preparing For An Unknown Admission Day

> So every day we sit and wait....cause is the phone gonna ring today? Are we next on the list are we 10th on the list or where are we? And um...it's it's just a constant waiting waiting and not knowing you know....(Sam-B,15-18).

The fifth theme, *Preparing For An Unknown Admission Day,* described the uncertainty of how to prepare for an admission day when the date is unknown. Caregivers used different stategies in the long-term planning for the eventual admission of their care-recipient to PCH. Three categories emerged and accounted for the fifth theme. The three categories were: (1) The challenge of "not knowing" when the bed offer would arrive (2) Planning the "moving in" day (3) Preparing in advance for the transition to nursing home residency.

The Challenge Of "Not Knowing" When The Bed Offer Will Arrive

> Yeah, yeah with with not knowing because it's out of everyone's control when the call will come or when anything will happen. And and you're already in a situation where you are out of control, not controlling a situation and in Mom's case because of her cognitive impairment but even if it was a physical impairment you're not in in control totally you know of of reactions....(Jan-A,1281-1286).

Caregivers described the challenge of "not knowing" the timing of the telephone call that announced a PCH bed offer. Caregivers were given vague time frames when they inquired as to when a bed offer might be made. One caregiver described his sense of uneasiness over the realization of an uncertain time frame.

> No [laughs] she was on the waiting list of Golden Gate Nursing Home, you know, but they they told me they cannot ....tell me, it could be tomorrow [laugh]) it could be in three months or four months you know....
>
> Interviewer: What was that like for you?....knowing that....
>
> Participant: Um, it was an uneasy feeling kind of you know...(Art-A,588-595).

Caregivers depicted the "not knowing" as a guessing process. Caregivers described this guessing as trying to predict when the actual call would come. Caregivers based predictions on advice received from other people, events surrounding the usual movement on PCH waiting lists, and/or simple intuition.

> You know and talking to the people then they said well, we don't know how long, it might take, it might take four weeks a month or two, you know, so I was already kinda thinking maybe when she is there [currently in respite at PCH] within the first four weeks they would phone me and they say "Oh we have a bed for her", but it doesn't happen ..happens...(Art-A,709-714).

> Exactly and and is it too soon? You know, like...originally we were sort of told ah it could be ten months to a year and all of a sudden like I know there's been a lot of deaths this last while and uh so is that really gonna speed this process up considerably and...(Sam-B,81-85).

> Yeah, well you do, you know cause cause I'm thinking [exhales – sighs] like and you know you have four million things go through your head but you think okay, like I keep thinking it's [PCH bed offer] gonna be somewhere between July and October, don't know why I think that but I think. (Jan-A,899-903).

Caregivers often wondered what position on the PCH wait list the care-recipient occupied (ie. close to the top, mid-way or bottom). Caregivers expressed uncertainty over the position the care-recipients held on the wait list and how they could be apprised of this information. The question most often posed by caregivers was "Where are we on the waiting list?".

> And we we talk about that like we could start ....phoning, making some phone calls and say kinda "where are we on the list?"...and ...
>
> Interviewer: that's right....
>
> Participant: You know and then you just become a pain in the ass to those people and really what do we even gain by it...
>
> Interviewer: yeah...
>
> Participant: Like you know, it it's gonna be still an unknown at the end of the day no matter what....(Sam-B,598-609).

> Yeah, the it it uh I wish there was an easier way of for a way of for us to know you know, how are things progressing as far as where we're at on this list…does it look like it's gonna be two months now or a month or or ten months or where are we? And uh, so it it's kinda it's the not knowing stuff that we is tough….(Sam-B,22-26)

> Yeah, yeah, well at least you might see some movement….I have no ideas if she has moved up the list since November, I have no idea…(Dan-A,397-398).

Caregivers expressed hope that the waiting list management system was fair. Caregivers held the expectation that the care-recipient was advancing on the waiting list in an orderly manner.

> Well it would be hard for me if you you weren't progressing on the list…I would have a real problem with that….
>
> Interviewer: Yeah, if you had a sense that…
>
> Participant: Yeah, if she's not further than she was in November there's something wrong….
>
> Interviewer: Yeah, okay….
>
> Participant: Yeah, then the system isn't working you know….you know….and I hope it isn't like that [laughs]….(Dan-A,866-876).

Several caregivers described the hardship of trying to plan social or work-related events when they had no idea when the call (bed offer) arrived. Caregivers wanted to make future plans such as organizing work schedules or taking a vacation but felt these should be postponed until date of PCH admission for the care-recipient was known.

> Even when Marg's [wife] mother moved in with us our lives changed but we could still plan…because we just involved her in the plan that's all, so we did different we did things differently or we did different things but we could still make plans for a quite a period of time ahead of time…now we're finding that…there there's just so much uh….you know we would like to go to Regina and take her with us, however, when we make those arrangements are we gonna get called and ….
>
> Interviewer: right, right…

> Participant: You know, so so everything kinda gets, it it's on these like living on hold sorta, you know....(Sam-A,727-739).

> Oofh [sigh] what if's it's when Sara [supervisor] is on holidays, what if you know...like....and I mean we can live with that too, I can run around with a pager and a cell phone and say [laughs] stoplight....but you know those kinda, busy, yeah,....those kinds of thing again play on...on your mind so if you had some kinda thing that you could make a plan....and you would just know, you know...(Jan-A,904-909).

The arrival of the PCH bed offer remained an unknown. Caregivers found it difficult to make future plans with the uncertainty surrounding the timing of the bed offer.

Planning The "Moving In" Day

> Whenever it comes now, me and Marg [wife] you know, we're saying okay, we're prepared for that....we're not very prepared [nervous chuckle] for telling her Mother that that's gonna happen...(Sam-A,759-761).

> And then the actual move, the actual physical move itself is gonna be....murder [whispers]...(Sam-A,769-770).

Caregivers gave considerable thought to planning the day of the actual move to the personal care home. Caregivers described their thoughts that surrounded the "moving in" day. Caregivers focused on the following concerns: (a) how to tell or broach the subject with the care-recipient of the definite move to PCH (b) which family members should be included in the moving day (c) fear and uncertainty that preparations are "right" (d) sources of advice for planning a move of this significance.

An aspect of planning the "moving in" day involved broaching the subject with the care-recipient. Caregivers especially felt the challenge of preparing for the move when the care-recipient was cognitively impaired. Caregivers queried how they should inform or approach the care-recipient with the news of the imminent move.

> We've sat down and tried to figure out "okay like when the call comes" um...how do we work that? How how are we going to prove or how do we break it to your Mom? ...Well, uh, I and the only thing that we think about initially is how do we...uh...tell your mother...(Sam-B,2127-2128).

> When that phone call comes and ...it...will be us that have to tell Pat [mother-in-law] um...we still don't know how we're gonna do that [nervous chuckle] totally...We've talked about it, but we don't know, and and I I guess maybe we won't know until it happens, you know, then we because there is so little time... (Sam-A,741-749).

Caregivers expressed uncertainty about how to involve the care-recipient in the moving to PCH process.

> Part that we're struggling with right now is uh when do we tell her, how do we tell her and how much do we involve her in the actual [emphasized] move, like should she help pack stuff, would that make her feel better or should we just kinda say guess what....we don't uh uh cause we haven't told her...and and uh so it it I guess that's why there's anxiety a little bit too, when there's four empty spaces [at local PCH] and we're thinking "Oh Jesus" it's going to come even quick you know and...(Sam-B,70-77).

Caregivers described their concerns on how they planned and implemented the care-recipient's move to PCH. One issue centered on preparing the care-recipient's PCH room. Several caregivers mulled over the option of preparing and setting up the PCH room prior to the care-recipient's arrival.

> If if there was a point where she was being difficult about it I would ask that I could prepare the room ahead of time and... you know, so she walks into something identical to where she has been in, rather than having her participate in the move and having her furniture moved in and watching this happen. I would want to do it in such a way as it works, her pictures would be on the wall her chair would be there and stuff like that. It would be there ahead of time....so it wouldn't be that much of a shock (Ann-A,562-569).

Caregivers were uncertain if the PCH room should be set-up prior to the care-recipient's arrival or if the care-recipient should be involved in the moving and room set-up.

> How do we decide what goes and what doesn't go? And how do we go about doing that, do we make your Mother a part of moving or do we or does Marg

> [wife] take her Mother to Edoras for a little shopping spree and nice supper and Cain [son] and I and Theodon [son] move the stuff in and it's all done when she gets there or like how do we…do that? (Sam-B,30-35).

> Um hum, you know, cause does it work better just one on one and and has it worked better like in you know for people to be part of the unpacking process and this is your stuff this is your stuff or is it better for it to be there and and just like sorta pop into a new situation, this is your….(Jan-A,1307-1311).

Caregivers who were employed realized they had to request leave from work when it was time to move care-recipient to PCH. Future preparations for the care-recipient's relocation to PCH involved notifying one's employer of the need for time off work and possibly making this request on short notice.

> The day and and ….uh and know so that so that even for my work I could say, you know like Arwen [supervisor at work] has already said like you know, we support you and you know if you need time to do stuff, like you know…you phone in, you do it, um so like I know that I can have the day or two days you know whatever…ugh…but just if you knew so that I could say even to her and Sandy [co-worker] like you know this is sorta you know…what I am planning …. (Jan-A,877-884).

Caregivers wondered which family members to include in the relocation process as they planned for the move of his/her care-recipient to PCH. Caregivers considered who to invite, who should have been present on moving day, and what role they held in the move.

> And if a call came tomorrow…um I probably would go with him too, I'd take my husb my husband and I we would both go, you know….uh and we'd make it sound…pleasant…you know…(Sue-A,697-700).

> You know, so…you know and I don't know you know…like does it work for like Bruce [husband] and I and Frank [son] to sorta be with her and you know or should it just be one of us or or…(Jan-A,820-822).

> And do we call, do we call all her other….brothers and her sister [spouse's siblings] and should they be here when she [care-recipient] moves or when that move takes place and that kind of thing and…(Sam-B,503-505).

Fear and concern over planning a well orchestrated move to PCH for the care-recipient was expressed by caregivers. Caregivers discussed the plans they had made for conducting the physical and emotional move to PCH for the care-recipient. An overall desire for an organized and acceptable "moving in" process for the care-recipient was expressed.

> When the call comes…it's up to you and I to sit down and say okay, which which one of those are we going to go with like what fits best with here today…..or in the situation that we're we're in and and for your Mom, like what will work the best? (Sam-B,514-518).

> And uh hopefully we…pick the right one. And again it's not knowing whether you're near or not I hate that uh…I don't like second guessing I I like to make a decision and say okay let's go with that…and right now that that's part of it, the fear of it too is is that we've got like four or five different scenarios and we don't know which is gonna be the right one, we don't know if any of them are right and we probably won't know till it happens and we may not even know than at like I don't even…(Sam-B,522-529).

Several caregivers desired outside advice or guidance on how to handle the "moving in" day. The advice solicited concerned the approaches other caregivers had tried and found helpful with the move to a PCH. One caregiver cited different sources where she thought advice could be sought, but she had been unsuccessful in locating any information. Sources included written material, personal accounts of moving one's care-recipient to PCH, and use of the internet.

> Like just written material like that even just anecdotal stuff you know like like you know, um…we came in with my Mom and we came in at 4 o'clock and stayed for supper and and spent the evening and and then she got prepared for bed and and that was a nice introduction or we came you know first thing or or you know or or you know we brought this you know…with her that somebody might you know like…(Jan-A,717-723).

> Yeah, Yeah what what worked for…, what have other people tried and and noticed that maybe worked and now that would be that would make just waiting like if there was like just something cause sometimes I love to read stuff like, I go

> on the internet and I read 4000 things but there is nothing like that that I found so far...on the internet [laughs]...(Jan-A,760-765).

Caregivers spent time and thought on planning the care-recipient's move to PCH. Caregivers considered how they would: notify the care-recipient of the moving day, invite other family member involvement and create a well-orchestrated move.

Preparing In Advance For The Transition to Nursing Home Residency

> Because we were pretty insistent that it be Dafoe Home (PCH) that it would be as little an upsetting experience for her as possible, she goes to South Harbour (EPH) which is all the same building, well you know that, uh she is familiar with some of the people and the surroundings and the building itself more or less and so we thought, well, you know that move will be less upsetting to her than it would all of a sudden she ends up in Brandybush (Sam-A,654-660).

Preparing the care-recipient for the relocation to nursing home involved short-term planning for accomplishing the physical move and long-term planning to prepare for the transition from home to facility living. Caregivers described strategies that were mostly aimed at ensuring that the care-recipient would be familiar with the PCH setting. Caregivers utilized these strategies to assist the care-recipient with the eventual and imminent move to a nursing home. Several of these strategies were also employed to assist the caregiver in preparing for their care-recipient's imminent relocation. The strategies identified were: (a) respite admissions to the PCH (b) attending an Adult Day Program (ADP) that was located in desired PCH (c) food and meals prepared similar to that provided in PCH (d) care-recipient residency in a juxtaposed Elderly Persons Housing Unit (EPH) (e) receiving support from the Home Care program and volunteer work at the chosen PCH. Caregivers voiced concern that the care-recipient needed opportunities to become familiar with the chosen PCH prior to eventual relocation.

Intermittent respite admissions to PCH of the care-recipient assisted one caregiver in preparing for the imminent PCH admission of his spouse. The caregiver suggested that the respite stays helped prepare him for the transition of his cognitively impaired spouse from home-based care to facility care.

> Because before it was where…she comes back after four weeks…and then they phone me, oh, she can stay another four weeks, and I said okay, then, she stays another four weeks and then she comes home….You know…it makes it maybe…a little bit….easier for me…since…I I'm getting used to this…(Art-A,742-754).

One caregiver described the strategy that she had used to help prepare her care-recipient for the eventual move to a PCH. The care-recipient attended an Adult Day Program (ADP) that was located in a juxtaposed Elderly Persons Housing Unit (EPH) to the chosen PCH. The caregiver felt that if the care-recipient attended the ADP located in the same site as the chosen PCH, the care-recipient would become familiar with the PCH setting. The knowledge that the care-recipient was admitted to a familiar PCH was important for the caregiver.

> Yeah, and that's why Adult Day Program, she uh like is nice because she becomes gives the the break that Bruce [husband] needs to do some of his buseness you know for those hours, but it also integrates her in to this building and because they do functions together with people here and it's very nice for me like like Arwen [Director of Nursing for PCH] now knows my Mom you know…So maybe when she comes in there will be as much familiarity as there is some days in my own home ……The waiting easier and and helped me in my mind with what the transition will be…(Jan-A,305-315).

Caregivers demonstrated creativity in the long term preparation for eventual nursing home admission of the care-recipient. Several caregivers expressed concerns they held about the amount and quality of food or meals that would be served to the care-recipient when they resided in PCH. Caregivers devised ways of serving food and meals in amounts similar to what the care-recipient would have received in PCH. One

caregiver hoped that this strategy would prepare the care-recipient for the transition to a PCH by minimizing any change in meal and nutrition presentation.

> So the the other thing that I see her being a little unhappy about is I know that that food gets pretty regulated, like measure or whatever you want to call it, which is great, I don't have a problem with that, but at home, we try and do the same thing at meal-times and stuff that she loves, food…so she eats like she raids the fridge uh often, lots……I think one of one of the biggest bones of contention that she will have when she moves there is they're not feeding me, I I honestly believe that she will say that time after time after time…and as hard as we've tried and we genuinely have, we've tried..instead of putting a big bowl of potatoes and stuff on the table we've tried okay we're gonna dish everything up at the stove… (Sam-B,1346-1361)

Familiarity with the PCH setting was paramount in the long term planning for the move to PCH. Caregivers identified the residency of the care-recipient in a juxtaposed Elderly Persons Housing Unit (EPH) to the chosen PCH as aiding in the familiarization process. Caregivers felt that care-recipients who lived in an EPH that was attached to the first choice PCH would have been familiar with the PCH setting. The acquaintance with the PCH setting would potentially ease the transition to PCH residency. Caregivers viewed this type of shift in the care-recipient's environment to have been an aid in the adjustment process.

> We're prepared like you know we've preparing for this for the last five years or so so…Yeah, and that sort of conditions my Mom, she knows herself um that the time will come and she's happy that it's adjacent to the complex that she is living in now and she wouldn't have to go to another town anyways…(Ann-B,86-94).

> And because the Personal Care Home is so close they get a chance to kind of, I I don't have to bring her from my home or her home and have her visit the care home, she's already had that gradual…adjustment because she can visit um there's bingo that goes on so they're encouraged to go to that so you get exposed to the….That is ideal, you know, adjacent housing…In the Rivendale [EPH] and uh the attached care home facilities have been able to let her go in there and visit with people and I'm sure while she is there she is seeing the kind of care they are getting she's hearing from them how good it is there um you get a chance to psychologically adjust to the inevitable…you know…(Ann-B,416-443).

Long term planning for the PCH admission included support from Home Care services. The support provided by Home Care encompassed both the care-recipient and the caregiver. Home Care offered counseling which seemed to assist in preparing for PCH admission.

> And they sort of uh they sort of do a little bit of counseling in a way uh with the elderly as they are taking care of them like if there are any concerns or anxiety that are raised by the elderly they are able to answer their questions for them and stuff like that so they kind do a bit of talking with them (Ann-B,151-155).

> I've been talking with Gina like the Home Care Coordinator and she's been very helpful and so we've been doing this for the last five years when things started to happen. So I've been communicating with her and she gave me some literature to read and stuff to read and she let me know if there was things happening and sort of get on it before it got out of hand kind of thing (Ann-B,170-175).

A strategy that welcomed familiarity with the PCH setting was when caregiver and care-recipient worked as volunteers in the local nursing home. One caregiver felt comfortable in the PCH environment as he continued to play music as part of the PCH activity program. The caregiver's spouse had volunteered in the PCH activity program when she had been cognitively well. The caregiver felt his care-recipient was familiar with the setting given her past volunteer work.

> She would volunteer at the lodge too for all those years…..So she's almost at home there…..(Oli-A,386-393).

Caregivers described various approaches they utilized which eased the move to PCH for the care-recipient. The goal of these strategies was familiarization with the PCH setting for the care-recipient.

Theme V. Summary

The fifth theme, *Preparing for an Unknown Admission Day,* discussed the challenge of not knowing the arrival date of the bed offer. Caregivers made attempts to

prepare themselves and the care-recipient for the unknown arrival of the bed offer. Preparations included planning the aspects of the actual physical move to PCH. Caregivers prepared the care-recipient well in advance of the relocation by utilizing different strategies. The strategies that were employed had the main effect of familiarizing the care-recipient with the PCH setting.

Summary of Key Thematic Area I. Experience of Waiting

The first key area described the caregivers' experience of waiting for a PCH bed offer. Five themes accounted and portrayed the caregivers' wait in the first key area. The first theme described how caregivers reviewed their decision to apply and persist with the wait for PCH. The review included rationalizing one's decision to apply, accepting the solitary nature of the resolution, timing of the decision and having felt supported by one's family. The second theme depicted the emotional turmoil experienced by caregivers during the waiting period. Caregivers described feeling mixed emotions such as guilt, relief and sadness as they waited for notice. The third theme described the many worries caregivers carried in their thoughts. Caregivers pondered on the safety and vulnerability of their care-recipient while they waited for a safe care option. The fourth theme presented the caregivers' perspective on receiving the actual PCH bed offer. Several caregivers felt a sense of dread when anticipating receiving the offer whereas others welcomed the call or felt uncertain in their response. The last theme recounted the manner in which caregivers prepared for an unknown admission. Preparations had not alleviated the challenge of the uncertainty regarding the arrival of the bed offer. The caregivers' experience of waiting was fraught with emotional sways and introspection.

Key Thematic Area II. The Admission Day Experience

The admission day experience commenced with the caregivers receiving the official bed offer from a chosen Personal Care Home (PCH) and encompassed the actual relocation of one's care-recipient into the PCH. Six interviews were conducted with caregivers after the PCH bed offer was made. Four of the ten caregivers were not interviewed as three were still waiting for a bed offer and one caregiver was unavailable for the concluding interview. Three themes emerged and accounted for this experience. These themes include: (1) The Bed Offer is Made: Feeling Yes/Saying Yes (2) Passing of the Torch: New Caregivers, New Location (3) Moral Support From Family Members.

Theme I: The Bed Offer is Made: Feeling Yes /Saying Yes

The caregivers waited from a few weeks to many months for the arrival of the PCH bed offer for their care-recipient. Once the bed offer was extended, caregivers faced the final decision of perhaps declining the offer or acceptance and negotiation of the PCH admission day. Three categories were developed from the data and supported the theme of *The Bed Offer is Made: Feeling Yes/Saying Yes*. The three categories are: (1) Presentation of the PCH Bed Offer (2) Negotiating Time to Respond to Bed Offer (3) Caregiver Accepts or Declines Offer.

Presentation of the PCH Bed Offer

The first category described the manner in which the PCH bed offer was presented to the caregiver participants. The arrival of the bed offer was anticipated but the time, day and month of the offer was an unknown. Caregivers were notified that a PCH bed was available for the care-recipient by a telephone call or through a chance

encounter with the PCH Resident Care Manager. Caregivers identified the manner in which the bed offer was extended as either professional or awkward. A few caregivers were notified by a telephone call that a PCH bed was now available for their care-recipient.

> Yeah, they phoned me....Um humm....They phoned and uh....that would be uh uh Tim Collins [Social Worker], Tim Collins called me and he said they have a room uh uh he didn't say room uh I think he said a bed or something to that effect...(Sue-C,196-206).

Two caregivers received notice of an available PCH bed via face to face contact with the PCH Resident Care Manager. In both instances the contact was a chance encounter with the manager.

> Okay, yeah, and that's why I happened to be in the building was to see Gina Bock [Home Care Coordinator] about that.....to inquire about it and that's when Robert [Resident Care Manager] caught me in the hall and said, "Oh by the way I was just gonna phone to tell you your Mother can come in today"...I'm going I'm sorry....today....no...I was just taken aback. (Ann-C,499-507).

Several caregivers described receiving a telephone call and an in person visit by the Resident Care Manager.

> Well, she just phoned us by telephone and let us know that uh a vacancy and if were interested in and uh my Mother's name had come up and she says you know, we would like to know by uh... as soon as possible.....and I said my Mother still has a lot of difficulty accepting it and she said ...uh ....well that's when she decided ...well she was nice enough, she said "well I'm going to Ituna and on the way back I'll stop...I'll drop in on them and see them and I'll talk to them about it". (Bob-C,658-666).

A representative of the PCH usually extended the PCH bed offer. One exception to this practice occurred when a caregiver was notified by the local hospital that a PCH bed was available for his care-recipient (who was an in-patient at the time).

> I was just told that uh by the hospital staff that umm that they had uh found a room for her down at Dafoe and that was it...(Oli-C,76-77).

Caregivers perceived the manner in which the bed offer was imparted as primarily professional and informative.

> So we couldn't have asked for it was very professional and it was very well done, so there you know was no problem with that. (Bob-C,685-687).

> But then she talked to Mother and she talked to me, and you know, explained what would happen…(Eve-C,386-388).

One caregiver relayed a negative experience surrounding the presentation of the PCH bed offer. The Resident Care Manager delivered the bed offer in the hallway of the PCH during a chance encounter when the caregiver was visiting her mother in the attached Elderly Persons Housing (EPH).

> How would I ever put it….Yeah, insulted, um….how would I put it….uh, very non-professional…so that would be my definition, it's not it was not professional. (Ann-C,465-475).

Negotiating Time to Respond to the Offer

The second category describes the time frame that caregivers were offered and the outcomes of the negotiations. Caregivers negotiated the actual admission day with the PCH Resident Care Manager once the PCH bed offer was extended. Caregivers were informed of the time frame or tentative date of PCH admission at the time the bed offer was made. The PCH bed offer was accompanied by a time frame that ranged from minutes to over one week.

One caregiver described feeling considerable pressure to accept the PCH bed for her Mother (care-recipient) at the time the offer was extended. The caregiver felt that she needed to respond instantly to the proposal or the PCH bed would be offered to the next person on the waiting list.

> It was just like "Oh by the way, I was gonna give you a call…your Mother has to move in today"….That was the notice…and then the pressure was on if she

> doesn't move in today she's losing her bed [tapped table for emphasis]. (Ann-C,13-19).
>
> Interviewer: How much time were you given before you had to respond to the PCH bed offer?
>
> Participant: Minutes…
>
> Interviewer: Minutes?
>
> Participant: Minutes (Ann-C,430-437).

Several caregivers were given short notice to respond to the PCH bed offer. These caregivers were accepting of the time frame as they desired receipt of the offer.

> I think we've been ex….we've been waiting for it, um possible Eowyn [Home Care Coordinator]had said or Arwen [Resident Care Manager], I'm not sure, that it would more likely be July than June, so I was surprised when it happened so quickly.(Eve-C,440-443).
>
> I didn't think it was uh I don't think I was under any pressure. (Sue-C,233).

One caregiver appreciated the compressed time frame as she felt it compelled her to continue with the PCH admission.

> Well what I liked about it is they didn't give us too much time to think and and to personally back off you know it was…it was quite quick…(Sue-C,992-994).

Caregivers were successful in negotiating extensions to the response (of PCH bed acceptance) deadline. One caregiver faced a difficult caregiving situation as he attempted to convince his parents that PCH admission was needed for the care-recipient (his Mother) and the PCH bed should be accepted.

> She [Resident Care Manager] says your time's gonna be extended till ahh next she said your sister's coming in we'll extend it for another three, four days after Easter. (Bob-C,175-177).
>
> Well, it's very short notice, although they extended that to over a week then….like uh Krista [Home Care Coordinator] was really working hard on this case and all this and also Arwen [Resident Care Manager] was really working you

> know, and so they did give us you know, and they were being very nice about it....(Bob-C,552-562).

Caregiver Accepts or Declines Offer

All caregivers who received a PCH bed offer felt "yes" but not all participants accepted the offer or said "yes". The initial response was acceptance of the PCH bed offer.

> So by the time they said the bed is there for her then I have already made up my mind so to speak, okay she's going to stay...(Art-C,51-53).

> Um hum....we accepted the bed offer....(Sue-C,269).

> I was ready for it, and Mother had been talking about it all the time, like "When are they gonna have a bed for me" or "When is that room gonna be ready" and so forth.....(Eve-C,412-414).

Two of the caregivers experienced different outcomes to the PCH bed offer. One caregiver voiced the mixed emotions that she experienced as she contemplated acceptance of the PCH bed for her Father (care-recipient). The caregiver felt "yes", thought "maybe" and said "yes". When the actual scheduled admission day arrived, the caregiver and her care-recipient viewed the PCH room and declined admission at the last minute.

> Well it was actually with mixed feelings um I would have liked to push it out another...you know....indefinite period...um..it's always it's always this back and forth for me...(Sue-C,274-276).

> Part of me said okay this is this is the way it's supposed to be, this is the way we had planned it and this is how it's you know...this is what we are waiting for you know. I thought to myself if he does refuse and I happened to find everything is great, how am I going to go and keep him there....(Sue-C,460-520).

Another caregiver encountered resistance from a family (Father) member when he tried to encourage his care-recipient (Mother) to accept the PCH bed. The deadline approached and the caregiver felt "yes" but was obliged to say "no" to the bed offer.

> I phoned up Arwen [Resident Care Manager] and I says "You know my Dad is being so ahh ox-headed that it is never gonna work out"…I says "you know I don't want to force my Mother in there against her will and all this ahh cause you know it should be a happy time for her. (Bob-C,146-151).

> If it would have been our wish, our way, we would we would have had her admitted but just because he's [Father] so terribly against it…and just to keep sorta uh peace in the family…(Bob-C,996-999).

The remaining caregivers accepted the bed offer and planned for the relocation day with the Resident Care Manager or PCH representative.

Theme I. Summary

The first theme, *The Bed Offer is Made: Feeling Yes/Saying Yes,* discussed the response of caregivers once the PCH bed offer was received. All the caregivers expressed the desire that the care-recipient would accept the PCH bed. A few of the caregivers were unsuccessful in negotiating acceptance of the bed offer with the care-recipient. The remaining caregivers planned the date of admission with the PCH representative once acceptance of the bed was confirmed.

Theme II. Passing of the Torch: New Caregivers, New Location

> Be prepared to still have....a lot of uh...different emotions coming at them before they break the tie kind of thing of their caregiving...um...to get maybe more information maybe...um, arrange to have a meeting or two with the resident or the care home caregivers....to get a little more comfortable with the care home itself, so that it's not sort of a shock for them. (Ann-C,1878-1884).

The admission day arrived and caregivers had the emotional and physical task of moving their care-recipient into the Personal Care Home. The move involved meeting the PCH staff, orientating new caregivers to the care of one's care-recipient and completing the official documentation of the relocation. The second theme describes the caregivers' experience of the actual admission day. Three categories emerged from the data and accounted for the second theme *Passing of the Torch: New Caregivers, New Location.* The three categories are (1) A Warm Reception (2) An Unfriendly Welcome (3) Admission Paperwork Triggers Emotions.

A Warm Reception

Several caregivers described feeling welcomed into the Personal Care Home. The staff approach set the tone for the admission day experience. Caregivers expressed a sense of comfort in the knowledge that the PCH staff demonstrated friendliness and an interest in the care needs of their care-recipient. Feeling welcomed by the PCH staff was important to caregivers. The welcome involved an orientation to the care-recipient's assigned room and the PCH building.

> What I think about that is that um I found the staff was very [emphasized] friendly and helpful....very...(Art-C,890-891)

> Yeah, um hum, and showed us you know, the rooms and where everything was and explained how what the rules were and so forth ....and...and so uh that worked out reasonably well....I was I'm extremely pleased at how the staff at

> River Lodge treat you when you when you're admitting or whatever you want to call it…(Eve-C,400-405).

Caregivers relinquished some of their caregiving tasks as part of the admission day process. Caregivers felt reassured when PCH staff were perceptive and acknowledged the individual care needs of the care-recipient.

> But there was somebody there and they took her in and you know, and they've been so good about all Mom's little quirks and stuff there, they're very good about trying to…and they were right from the beginning they were very friendly. (Eve-C,834-837).

> That's right….and allowing so many things to keep her still her individualism, you know, just like the things in the room or the dressing and all this sort of stuff. (Eve-C,932-937).

An Unfriendly Welcome

> It was a rush job um there didn't seem to be any kind of a welcoming atmosphere…it didn't seem to include the resident that's coming in…it was just sort of a nonchalant casual, you know, just an everyday thing. (Ann-C,208-215).

The second category describes an admission day fraught with concerns and uncertainty. Several caregivers encountered an unsettling experience as the admission day unfolded. Caregivers revealed feelings of concern surrounding the perception of an unwelcome atmosphere and loss of independence for the care-recipient. One caregiver felt rushed during the PCH admission day. The caregiver described encounters with PCH staff as occurring in a business-like or detached manner.

> Like I say, it wasn't a welcoming situation. Although they probably thought they were doing whatever….Not welcoming, no no, it was business, it was you know, "You do it then, or you don't do it at all".(Ann-C,247-266).

> So the head nurse sat on the bed and the other two started and then there was a third one um and her name was mentioned and they sort of stood and um…didn't speak to Mom directly not loudly, not slowly um…in a way said you know, welcome kind of thing but very business-like way. (Ann-C,851-856).

A daughter caregiver relayed an unsettling admission experience. The manner in which the caregiver and her care-recipient were greeted by the PCH nurse on admission caused concern. The nurse met the family at the door with a wheelchair in hand and requested that the care-recipient ride in the "limousine" (referring to the wheelchair). The caregiver perceived this overture as the PCH removing control of certain activities of daily living from the care-recipient.

> She came with a wheelchair and I said to her "My Dad can walk" and she said, "Oh no", she says "we'll give him the limousine treatment" and I didn't like that. (Sue-C,658-661)

> I just thought you know, I just said I responded to her "Oh he can walk" you know, "he can walk" I mean, that's…."Why can't he walk?"..you know, it's sort of like okay where you're in our control now and um we're going to be doing it his way now, from this point on we're going to be …pushing you around….(Sue-C,1043-1051).

> In all the truth and honesty they only put him in the wheelchair for their benefit…so it will go quicker, so they can get him from point A to point B…I mean if he goes and waddles down there it will take … a little bit longer…and then I thought to myself ….why why would it not be also that they put him in diapers because it's more convenient…(Sue-C,1021-1027).

The same caregiver perceived the PCH room setting as bleak and bare. Her Father would be sharing a room with another resident. The room setting added to the caregiver's feeling of unease on admission day.

> Then we went to the room and … it was a double room…and I must say it was very bleak, very bare….uh the bed that my Dad was supposed to um use was standing a little bit on the crooked side. (Sue-C,663-672).

The caregiver (Sue) and care-recipient declined the PCH bed and returned home.

Admission Paperwork Triggers Emotions

The third category describes the caregivers' experience of completing admission documentation and the surge of emotions that sometimes accompanied this task. Several

caregivers were amazed at the amount of required documentation and the emotions that surfaced at that time. The PCH provided caregivers with many forms to complete on day of admission. The signing and completion of the admission documentation made the PCH admission and transfer of many caregiving tasks official. Caregivers were prepared for some admission paperwork and described some of the information requested.

> Quite a bit of paperwork. (Oli-C,334).

> Then I know already what I have to fill in there, you know, so it was not kinda surprise to me I …knew more or less what they wanted to know…also about her previous life…what she did how she worked…you know…home kinda stuff….things she likes to do you know they want to know that, and now I don't know whether if that's of any help because she can't tell us you know. (Art-C,739-752).

Caregivers described their thoughts and emotions as they filled in numerous forms provided by the PCH. One caregiver voiced the realization that filling in the PCH paperwork made the exchange of caregiving tasks official.

> And then when I started doing all the paper work it was overwhelming it was all of a sudden you're signing…someone away…you're confining someone…and it was kind of…I didn't realize that there would be another gamut of emotion that comes with all this again…[voice tone of surprise]…(Ann-C,142-146).

One caregiver felt a renewed sense of guilt as he completed the admission documentation.

> [Pause] huh….somewhat guilty….somewhat guilty…you know, uh…why are you doing that….(Art-C,524-525).

Anticipation of having to complete the admission paperwork created stress for one caregiver when she lost her Power of Attorney documents.

> The day before I'm looking for my Power of Attorney papers, I couldn't find them, I mean I couldn't find them [emphasized]. And you have to sign papers you know…So that was pretty stressful, stupid thing to happened, that shouldn't have, you know, but these things do…Stupid paperwork gave me a lot of stress, but [laughs], you know…(Eve-C, 685-731).

Theme II. Summary

The second theme, *Passing of the Torch: New Caregivers, New Location,* spoke to the caregivers' experience of relinquishing some of their caregiving tasks to the PCH. This was a time of change for the caregivers as they met the new formal caregivers and encountered the care-recipient's new residence. Caregivers formed impressions of the new care setting. Several caregivers recognized the reality of the care-recipient's relocation and and change in caregiving context once the formal admission (PCH) documentation was completed.

Theme III. Family Members' Moral Support

The third theme describes the caregiver's desire to have the support of other family members during the admission process. Caregivers sought moral support from family members when the bed offer was made and during the relocation or admission day of one's care-recipient. Caregivers approached family members for assistance in encouraging a reluctant care-recipient to accept a PCH bed offer or in helping the care-recipient during the moving (to PCH) day. Two categories supported the third theme of *Family Members' Moral Support*: (1) Encouraging a Reluctant Care-recipient (2) Family Members Ease the Stress of Relocation.

Encouraging a Reluctant Care-recipient

Caregivers turned to family members for support when a care-recipient expressed reluctance in accepting a PCH bed offer. Several caregivers felt their care-recipients were reluctant to accept the PCH bed offer and eventual admission. Two care-recipients declined the PCH bed, one care-recipient at time of the bed offer and one on admission day. One caregiver experienced great difficulty as he encouraged his parents to accept the PCH bed offer for his Mother. This caregiver contacted his sister (who lived out of province) and asked that she help him convince his parents that admission was needed.

> And so then of course the way it worked out then my sister couldn't come right away as soon as I found out the home on Monday morning that they had given us placement for my Mother, I phoned her up right away and she says "well okay I'll get down there as soon as I can."....Well uh like our whole family.....we talked to and then you know and we talked to different people that were in that situation. (Bob-C,699-703).

One caregiver anticipated that her care-recipient might decline the PCH bed on the actual admission day. The caregiver accepted the PCH bed on behalf of the care-recipient but

had not informed the care-recipient of the decision until the actual admission day. The caregiver asked close family member to be in attendance on admission day for moral support.

> Well I did want some moral support because I didn't know how I was going to feel actually leaving him there....and knowing my Dad I thought maybe he is going to...cause a problem maybe he is going to have a last minute change of mind...how am I going to keep him there....so I wanted my husband to come and take a day off or a few hours off and he couldn't so my daughter she came. (Sue-C,501-526).

Family Members Ease the Stress of Relocation

Family members were invited to assist with the physical and emotional move of one's care-recipient to PCH. Caregivers planned the relocation of the care-recipient and the role of other family members in the move. One caregiver expressed relief and appreciation with the role that her sister played on admission day. The caregiver's sibling accompanied and remained with the care-recipient for the entire moving in period while the main care-giver attended to the many other tasks of the move.

> Oh Yeah, this is what made such [emphasized] a difference, well I probably would have if if Teresa [sister] hadn't been there, I probably would have stayed at the suite and done the same thing because I think this makes a lot of difference, that she was there for her...oh yes, yes [laughs] and um so there was all those things that I didn't need to do which made such a difference to me. It made such a difference, um that Teresa was there for her all those days, and I think it made a great deal of difference to Mother's admittance to...to have her there...(Eve-C, 784-804).

Caregivers enlisted the help of family members to ease the transition from home to PCH for the care-recipient.

Theme III. Summary

The third theme, *Family Members' Moral Support,* discussed the importance of receiving support from other family members during the PCH bed offer and admission

time periods. Family support occurred in two contexts. The first context was the receipt of support from other family members when trying to convince a reluctant care-recipient to accept a PCH bed offer. The second context was the planned invitation of family members to accompany the care-recipient for the duration of the admission day.

Summary of Key Area II: The Admission Day Experience

Caregivers were interviewed after the care-recipient was admitted to Personal Care Home (PCH). The second key area described the caregivers' experience of receiving the notice of the PCH bed offer and the actual admission day. Three themes emerged from this experience. The first theme described receiving the PCH bed offer from the PCH representative and having to accept or decline the bed. Caregivers were sensitive to the manner and context that the bed offer was extended within. The second theme portrays the experience of the actual admission day. Caregivers described the reception at admission time as either welcoming or uninviting. A surge of emotions occurred during admission paperwork as caregivers acknowledged the transfer of some caregiving tasks and responsibilities. The third theme represented how caregivers valued the support received from other family members. Support transpired in two contexts, encouraging a reluctant care-recipient to accept the PCH bed offer and having family members in attendance on the actual admission day. Caregivers received the PCH bed offer, conveyed the response once they confirmed intentions with the care-recipient and then accompanied the care-recipient on actual admission day.

Key Thematic Area III. Anticipated versus Actual Admission Experience

The third key area concerned the caregivers' description of how they anticipated the PCH admission experience would unfold compared to the actual PCH acceptance and admission experience for the caregiving dyad. Caregivers offered their perspectives and anticipated outcomes during the waiting interview. Caregivers were interviewed following a decline of PCH bed or the PCH admission of the care-recipient for their perception of the actual events. Two themes surfaced and described this experience. The themes were: (1) Anticipating Difficulties (2) Mismatched Expectations.

Theme I. Anticipating Difficulties

Caregivers predicted that the future admission to PCH might yield an experience with some difficulties. Challenges encountered were anticipating a declined PCH admission or an admission day experience that was difficult. One category was developed from the data and supported the theme of *Anticipating Difficulties.* The category was Anticipated Outcomes Emerge.

Anticipated Outcomes Emerge

Several Caregivers predicted that the admission experience would be a challenge. The challenge emerged on two fronts. One area was that the PCH bed would be declined by the care-recipient at some point after the bed offer and admission were planned. The second area was caregivers expected and experienced an admission day that would be emotionally taxing.

Two caregivers felt they would have difficulty convincing the care-recipient to accept admission to PCH. The caregivers anticipated a negative outcome that was

described as the care-recipient declining or refusing the PCH admission. Both of the respective care-recipients refused to be admitted to PCH and caregivers reported a confirmed prediction.

> But then you know if she is going to be better then we will pretty well have trouble getting her in the home you know…(Bob-A,1495-1497).

> We went to the home [care-recipient's] and of course my Mother was already cursing like crazy "I'm not going there" and all this…(Bob-C,63-65).

> I think if it came tomorrow….um..he might [emphasized] refuse….if that call came tomorrow I think he would refuse….and I think he would not…go willingly not today. (Sue-A,646-662).

> So uh I don't know, it just kind of, my Dad walked in and he looked at me and he said "I don't like it"…so he said to me "I don't like it here, I'm not staying" then he turned to me and he said to me "and you stay out of this" [laughs]….so I said "I'll stay out of it". (Sue-C,677-686).

Caregivers' unfavorable predictions were often matched by the PCH admission outcome experience. A few caregivers anticipated the "worst" would occur on admission day. The caregivers were not able to describe the meaning of worse, rather it was more a feeling of unease was expected on admission day. Several caregivers felt overwhelmed and at times greatly stressed on the actual admission day.

> So, uhh, in a sense maybe I'm not sure that I'm even expecting the worst enough, because think what could be worse was like Bob's [husband] Dad. (Eve-A,666-667).

> It will be hard, you know, it it will still be hard. (Eve-A,711).

> Oh Yeah, like it it, like um…I was fairly overwhelmed. (Eve-C,68-69).

Theme I. Summary

Caregivers were able to predict with some degree of accuracy the outcome of the bed offer or admission day event. Several caregivers anticipated that the care-recipient would decline the PCH bed offer and this turn of events transpired. A few caregivers felt

admission day would be difficult for both the care-recipient and caregiver. The admission day was emotionally taxing for both parties when this was an expectation.

Theme II: Mismatched Expectations

Caregivers' predictions were at times mismatched by the actual PCH admission outcome. Caregivers anticipated they would experience certain emotions or events during admission of the care-recipient. The admission day arrived and caregivers relayed varied emotional experiences. Two categories emerged and accounted for the theme *Mismatched Expectations*. The categories were: (1) Abandoning, Not Relief (2) Not Prepared When The Time Comes.

Abandoning, Not Relief

The first category described the discrepancy between expecting a sense of relief on admission day and instead experienced the feeling of abandonment on leaving the PCH. Caregivers anticipated they would have felt relief once the care-recipient was admitted to PCH and have received care in this safe environment. Caregivers did not report or describe feeling relieved at the post-admission interview. Several caregivers felt as if they had abandoned the care-recipient as they departed from the PCH. Caregivers anticipated relief on admission but instead described how difficult it was to leave the care-recipient in the care of others.

> But uh...um...[pause] it will be a relief too, you know, it will be that that relief...(Eve-A,716-717).

> Happy and excited, yeah, to know that you know that those other concerns that I have had to deal with are not going to be there. That I can put that onto somebody else in the LTC [Long Term Care], and work with them to have that care for her. (Ann-A,348-351).

> Yet you're feeling like....you're abandoning them....type of thing [nervous chuckle] uh...it's amazing, like yeah...um...you know, in time I'm sure that uh with some of the concerns I have through my observations I'm still not quite....it

> will take me a little while longer too feel comfortable to know that while I'm gone she's not going to be sorta ....abused um...so to speak...(Ann-C,1716-1721).

The sense of abandonment was perceived by caregivers in two ways. The caregivers own sense and the care-recipient's experience. One caregiver expressed concern that the care-recipient would not feel abandoned or "dumped". The caregiver invited her sister to accompany and remain with the care-recipient during the admission day to minimize a sense of abandonment.

> It made a great deal of difference to mother's admittance to....to have her there, that she wasn't just dumped and and left.....(Eve-C,803-805).

Not Prepared When The Time Comes

Caregivers prepared themselves and their care-recipients for imminent PCH admission. Several caregivers recounted how ready they were for the admission but on the actual admission day realized they were not prepared adequately. One caregiver voiced excitement and looking forward to admission day for her care-recipient. The participant felt she would handle the day well. The caregiver felt overwhelmed and not as prepared as she originally thought.

> It's going to be an easy transition, I'm not going to have to prepare the room ahead and put all her stuff in first. (Ann-A,554-555).

> It's just like I say, they the you know, you're prepared and yet you're not prepared when the time comes you think you are, um, but you aren't...Yeah you think you're ready for it...[laughs] and the what do I do [emphasized]...why is it crying, why won't it stop crying kind of thing....(Ann-C,1920-1928).

Theme II. Summary

A surprising turn of emotions awaited caregivers as they departed the PCH on admission day. Several caregivers expected to feel relief once their care-recipient was admitted to PCH yet not one of the caregivers described this emotion. Caregivers felt as

if they had abandoned the care-recipient and felt unease when departing the PCH. Caregivers were surprised as they discovered the preparations made for PCH admission were not as well organized as originally thought.

Summary of Key Area III: Anticipated versus Actual Admission Experience

The two themes that composed Key Area III. *Anticipated versus Actual Admission Experience* described expected and a few unexpected outcomes of the PCH admission experience. A few caregivers expected the care-recipient to decline the PCH "bed offer" and this occurred in two situations. Caregivers anticipated the occurrence of certain emotions or events and these did not always transpire. An expectation of relief was anticipated as the care-recipient was admitted to PCH. Caregivers were surprised when they discovered having felt more a sense of loss than relief as they departed the PCH. Caregivers expressed how they felt the planning for the admission day was not the ideal they had hoped for. The PCH admission event was a first time experience for many of the participants. Caregivers described their experiences and how these resembled one's expectations.

Summary of Chapter IV

Chapter IV presented the research findings. A description of the caregivers was presented. Of interest here is the larger number of male caregiver participants versus female participants in the sample. The findings were discussed within three key thematic areas. The three areas were (1) waiting for notice of an available PCH bed or the "bed offer" (2) the admission day experience (3) anticipated versus actual admission analysis.

The first key thematic area discussed the caregivers experience of waiting for notice from PCH that a bed is available for the care-recipient. Caregivers described the

waiting period as an emotionally taxing period. The second key thematic area described the caregivers' experience of responding to the PCH bed offer, respecting the care-recipient's decision and the events of PCH admission day. Several caregivers depicted the stress and crisis experienced when their care-recipient declined the PCH bed. The remaining four caregivers accepted the bed offer, negotiated the admission day, accompanied and helped the care-recipient settle into the PCH. The third thematic area presented the caregivers anticipated experience to the actual admission day. Caregivers anticipated a sense of relief would occur with placement but rather found they felt as if they had abandoned their care-recipient. Several caregivers felt they were prepared for the admission day but after the event passed, caregivers expressed that they were not as well prepared as originally thought.

CHAPTER V

DISCUSSION OF FINDINGS

Introduction

Chapter V provides a discussion of the findings. The purpose of this exploratory and descriptive study was to provide further understanding of the rural caregiver's experience as they waited for PCH admission for their care-recipient. The applicability of Transition Theory as the conceptual framework is described. The discussion of research findings is presented under the headings of the four main research questions and demographics. The methodological strengths and limitations are presented. Reflexivity and reflection on this study are discussed. Recommendations for further areas of study and nursing practice are presented.

Transition Theory and Understanding of the Caregiver's Experience of Waiting and Admission

The conceptual framework that guided this study was Transition Theory (Meleis et al., 2000). Chapter II described this theoretical framework and how it has been used to guide other caregiver studies. Transition Theory was chosen as the theoretical framework as it is a descriptive rather than prescriptive theory. "There is a danger that we will impose explanation rather than allow understanding of the concept to emerge from evidence of how transitions are actually experienced by those undergoing them" (Chick & Meleis, 1986, P.246). The purpose of this study was to explore and describe the caregiver's experience of nursing home admission of their care-recipient. The qualitative interviews with caregivers provided descriptions that enriched the evidence of how

transitions were experienced. These descriptions are discussed under the main concepts of Transitions Theory.

Nature of Transitions

Transition Theory proposes that family caregiving is a situational transition that may occur within the context of other life transitions such as illness or career change. Caregivers in this study described other transitions they had experienced, for example, one caregiver was in the process of retiring from full time employment and another caregiver was a new grandparent.

The properties of the transition experience were interrelated and influenced transition conditions. Transition Theory proposes that "awareness is related to perception, knowledge, and recognition of a transition experience" (Meleis et al, 2000, p.18). Caregivers in this study identified the onset of the caregiving role as either gradual or sudden and were aware that they needed to be involved in providing care over time. Engagement (in the process) is one of the properties of transitions. Caregivers described how they engaged in the transition of caregiving by making decisions for care arrangements (ie. Home Care) and waiting for PCH admission. Caregivers described their role in the decision making related to planning long term care services for the care-recipient.

Change and difference is the third property of the transition experience. Caregivers described the changes in their life that caregiving produced. Several participants talked about how they would have to drop whatever they were doing and hurry to the care-recipient's home to provide additional care. Sometimes this resulted in

employment or other family commitment interruptions. A few caregivers reported that they felt frustrated with being on call 24 hours a day.

The fourth property of the transition experience is time span or flow and movement over time. Caregivers perceived movement or progress over time in the caregiving transition as they moved closer to receiving a PCH bed offer. Caregivers talked about reaching the decision to apply for nursing home, waiting for the Home Care Panel results, having the care-recipient's name on a PCH waiting list, hoping the care-recipient's name was advancing on the wait list and then anticipating an admission day.

Transition Theory proposes that "...some transitions are associated with an identifiable marker event..."(p.21) or critical turning point or events associated with increasing awareness of change (Meleis et al., 2000). Caregivers described being confronted with significant events along the caregiving trajectory such as the panel reviewing the nursing home application, having the care-recipient's name placed on a PCH waiting list, or unexpected incidences on the care-recipient's well-being (care-recipient burning food on stove). Caregivers described periods of uncertainty and ambivalence over receiving the PCH bed offer. Receiving the PCH bed offer was a critical point or event as caregivers had to respond to the offered admission. Declining a PCH bed offer precipitated a crisis event for several caregivers.

Transition Conditions: Facilitators and Inhibitors

Transition Theory proposes that there are personal and environmental conditions that facilitate or hinder progress through a transition and achieving a healthy outcome. Three main conditions influence the patterns of response. The first of these is personal conditions of which there are four aspects. The first aspect is meanings ascribed to the

transition process. Caregivers described their views on PCH care versus family care. Most caregivers felt PCH was an acceptable choice for long term care service provision. Several caregivers felt that PCH symbolized the "end of the road" or the ending of the care-recipient's life cycle. The second aspect, cultural beliefs and attitudes, was evidenced by descriptions of the expectations of the caregiver role. One caregiver talked about the European culture of expecting family members to provide elder care. A husband caregiver described how his role was to care for his cognitively impaired spouse but found he was exhausted and unable to continue with this ideal. He experienced guilt when he had to consider other care options.

The third aspect, preparation and knowledge, proposed that anticipatory preparation facilitates movement through transitions. Caregivers that were not prepared or had not prepared the care-recipient for the PCH admission declined the PCH bed offer. Caregivers and care-recipients who were prepared accepted the PCH admission. The fourth aspect, community conditions, proposes that community and family resources can either inhibit or ease the transition progress. Caregivers relied on many community resources such as respite admissions, EPH, Adult Day Program and Home Care, as they waited to receive a PCH bed offer. Support received from other family members and professionals, especially Home Care Coordinators, was viewed as helpful. Family conflict or non-support hindered the progress through this transition. One son caregiver described the conflict he encountered with his father when his cognitively impaired mother required PCH admission. The father was totally opposed to the PCH admission and plans for this care option halted at this point. The last aspect is societal conditions.

The location of nursing homes in the local communities was viewed as a resource and as acceptance of this care option.

Patterns of Response

Transition Theory proposes that certain factors indicate a positive transition outcome. Process and outcome indicators characterize the patterns of response that move in the direction of health. There are four aspects of the process indicators. The first aspect is feeling connected in relationships. Caregivers described how they continued their relationships with the care-recipient after admission or if admission was declined. Some caregivers initiated relationships with PCH staff by expressing a desire to share information on the care-recipient's care routines. One caregiver worked as a volunteer in the PCH, by volunteering he felt like he belonged in his spouse's new home (PCH). The second aspect is interaction and reflection on the new relationship. Caregivers described visiting their care-recipient in PCH.

Outcome indicators are characterized by mastery and fluid integrative identities. Caregivers described mastery as learning how to relate to PCH staff or negotiating the PCH application and waiting system. Transition experiences resulted in identity or role reformulation. Caregivers described the changes in their caregiving role from 24 hours a day care provider or worrier to visitor and advocate for the care-recipient.

Limitations and Strengths of Transition Theory in Regards to Study

A strength of Transition Theory is that it facilitated understanding of the concepts involved in caregiver's waiting for PCH admission of the care-recipient. Transition Theory proposes that certain elements and conditions influence the outcome of the transition and with or without interventions an outcome of well-being can be achieved.

This study encountered many of the elements of transition theory when describing the caregiver's experience. An example of this was the effect of preparing for PCH admission and having the care-recipient admitted to PCH as a permanent residence.

A few limitations were encountered with the applicability of Transition Theory. Caregivers described their emotions and emotional responses thoughout the transition events with sensitivity and clarity. The role of emotional responses and reactions is not well described in Transition Theory. The psycho-emotional response by an individual to a transition is critical and may hinder or facilitate progress through the transition. Perhaps this element could be included as one of the aspects of the Personal Transitional Conditions.

A second limitation in Transition Theory's descriptive ability is the inclusion of crisis events as part of transition. This theory describes critical points and events as part of the properties within the nature of transitions. The element of critical points and events could include the role of crisis within transition. An example of this occurred when a caregiver had to decline a PCH bed offer as a significant family member was opposed to the admission. The caregiver experienced a crisis within the caregiving transition as he was concerned about the safety and well-being of the care-recipient. The caregiver eventually resolved his crisis with support from his Home Care Coordinator, acceptance of the outcome of the decision at that time and a renewed interest in seeking nursing home admission at a later time. Crisis can be resolved while the caregiver remains within and progresses through a transition experience.

Transition Theory could be used to undergird future research on understanding the concepts related to the caregiver's experience of waiting and admission to PCH of

their care-recipient. Certain elements were meaningful to caregivers such as the role of values when making the decision to apply for PCH, persist with the wait and either accept or decline the "bed offer". Transition Theory proposes that values are encompassed within cultural beliefs and attitudes under transition conditions. These cultural beliefs and attitudes can facilitate or inhibit the outcome of the transition experience. Transition Theory helped me understand how the data fit together within the nature of transitions, transition conditions and patterns of response. Caregivers anticipated change and an exit to their 24 hour a day caregiver role with a PCH admission of the care-recipient. A few participants were not able to achieve this outcome. Transition Theory guides us in our understanding of different outcomes by examining all the related concepts and events.

Research Question 1: What is the nature of the experience of waiting for notification of actual admission to PCH of one's care-recipient?

Caregivers described their experience of waiting for a PCH "bed offer" within the context of emotional, cognitive and physical responses during this time period. Six features characterized the caregivers' waiting experiences. The six features were: (1) reviewing the decision (2) emotional turmoil (3) expressions of guilt (4) anticipating mortality (5)hardship of the caregiving role (6) worry.

Reviewing the Decision

Caregivers relayed that they continued to revisit the decision to apply and wait for a PCH admission of their care-recipient. The waiting period was somewhat lengthy and this presented caregivers with an opportunity to reflect and mull over decisions made. Caregivers reviewed their decision by considering reasons that justified the decision. This rationalizing of the decision was consistent with Bell (1996), Johnson (1990) and

Lundh, Sandberg and Nolan (2000). Caregivers described how they felt singular in persisting with the decision to wait for a PCH bed offer even though family support was made at time of original decision. This finding reflected Bell (1996), Johnson (1990) and Travis and McAuley's (1998) research that had identified main caregivers as having the responsibility to oversee the implementation of the decision even though other family members supported the original decision.

The timing of the decision and receiving the bed offer was an important factor when revisiting the decision. Caregivers expressed hope that the arrival of the bed offer would match the care-recipients need for the PCH admission. Several caregivers relayed the concern that the bed offer may have been declined if the care-recipient's needs for admission were not matched. This particular finding was a feature of the waiting experience and presented a new element in the decision context of applying for and accepting an offered PCH admission. This finding is consistent with Johnson (1990) but has been minimally identified in the literature and is worth further exploration.

Family support during the waiting experience was valued by caregivers. Husband caregivers in this study received support and encouragement from their family members to apply and persist with the wait for a PCH admission of their care-recipient. This finding differs from Gaugler, Zarit and Pearlin's (1999) research that identified husbands were "...more likely to perceive criticism from family members" (p.21). The sample of husband caregivers was dramatically smaller in this study compared to Gaugler et al.'s (1999) robust sample, therefore this study's finding on husband caregivers, must be viewed with some caution.

Emotional Turmoil

Caregivers described the emotional swings they felt during the waiting period. Caregivers used the term "roller-coaster" to depict the mood and emotion fluctuations they experienced. This finding is consistent with Dellasga and Nolan (1997) and Travis and McAuley (1998). Caregivers described having felt many mixed emotions such as happy, calm, feeling a sense of comfort and then feeling on edge, ambivalence, uncertainty and pressure in response to the waiting period. The expression of emotional turmoil particularly that of uncertainty and ambivalence was often in response to the imminent PCH "bed offer". Caregivers described feeling a sense of dread or ambivalence when thinking about receiving the call from the PCH with a "bed offer". Caregivers realized they would be faced with following through to completion the decision to have a PCH admission for the care-recipient. The emotional turmoil persisted throughout the wait, admission and early post-admission periods.

Expressions of Guilt

Caregivers expressed feelings of guilt over the decision and waiting period for a PCH admission of their care-recipient. Caregivers' expression of guilt has been well documented and supported in the research (Bell, 1996; Hagen, 2001; Ryan & Scullion, 2000). Caregivers ventured that guilt was experienced because of conflict over what they felt were their duties or obligations (values) as a caregiver to what care options were actually needed or realistic. Hagen (2001) referred to this as "...the extent to which caregivers felt guilty over somehow 'not doing enough' for the family member with dementia in their care" (p.51). This study's finding of expressions of guilt in this context is consistent with the literature.

The second context in which guilt was expressed pertains to desiring a PCH bed vacancy in the rural setting. Caregivers and care-recipients in this study resided in small communities and were often familiar with the residents of the local PCH. This finding concurs with Bell (1996). Friends, acquaintances and other family members (of the caregiver) may have been residents in the local nursing home. Caregivers expressed feelings of guilt when they desired a PCH bed vacancy for their care-recipient but acknowledged they might know who passed away to create the vacancy. Caregivers made the connection that by desiring a PCH vacancy they were unintentionally desiring someone's passing – this unintentional desire evoked feelings of guilt. This finding indicated that further investigation is recommended as confirming or contrary literature was not located.

Anticipating Mortality

Caregivers described the anticipated nursing home admission as "the end of the road" or "last stop" for their care-recipient. Caregivers reported that the care-recipients expressed the same sentiment. This realization was a source of sadness, guilt and anticipatory grief for caregivers. This finding is consistent with past research (Ade-Ridder & Kaplan, 1993; Farkas, 1981; Hagen, 2001; Nay 1995). Hagen (2001) referred to the sense of existential self as a factor influencing the caregiver's placement related decision and the "…profound realization that their family member is dying" (p.50). Hagen's (2001) study identified that caregivers questioned the meaning life held for them and the brevity of life whereas the caregivers in this study expressed more concern on the anticipated and imminent mortality of their care-recipient. The concern was expressed in a context of sadness, crying, fear and dark humor. The imminent nursing home

admission symbolized the end of the life cycle of one's care-recipient. The strength of emotional responses to this concept was evidenced and warranted further investigation on this aspect.

Hardship of the Caregiving Role

Two aspects characterized the ongoing hardship of the caregiving role. The two aspects were rural travelling and being on call 24 hours a day. Caregivers described the difficulties they encountered as they continued to provide many aspects of care during the PCH waiting period. A unique aspect of the rural caregiving context was the distance caregivers had to travel matched by the corresponding time commitment. Travelling during Manitoba winters was a challenge as roads were often blown in by snow drifts or were icy and treacherous. These factors pose an additional hardship for rural residing caregivers in providing caregiving tasks. The further a caregiver lived from the care-recipient the more time was taken up by travelling and being away from one's home or other responsibilities. This finding was consistent with Bell (1996) and Hallman and Joseph (1999).

The second aspect that caregivers described was the sense of being on call 24 hours a day. Caregivers were aware of the necessity of being available for the care-recipient but found they desired an end to being constantly on call. This finding was consistent with past research (Bell, 1996; Noonan, Tennstedt & Rebelsky, 1999; Rodgers, 1997). Noonan et al. (1999) referred to this situation as "...the subjective sense of being overwhelmed and overloaded" (p.14).

Worry

Caregivers in this study described how they frequently worried about the care-recipient's well-being. Caregivers who did or did not live with the care-recipients expressed similar and dissimilar worries. Caregivers worried about adequate nutritional intake, risk of falls or other injuries. Similar findings were identified in Bell (1996); Noonan et al. (1999) and Rodger's (1997) research. Of interest here is the worry and concern caregivers perceived on the vulnerability of the care-recipient. Caregivers presented the analogy of a child when they spoke of their care-recipient's vulnerability.

Research Question 2: What is the nature of the experience of the rural caregiver when they plan and are faced with preparing one's care-recipient for the actual admission (to PCH) day?

Caregivers had the challenge of preparing their care-recipient for a major move yet had no idea on when that day would arrive. Caregivers were creative in long term planning for an unknown moving date. Once the PCH bed offer was made caregivers received little time to plan and respond to this offer. Two areas characterized the caregivers experience of preparing their care-recipient for PCH admission: (1) preparing in advance for an unknown admission day (2) responding to the PCH bed offer.

Preparing in Advance for an Unknown Admission Day

Many of the caregivers in this study felt it was important to prepare their care-recipient for the eventual relocation to PCH. Caregivers demonstrated ingenuity and creativity in the strategies they utilized. Long term preparations centered on having the care-recipient familiar with a PCH environment.

Caregivers used strategies such as respite admissions to PCH, attending adult day programs that were located in the local PCH, and/or residency in an EPH juxtaposed to desired PCH. Eight of the caregiver participants in this study used these and other various strategies to prepare their care-recipient for future PCH admission. This finding differs from studies such as Collins et al.'s (1994) research that indicated caregivers used these resources to postpone PCH admission. Lundh et al.'s (2000) research presents a contrary finding as their study indicated caregivers did not plan for PCH admission in advance. The participants' care-recipients in this study were on lengthy PCH waiting lists and had the opportunity for engaging in long-term planning and preparation for admission. The long waiting period may account for the differences in research findings. There are many situations where PCH admission occurs quickly such as when care-recipients are in hospital and must accept an emergency PCH admission. Emergent admission precludes an opportunity for planning and preparation. Future research is warranted in the area of long term planning for PCH admission.

Responding to the PCH Bed Offer

Caregivers were uncertain when the PCH bed offer would arrive. This uncertainty created difficulties in setting a specific plan in motion. Caregivers were notified of a PCH bed availability in different manners and contexts. The notification was usually presented by the PCH's director of nursing. An exception to this practice occurred when one caregiver was notified by the hospital (care-recipient was an in-patient) that a PCH bed was available in another town and the expectation was that the care-recipient would be transferred as soon as possible. The bed offer was usually presented in a diplomatic way with one exception. One director of nursing extended the

bed offer in the middle of a busy hallway via a chance encounter with the caregiver. The caregiver expressed dismay at the unprofessional manner in which she received the notice of admission. Most caregivers perceived that the bed offer occurred in a climate of urgency for a response. This finding was consistent with Cheek and Ballantyne's (2001) research that identified caregivers who felt the need to make an "on-the-spot decision" once a PCH bed was available and offered.

Caregivers were uncertain on how to approach the care-recipient with the bed offer especially in situations of a cognitively impaired elder. Of six caregivers who received a PCH bed offer, four accepted and two declined the admission. Two elderly husband caregivers accepted the PCH bed offer without consulting with their cognitively impaired spouse. Both of these care-recipients were in other facilities waiting for a PCH admission. The remaining four caregivers (adult children) who had received a bed offer met with their care-recipients to discuss acceptance. These findings are consistent with Cheek and Ballantyne (2001) and McAuley et al. (1997). Two adult children caregivers accepted the PCH bed offer and the remaining two had declined the bed offer. Once the PCH bed was accepted caregivers went about the tasks of negotiating the actual admission day and planning the mechanics of the move. One son caregiver negotiated an extended response time in light of opposition that he encountered on accepting the bed offer from his care-recipient (mother) and father. Caregivers were not prepared to force an admission if the care-recipients were opposed. Caregivers felt they would be violating the parent-child roles and relationship if they persisted with a PCH admission. This caregiving response indicates an avenue for further research. Past research has not

focused on a declined PCH bed offer but rather the guilt associated with an opposed PCH admission (Bell, 1996; Matthiesen, 1989).

Research Question 3: What is the experience like for rural caregivers when accompanying and assisting the care-recipient during the day of admission to PCH?

Caregivers described their experiences of the PCH admission day. The manner in which the PCH staff greeted and extended a welcome to the nursing home set the tone for the caregiver's admission day experience. Caregivers experienced an intensity of some emotions on admission day. Caregivers held the realization that some of their tasks and responsibilities were being relinquished at time of admission. Caregivers expressed an appreciation for family support and presence during PCH admission.

Feeling Welcome or Unwelcome on PCH Admission Day

The manner in which PCH staff approached and welcomed the caregiver – care-recipient dyad set the tone for the admission day. Caregivers described various welcoming experiences ranging from positive to negative. Some caregivers perceived that the PCH staff were genuinely interested in the well-being, individuality and care needs of the care-recipient. These staff included the caregiver in the welcome and admission process. Several caregivers perceived an unwelcoming atmosphere as demonstrated by PCH staff who did not inquire about the care-recipient's abilities, interests or individuality. One caregiver eloquently described her experience of being greeted at the PCH door by a staff nurse with a wheelchair in hand. The caregiver's care-recipient was capable of independent ambulation but the nurse insisted on wheelchair use. The nurse's approach was perceived as robbing the care-recipient of his independence and abilities. These caregivers felt PCH staff were either not interested or

would not listen to expert knowledge the caregivers had on the care needs of the care-recipient. This finding is consistent with Lundh, et al. (2000). Further research is warranted on the actual admission day experience as the majority of the research has centered on the post-placement time frame.

Resurgence of Emotions

The admission day elicited a resurgence of emotions such as guilt, grief, stress, being overwhelmed and sense of unease. Caregivers had to complete a considerable amount of PCH admission paperwork. Caregivers perceived the admission paperwork to symbolize "signing away control" over their care-recipient. This action evoked feelings of guilt, loss, and a general sense of unease. This is consistent with the findings of Kammer (1994), Kellett (1990) and King et al. (1991), yet contrary to Courts et al. (2001). Courts et al. (2001) found that caregivers did not feel guilt during the PCH admission. This study had a few weaknesses. The study was conducted two years post-placement. Thus results were limited by the retrospective timing and a specific religious denomination affiliated sample.

Caregivers described feeling overwhelmed, stressed and not as prepared for the PCH admission as they should have been. Caregivers were not prepared for the vast amount of paperwork required during the admission process and other aspects of the move. Further research on this finding is warranted as literature could not be located that addressed this particular aspect of PCH admission.

Family Support During Admission Day

Several caregivers expressed an appreciation for the presence and support of other family members during the admission day experience. The presence of family members

provided the caregiver and care-recipient with emotional support during this time period. The role of other family members or significant others in supporting the caregiver during the admission day has received little attention in past research. Lundh et al. (2000) referred to the positive experience of "the whole family" involvement in furnishing the PCH room prior to admission. The role of other family members or friends' support on the actual admission day is not adequately depicted in the literature.

Relinquishing Tasks and Responsibilities

Caregivers described the realization that they were "handing over the care" of their spouse or parent to the staff of the PCH. Two events appeared to prompt this realization. The first event was completing the paperwork and the second was sharing the care-recipient's care needs, preferences and activities with PCH staff. Caregivers described relinquishing the physical care needs of their care-recipient yet intended to maintain other aspects of their care-giving role. An individual caregiver shared her perception that one of her ongoing responsibilities was to monitor the care her mother received in PCH. This transition of caregiver roles and responsibilities was consistent with the literature and has been well researched (Fink & Picot, 1995; Zarit & Whitlatch, 1992).

Research Question 4: What is the nature of the feelings and concerns rural caregivers have upon leaving one's care-recipient and departing from the PCH on day of admission?

Caregivers anticipated that a sense of relief would be experienced on the admission day. Surprisingly, not one caregiver reported feeling relief on or shortly after

the PCH admission of their care-recipient. This finding is contrary to past research (Cheek & Ballantyne, 2001; Gold et al., 1995; Ryan & Scullion, 2000). The difference in findings may be partly due to timing of research methods. Caregivers in this study were interviewed shortly after the PCH admission event (from approximately ten to twenty-one days post-admission) and this experience was of a recent nature. Caregivers in past research were interviewed post-placement and when many months had elapsed from the admission event. The passage of time may facilitate caregiver adaptation and an evolving sense of relief.

Several caregivers described leaving the PCH and feeling as if they had abandoned the care-recipient. This finding would seem to support the report of Ross, Rosenthal and Dawson (1997) that wives who institutionalized their husbands felt they had abandoned them. One caregiver expressed the concern that she did not wish for her care-recipient to feel as if she had been abandoned. It was important to caregivers that the care-recipients felt supported in this transition. Caregivers felt somewhat exhausted when exiting the PCH.

Summary on the Rural Context of the Waiting Experience

Certain unique aspects of rural caregiving and waiting for a PCH bed offer pertains to the rural context of this study. The first of these is the additional hardship to the caregiving role when attempting to provide care over a large geographical area. Caregivers endure having to travel many miles over hazardous roads and conditions so that they are able to provide care to their care-recipient. The second unique aspect in the context of rural caregiving is the feeling of guilt when desiring a PCH bed vacancy. Rural residing caregivers may know the person who created a PCH bed vacancy. Rural

caregivers feel guilt in their desire for a bed offer as they associate this as an indirect or unwanted wish for someone to expire to create a vacancy. Urban residing caregivers do not usually know the residents of the district PCH as the occupancy may number in the hundreds. The third aspect pertaining to the rural context of caregiving encompasses the worry that rural caregivers experience as they are waiting for a PCH bed offer. Rural caregivers often live far from their care-recipient and they experience concern for the well-being and safety of the care-recipient. Hospitals, emergency medical services, home care services and physicians are of considerable distance and at times not accessible to the rural residing care-recipient (due to inclement weather). This aspect of rural residency may be a factor that intensifies the caregivers' worry about the well-being of the care-recipient as they wait for PCH admission.

Discussion of Demographic Findings

Of interest here was the gender composition of the sample. Past research indicates that females outnumber male caregivers, with male caregivers consisting of 15 to 25 percent of filial caregivers (Campbell & Matthews, 2000). The sample in this study had six male participants (2 spouses, 1 son, 1 brother, 1 nephew, and 1 son-in-law). Two female spouses were originally recruited for this study but became ineligible when their spouses died. The remaining sample was well represented with male caregivers but one that differs from the majority of research on caregivers. Two of the male respondents provided rather brief responses to the interview questions whereas the remaining respondents provided detailed responses. This finding is consistent with Mathew, Mattocks and Slatt (1990). These researchers identified that male respondents provided brief descriptions during interviews as compared to female respondents.

The sample in this study consisted of individuals of different relationships to the care-recipients, such as daughters, son-in-law, husbands, nephew, son and brother. The age of caregivers varied (range of 43 to 89 years) considerably, thus the sample was not homogeneous. These differences in the sample make it difficult to link the sample demographics to particular aspects of the findings. An example to clarify this point is the two caregivers who declined a PCH bed were adult children with a cognitively impaired parent, but this was the only demographic that was similar. The care-recipients were different genders, the caregivers were different ages (40+, 60+) different genders. A more homogeneous sample is recommended for future research.

Methodological Strengths and Limitations

This section includes a discussion on the strengths and limitations of the study. One of the limitations of this study was the sample size (interview number) and representation. Twelve interviews were conducted prior to the bed offer and PCH admission. Only six interviews were conducted post-admission or post-declined PCH bed. Three of the caregivers had not received a bed offer and one caregiver could not be contacted at the study's end of data collection time. These participants may have shared different experiences and outcomes in respect to the six participants who were interviewed. A great deal of time is required to complete a prospective study that involves a waiting and admission period. Caregivers in Manitoba can wait from a few days to a maximum of two years to receive a PCH bed offer depending on the particular nursing home. The time allocated in this study for data collection was 5 months. This time frame was inadequate for data collection as three caregivers had not received a PCH

bed offer at the 5 month scheduled time period. This time commitment exceeded the thesis study's time frame.

The caregiver participants were varied in their relationship to caregivers. There were daughters, husbands, a son, brother, son-in-law, and nephew participants. Unfortunately, no wife caregiver participants were successfully recruited for this study. Two wife caregivers were initially enrolled but became ineligible when both husbands died prior to the first interview date. The addition of wife caregivers would have provided more depth to representation in the sample. This study could have been strengthened with the addition of wife caregivers and increased time span to conduct the research.

Most of the sample's care-recipients were cognitively impaired. Considerable research has been conducted with caregivers of cognitively impaired care-recipients. A limitation to this study is the descriptive ability applies more to caregivers of cognitively impaired care-recipients than physically impaired. This study could be strengthened by having equal representation from caregivers of cognitively and physically impaired care-recipients.

One strength of this study was the site of sample recruitment. Rural caregivers have been traditionally under-represented in studies. The main rationale for this is difficulty accessing this population due to long distance travel and poor road conditions. This study was able to recruit and enlist rural caregivers. As a rural residing researcher I had knowledge on how to navigate the country roads and obtained contact people (and programs) that assisted me with sample recruitment. The participants were recruited through the Home Care Program as they were currently waiting for a PCH admission.

The second strength of this study was that it was prospective in nature. Caregivers were interviewed in the midst of their experience while waiting therefore they did not have to rely on recall to retrieve long past events and experiences. Caregivers were interviewed shortly after the PCH admission or bed offer decline. This short time interval minimized reliance on recall and provided more depth and accuracy of their experience.

Reflection and Reflexivity

Reflection and reflexivity practices remind the researcher that they are "...part of the social world(s) that he or she investigates" (Berg, 2001, p.139). Qualitative research allows the researcher to enter the world of the participant and retrieve their intricate story (Rew, Bechtel & Supp, 1999). The researcher is a person replete with their experiences of their social world. The qualitative researcher has the responsibility to recognize their role and impact on the research process through reflection. My interest in caregiving originated from personal and professional experience. As a mother of two active children I became a caregiver to my grandmother after she fell and fractured her hip. I would bundle up my toddler son (after my daughter went to school) and we would spend the day with "Nana". The day involved cleaning house, helping Nana with her bath and lots of laughing while we visited. My parents and grandmother encouraged me to value the role of family caregiving by their modeling and expectations. The culture (Italian) I was raised in valued the importance of family and caring for family members.

As a Home Care Coordinator I had numerous opportunities to provide service to clients and their caregivers. Some tasks of service provision involved supporting clients and caregivers as they arrived at the decision to apply for PCH and wait for an admission.

At times I found this to be a difficult endeavor for clients and families. When the bed offer was made some clients and their families experienced a crisis. I wanted to know how I could be of more assistance during the waiting period and PCH pre-admission.

As I was interviewing caregivers I found myself agreeing and relating to some of their experiences. I was touched by their stories and felt empathy for their plight. I was amazed by the guilt that was expressed when I considered the wonderful job they had performed as caregivers. I suspected that values played a role in the aspect of caregiving. The caregivers in this study were often embroiled in an inner battle of what they should or should not do in their caregiving role. I learned that this turmoil is an important aspect to consider during the PCH waiting period. I have learned to be more understanding of this turmoil when a caregiver calls and informs me that they cannot accept a bed offer or that they are unsure if they should accept. I can be supportive and validate their experience when they weigh the pros and cons of accepting or declining a PCH bed for their care-recipient. These caregivers have also inspired me with their creativity on problem solving while they prepared their care-recipient for PCH admission.

Recommendations

The completion of this study opens the door to future directions nursing can pursue with caregivers and research. Some recommendations are presented in the areas of nursing practice, nursing administration, nursing education and future nursing research.

Nursing Practice

Nurses need to understand and at times intervene in the challenging situation experienced by caregivers as they seek nursing home admission for their care-recipients.

Nurses in Home Care Programs can prepare clients (care-recipients) and caregivers for PCH admission by: (1) validating and acknowledging the emotional, cognitive and physiological responses by care-recipients and caregivers (2) providing evidenced based counseling on how to prepare for PCH admission (3) providing written and verbal information on the PCH care option (4) empowering caregivers and care-recipients on how to advocate for self once admitted to PCH (5) assessing the impact of values and other factors that play a role in accepting or declining a PCH bed offer (6) encouraging caregivers to invite other family members or significant others as appropriate to assist with the PCH admission day (7) providing options and approaches for encouraging a reluctant and/or cognitively impaired care-recipient in respect to an imminent PCH admission. In the PCH post-admission phase, approximately one month post-placement, Home Care Nurse Coordinators can provide a follow-up contact either in person or via telephone. The contact could focus on the admission day experience and how the caregiver is managing currently.

Nurses in PCH (and LTC) facilities need to be aware of the significance and impact of the admission day on family and clients. Nurses in long term care can facilitate a more positive transition to PCH by: (1) providing a welcoming atmosphere at time of PCH admission, such as – being prepared for arrival; meeting the caregiver and care-recipient at the door; inquiring as to the care-recipient's abilities and routines; orientating dyad to facility (2) demonstrating respect and inquiring as to the care-recipient's abilities and individualism (3) encouraging caregivers to bring information (in writing if possible) on the care-recipient's care routines, interests and activities (4) giving consideration to the concept that the caregiver may also be a client initially but also a partner in caring for

the care-recipient (5) assessing care-recipient and caregiver for responses to this admission [(ie.) crisis response] and planning appropriate interventions if warranted (6) providing counseling on the role changes caregivers experience during PCH admission of the care-recipient. The PCH nurse can assist the caregiver in deferring non-urgent required paperwork to perhaps a later day rather than on the admission day.

Nursing Adminstration:

A few recommendations for nursing administration are suggested. Nursing administration should have clear policies on the PCH waiting list practice and status of care-recipients on these lists. Caregivers should be apprised in a timely manner of the care-recipient's progress on this list to minimize the uncertainty experienced by these individuals. Caregivers should have the name of a consistent contact person in the PCH during the waiting period. The PCH could invite caregivers to make an appointment to complete some of the required paperwork prior to the actual admission day. Caregivers and care-recipients may benefit from having one individual nurse assigned to their care for the PCH admission day process and event. Nursing administration could include in the nursing staff budget an allocation for additional staff hours to offer a one on one support for the care-recipient on admission day. The PCH administration could develop a policy that addresses staffing complement on PCH admission days for new residents.

Caregivers described the sense of urgency to respond to a PCH bed offer. Nursing administration needs to be aware of the stress this creates in families and perhaps make allowances for negotiating times to respond.

Nursing Education

Nursing education has a role in preparing nurses for long term care with caregivers and care-recipients. Nursing education should include the development of assessment and intervention skills pertaining to caregivers. Theory and skills on caregiver appraisal (burden), transition and crisis theory, caregiver career, role of values in caregiver decision making and family assessment are crucial components of nursing education pertaining to this area of interest. Continuing education for PCH nurses should include protocols and best practice for welcoming new residents into PCH.

Future Nursing Research

This research complements and supplements past research on caregivers. Future research is now recommended in the direction of caregiver intervention studies. A few areas have been identified for future exploration. Intervention studies on preparing caregivers and care-recipients for PCH admission would provide evidence on best practice initiatives. Is counseling beneficial for reducing feelings of ambivalence, guilt, stress or other concerns during the waiting period? Would one-on-one counseling or a family conference approach be more effective? Would written material and resources have a more beneficial effect in preparing families for PCH admission? What role do values play in accepting or declining a PCH admission? Caregivers expressed how they just did not know how to broach the subject of the PCH bed offer with the care-recipient. Is there a role for nurses in this situation and what strategies could they share with caregivers for approaching this dilemna? Research could be conducted on strategies or interventions that assist caregivers during this particular experience. Intervention research is recommended on nursing PCH admission practices. What type of welcoming

approach and atmosphere creates a more positive PCH admission experience for caregivers and care-recipients? Many directions for future nursing research were uncovered, the most pertinent were presented in this discussion.

Summary of Chapter V

Chapter V presented the discussion of the findings. Transition Theory was used as the compass to explore the caregiver's experience. This theory allowed understanding of the concepts as they evolved from the data. The discussion of the findings was organized under the appropriate research questions. There were four research questions. The questions focused on exploring and describing the caregiver's experience with PCH admission of the care-recipient. Discussion of the demographic findings indicated a strong representation from male caregivers. Methodological strengths and limitations were presented such as small post-admission sample size and lack of wife caregiver representation. The researcher's reflection on this study was presented such as personal and professional values pertaining to caregiving. Recommendations for nursing practice, education, administration and future research endeavors were suggested.

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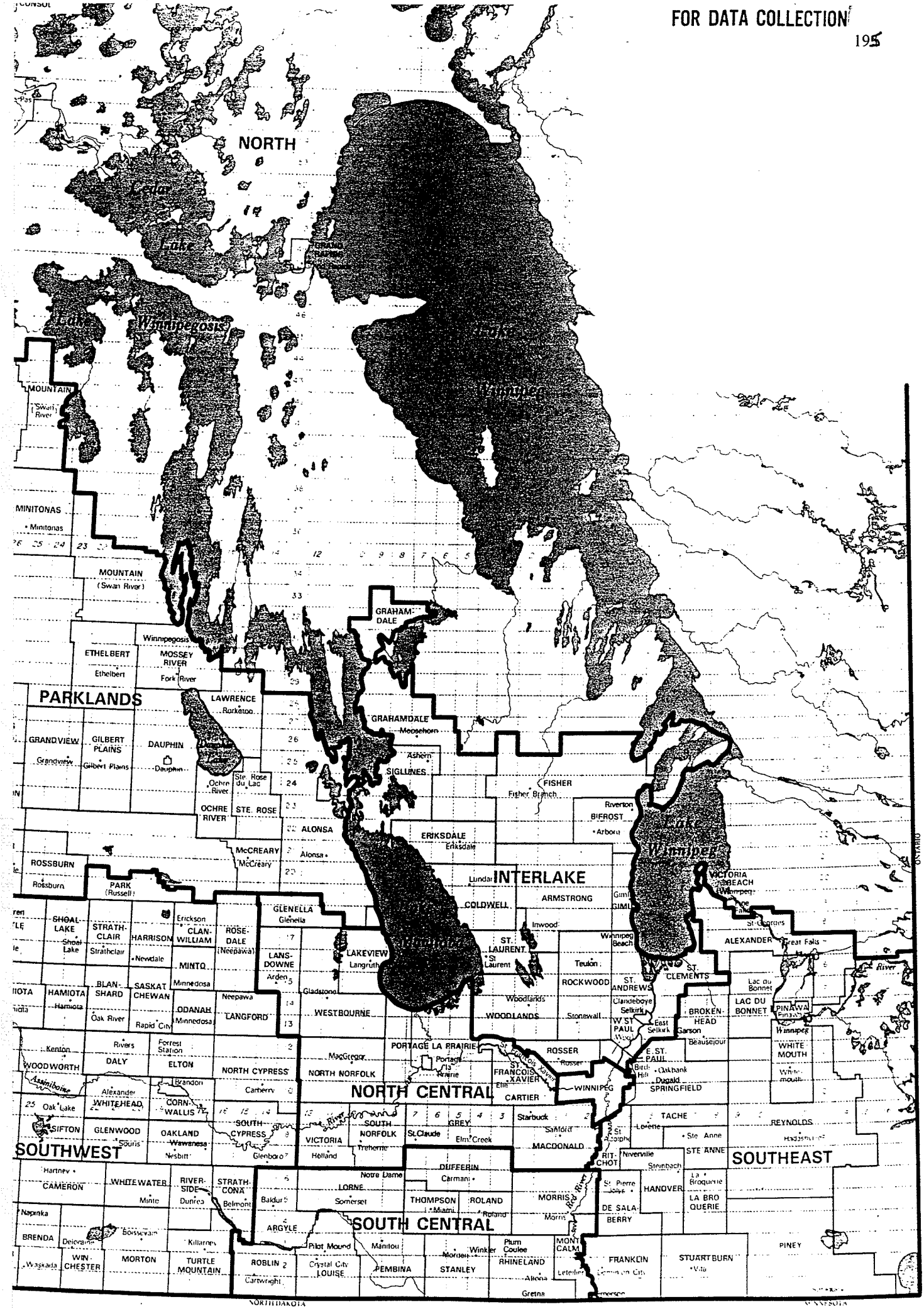
APPENDICES

Appendix A

Map of Manitoba

Rural Regional Health Authorities

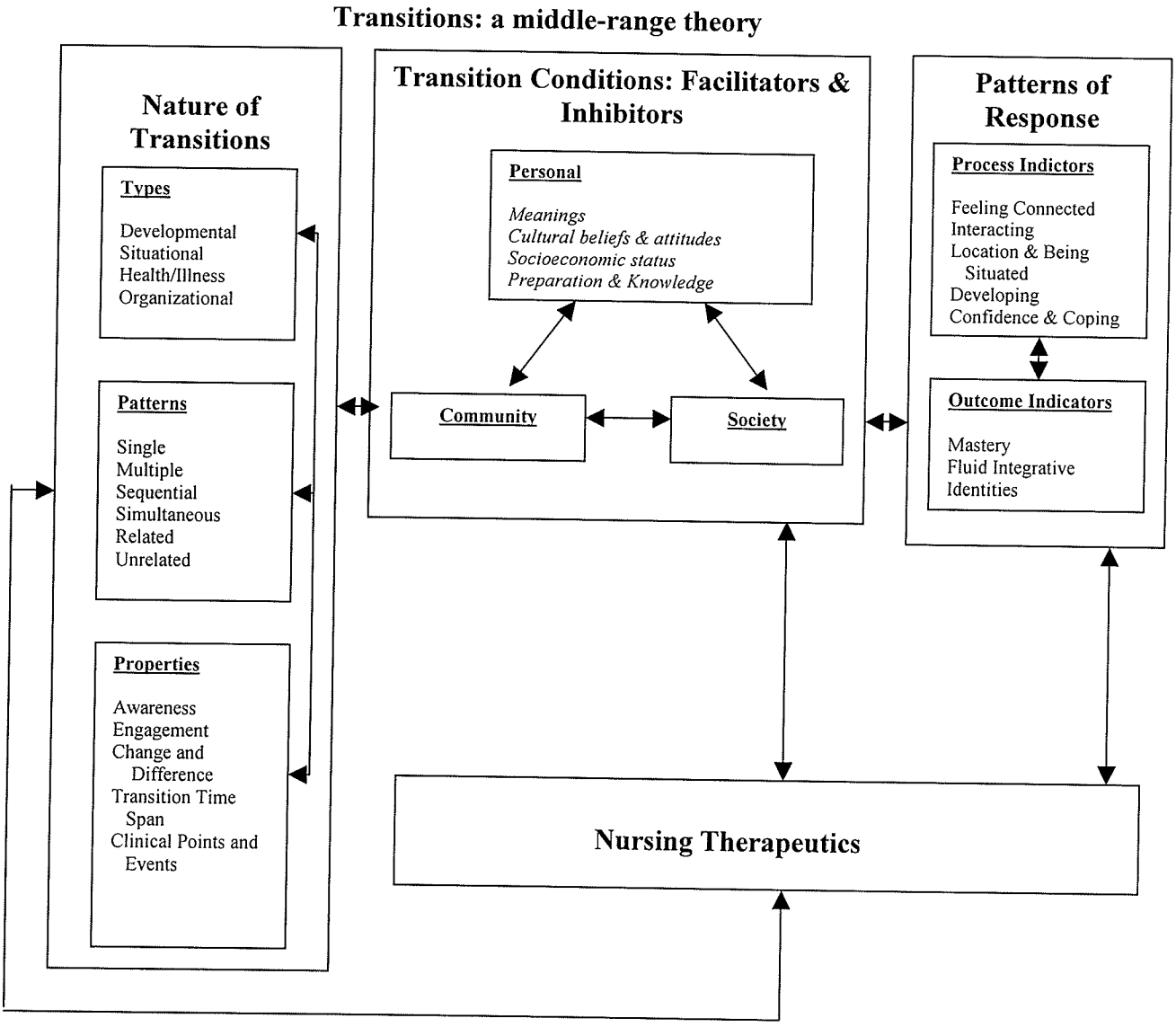


Appendix B

Conceptual Framework

Transitions: a middle-range theory

Appendix B



Source:

Meleis, Sawyer, Im, Messias, & Schumacher (2000).

Appendix C

Letter to Rural Regional Health Authority requesting permission to access participants.

Appendix C

Box

MB.

2002

Vice President Planning
RRHA

Dear V.P.,

My name is Mary Meisner and I am a graduate student in the Master's of Nursing Program at the University of Manitoba. I have completed my required course work and I am in the process of submitting my thesis proposal. I am writing this letter to request permission to access RRHA caregivers of elders and to be able to conduct my study in the RRHA Region. Included in this letter of request is a copy of my application to the Faculty of Education/Nursing Research Ethics Board (ENREB) at the University of Manitoba. Once Ethical approval has been granted I will forward a copy to you.

I am conducting a study on caregivers as part of the thesis component of my program. My thesis is entitled: Transitions in Caregiving: The Experience of Family Caregivers as they wait for Their Family Member to be Admitted to Personal Care Home. A qualitative research design will be employed. For my thesis topic I plan to study the experience of caregivers as they await notification and actual admission of the older family member to Personal Care Home. Home Care Case Coordinators and Hospital Discharge Nurses in clinical practice have expressed concern about this difficult transition event for caregivers. Little is known of the rural caregiver's experience of the waiting period for their Elder. To acquire a better understanding during this phase of caregiving, I would like to interview caregivers who reside in the RRHA geographical region and who have a relative (parent or spouse) on a waiting list for Personal Care.

With voluntary participation, I would like to interview 8 to 10 caregivers (spouse or adult children) whose relative has been paneled and is on the waiting list for PCH admission. Informed consent would be obtained prior to participants entering study. The interview would focus on the perceptions, thoughts, feelings, perspectives and values that the caregiver experiences during the waiting period and actual admission event to PCH of the family elder. I would also like to find out what things helped make the waiting period easier to manage or/and what things made it more difficult.

I would kindly request the assistance of Home Care Case Coordinator Nurses/Social Workers and Hospital Discharge Coordinator Nurses in the recruitment and accessing of potential study participants. These nurses and social workers would be given copies of a letter of invitation to participate in a nursing study (see attached). The nurses and social workers would have a list of criteria for participant invitation. The nurses and social workers could then decide which caregivers would receive an invitation to participate and provide a brief overview of the study purpose. The identity of potential participants will be kept confidential, I will not have direct access or contact with potential participants until permission has been granted by same. I will be notified of family caregiver's intent to participate in this study through the nurse or social worker. Participants are under no obligation to participate in this study and are free to withdraw at any time without prejudice.

If you require further information please contact me at 768-(work) or 768-(home). I can also be reached at e-mail . You can also contact my thesis chairperson, Dr. David Gregory at the University of Manitoba, (204) 474-9201.

I would like to take this opportunity to thank you for your time and attention to my request.

Yours truly,

Mary Meisner R.N.,B.N.

Appendix D

RRHA Permission to Access Participants

e-mail received from Vice President of Planning of RRHA

Mary Meisner

From:
Sent:
To:
Cc:
Subject:

Yes you now have permission to begin. I think a memo from you to mgmt and the home care staff in the district stating in brief the objectives of the survey and what support you will need, just to keep everyone informed.

You and ! ___ can work out the details and let me know if you need my help in any way.

Good luck and you know I am interested in the results, as is the Board (I promised them the results)

Appendix E

Letter of Explanation to HCC and Discharge Coodinator

Appendix E

Letter of Explanation to HCC and Discharge Coordinator

Box

R
2002

Home Care Coodinators
Hospital Discharge Coordinator
RRHA

Dear Home Care Coordinators and Hospital Discharge Coordinators,

My name is Mary Meisner and I am a graduate student in the Master's of Nursing Program at the University of Manitoba. I am conducting a study on caregivers as part of the thesis component of my program. My thesis is entitled: Transitions in Caregiving: The Experience of Family Caregivers as They Wait for Their Family member to be Admitted to Personal Care Home. I will be using a qualitative research design. For my thesis topic I plan to study the experience of caregivers as they await notification and actual admission of the older family member to Personal Care Home. On different occasions, Home Care Coordinators and Hospital Discharge Nurses in clinical practice have expressed concern about this difficult transition event for caregivers. Little is known of the rural caregiver's experience of the waiting period for their Elder. To acquire a better understanding during this phase of caregiving, I would like to interview caregivers who reside in the RRHA geographical region and who have a relative (parent or spouse) on a waiting list for Personal Care.

With voluntary participation, I would like to interview 8 to 10 caregivers (spouse or adult children) whose relative has been paneled and is on the waiting list for PCH admission. Informed consent would be obtained prior to participants entering study. The interview would focus on the perceptions, thoughts, feelings, perspectives and values that the caregiver experiences during the waiting period and actual admission event to PCH of the family elder. I would also like to find out what things helped make the waiting period easier to manage or/and what things made it more difficult.

I would like to request your assistance in the recruitment and accessing of potential study participants. The possible participant's identity would be kept confidential and would only be shared with me if the caregiver is interested in participating in my study. Enclosed is a copy of the participant eligibility criteria for your information. If you decide to assist me in the recruitment of potential participants, I

would be asking you to give caregivers (who meet the eligibility criteria) a copy of my Invitation to Caregivers (to participate in a study of caregivers). Interested Caregivers would contact you to give permission to forward their name to me.

I will also plan to meet with you to further discuss any questions you might have in regards to this study. I appreciate any assistance that you are able to provide in regards to recruiting and accessing participants.

If you require further information please contact me at 768-2585 (work) or 768-9405 (home). I can also be reached at e-mail You can also contact my thesis chairperson, Dr. David Gregory at the University of Manitoba, (204) 474-9201.

I would like to take this opportunity to thank you for your time and attention to my request.

Yours truly,

Mary Meisner R.N., B.N.

Appendix F

Home Care Coordinators (HCC) and Discharge Coordinator's Invitation to Participate in Study Script.

Appendix F

Home Care Coordinators (HCC) and Discharge Coordinator's Invitation to Participate in Study Script

Hello, this is _____ (name and title) of the Rural Regional Health Authority (RRHA). The RRHA has received a request from Mary Meisner, R.N., a student in the Masters of Nursing Program at the University of Manitoba, to conduct a study with caregivers. Mary is interested in learning about the experience of caregivers while they are waiting for their family member to be admitted to a personal care home. I am calling to ask if you would be interested in participating in Mary's study. You are receiving this invitation to participate in this study because I am aware that you are the main caregiver for _____ (name of care recipient) and that _____ (care recipient name) is waiting for personal care home admission. The study would involve two to three interviews. Two of the interviews will be held during the waiting period for a personal care home bed to be offered to _____ (name of care recipient). The last interview will be scheduled about one week after _____(name of care recipient) has been admitted to the personal care home. If you agree to participate in this study you will be interviewed at a time and place of your convience. Are you interested in participating in this study?

If yes, I would like to thank you for your consideration of this request. Could I please have your phone number where you can be reached and best times to contact you?

Name: _____ Phone:_____ Times/Days: _____

If no, I would like to thank you for your time and consideration of this request.

Appendix G

Researcher's Script of Invitation to Participate in Study

Appendix G

Researcher's Script of Invitation to Participate in Study

Hello, my name is Mary Meisner, R.N. I am a student in the Masters of Nursing Program at the University of Manitoba. Your name and number was given to me by _____(Continuing Care Case Coordinator or Discharge Coordinator's name). I am conducting a study with caregivers while they are waiting for their family member to be admitted to a personal care home. My study will look at the caregiver's experience of this waiting and admission period. Should you decide to participate in this study, two to three interviews will be planned with you. The interviews will last for approximately one hour. The first one or two interviews will be held while you are waiting for your family member to be admitted to a personal care home. The last interview will be held about one week after the admission to personal care home has occurred. There is absolutely no obligation on your part to participate, this is voluntary. If you do decide to participate, you are free to withdraw at any time without prejudice. Any information you provide to me will be held in strict confidence. Do you have any questions or require any further information?
Are you agreeable to participating in this study?

If yes, I would like to thank you for your participation. Now I would like to schedule a time to explain more about the study and for our first interview. What time and day would be good for your?

Date: _____ Time: _____ Place: _____

I will also give you my name and phone number in case you need to get a hold of me: Mary Meisner, R.N. Phone: (work) 1-204-768-2585 (home)

If no, I would like to thank you for your consideration and time.

Appendix H

Interview Guide and Form

Appendix H

INTERVIEW GUIDE AND FORMAT

PART A: DEMOGRAPHIC QUESTIONNAIRE

Caregiver's Relationship to Care -recipient	Spouse/Child/Niece/Nephew/Sibling Other: _____
Gender of Caregiver	Male/Female
Caregiver date of birth	
Gender of Care-recipient	Male/Female
Care-recipient date of birth	
Onset of caregiving	Sudden/Gradual Other: _____
Length of caregiving	3 months or less/3 to 6 months/6 months to 1 year Other: _____
Employment Status of Caregiver	FT/PT/Retired Other: _____
Current Location of Care-recipient	Hospital/Community (own home/EPH)/Supportive Housing/With Caregiver Other: _____
Care-recipient in receipt of Home Care Services	Yes/No
Medical Diagnosis of Care-recipient	Cognitive/Physical/Both Diagnosis: _____
Date Care-recipient Panelled for PCH	Date: _____
Are finances an issue for you (caregiver) in provision of care for your family member (care-recipient)?	Yes/No _____

SEMI-STRUCTURED INTERVIEW GUIDE

PART B:

TIME 1 Interview:

Waiting for Admission Experience

1. I am interested in your experience of waiting for your family member to be admitted to a Personal Care Home (PCH). When was your family member paneled for PCH?
2. What was it like for you when you applied for PCH for your family member? **Probe:** What circumstances led you to apply for PCH?
3. After you made the decision to apply for PCH what feelings did you experience?
4. Some caregivers wonder as to whether they should be applying for PCH for their family member, did this happen to you? **Probe:** If so, what made you wonder if this was the right plan for your Mom/Dad/Uncle/Aunt/etc.?
5. Some caregivers experience a lot of different emotions while waiting for a bed offer (PCH) for their family member, did this happen to you?
6. What is it like to wait for the phone call or notice from the PCH (or nursing home) saying that a PCH bed is now available for your family member?
7. What thoughts or feelings do you have about the upcoming PCH admission of your family member? **Probe:** What makes you think that?
8. What do you think it will be like for your family member on the day of admission? **Probe:** What makes you think that? What do you believe could happen?

9. What do you think it will be like for you on the day of your family member's admission to PCH? **Probe:** What makes you think that?
10. What helps in making this waiting period easier for you or what makes it more difficult?
11. I'd like to review the highlights of our interview(s) to make sure I have it right.
12. Is there anything else you think I need to know?

Time 1 Interview:

Second sitting interview – continuation of above.

PART C:

TIME 2 Interview:

Five to Twenty-One Days Post-Admission to PCH

1. When did you receive notice that the PCH bed was available for your family member?
2. How much time were you given before you had to respond to the PCH bed offer?
3. Tell me about the manner in which the PCH bed offer was made. **Probe:** How was the offer made, who made it, explanations provided, sense of urgency to respond ……?
4. At the time of the call, what information was given by the PCH in terms of practical ideas such as what to bring, and other information you might need?
5. How did you feel about accepting/declining the PCH bed offer after getting the call (from the PCH)?
6. Who did you talk to about accepting/declining the PCH bed offer after getting the telephone call (from the PCH)?
7. What did you like about the way in which you were notified of a PCH bed being available for your family member? What made the notification hard for you? Can you suggest things that would make it better?
8. Tell me about the admission day?
9. What was the admission day like for your family member?
10. Was this what you expected?

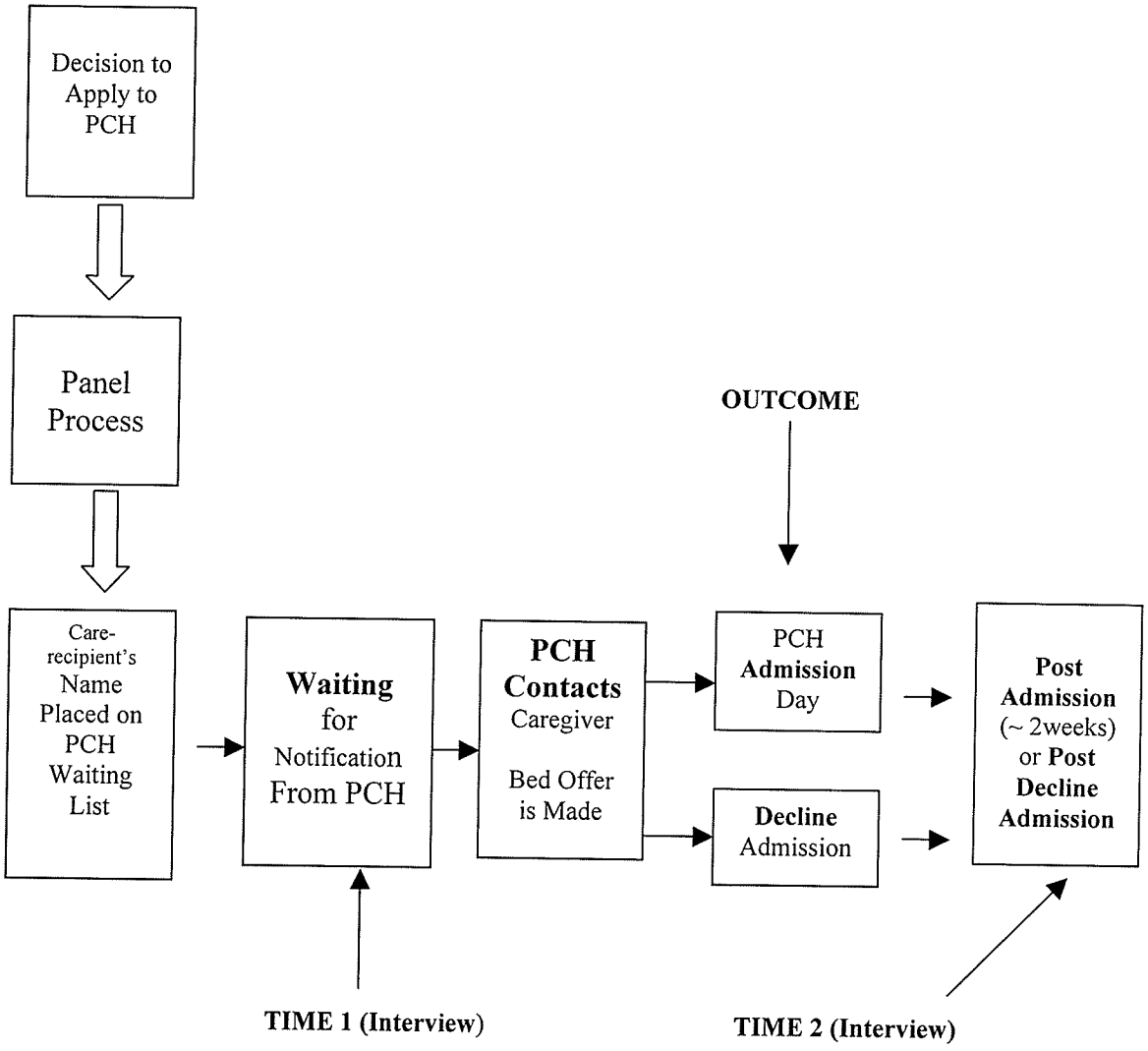
11. What did you like about the day of admission (for your family member to PCH)? What made the day of admission hard? Can you suggest things that would make it better?
12. I'd like to review the highlights of our interview to make sure I have it right.
13. Is there anything else you think I need to know?
14. I'd like to thank you for helping me in this study.

Appendix I

Data Collection Time Frame of Study

Appendix I

DATA COLLECTION TIME FRAME OF STUDY



Appendix J

Renewed Ethical Approval from Education/Nursing Research Ethics Board (ENREB)

Certificate of Ethical Approval from Education/Nursing Research Ethics Board (ENREB)

APPROVAL CERTIFICATE

06 February 2003

TO: **Mary Meisner** (Advisor D. Gregory)
Principal Investigator

FROM: Stan Straw, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: **Protocol #E2003:002**
"Transitions in Caregiving: Waiting for One's Family Member to be Admitted to a Personal Care Home"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note that, if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

UNIVERSITY OF MANITOBA

RESEARCH SERVICES & PROGRAMS
Office of the Vice-President (Research)

244 Engineering Bldg.
Winnipeg, MB R3T 5V6
Telephone: (204) 474-8418
Fax: (204) 261-0325
www.umanitoba.ca/research

RENEWAL APPROVAL

14 January 2004

TO: **Mary Meisner**
Principal Investigator

FROM: **Stan Straw, Chair**
Education/Nursing Research Ethics Board (ENREB)

Re: **Protocol #E2003:002**
"Transitions in Caregiving: Waiting for One's Family Member to be Admitted to a Personal Care Home"

Please be advised that your above-referenced protocol has received approval for renewal by the **Education/Nursing Research Ethics Board.** This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Appendix K

Consent Form For Study Participants

Appendix K

CONSENT FORM FOR STUDY PARTICIPANTS

Transitions in Caregiving: Waiting for One's Family Member to be admitted to a Personal Care Home

Researcher: Mary E. Meisner, R.N.,B.N.

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Overview of Consent

I understand I will be a participant in this study that will focus on the experience of family caregivers when their family member is waiting for and is admitted to a personal care home. My decision to be interviewed is entirely voluntary. I understand that I will be interviewed at a place and time convenient to me. I will be asked some questions on my experience and feelings about waiting for my family member to be admitted to a personal care home (PCH). The interviews will last for approximately 60 minutes. There will be two to three interviews over the waiting and admission period. The interviews will be recorded and later typed word for word.

I understand that I was selected to participate in this study because I am a family caregiver of an individual who is in need of nursing home admission and is currently on a waiting list. I am giving my consent to be interviewed by Mary Meisner, graduate student, from the University of Manitoba.

CONFIDENTIALITY

I have been told that my answers to questions will only be shared with members of the thesis committee and the transcriber. No reports of this study will identify me in any way. Transcripts will be identified by code numbers, not name, and will be stored in a locked filing cabinet. I have also been informed that my participation or nonparticipation or my refusal to answer questions will have no effect on services that I or any member of my family may receive from health care services providers.

VOLUNTARY PARTICIPATION

I have been informed that the interviews are entirely voluntary and that even after the interviews begin I can refuse to answer any specific questions or decide to end the interview at any point. To end the interview at anytime I can leave the room or state that

the interview is over. I can ask to have the tape recorder turned off at any time. I understand that the researcher can stop the interview if she feels I need a break or that I am stressed. The researcher may request a break from the interview by stopping the tape recorder and stating it is time for a break. The researcher will ask me if I want a break or to end the interview for the day. I can withdraw from the study at any time without any negative consequences and question by simply telling the researcher. My tapes and transcripts will be destroyed if I decide to withdraw from the study.

BENEFITS AND RISKS

I understand that I will receive no direct benefit as a result of my participation in this study. However, this study will help develop a better understanding by nurses of the experience of family caregivers during the waiting and admission period of their family member to nursing home. Participation in this study will require two to three interviews which may last approximately 60 minutes and I may have uncomfortable feelings as I will be thinking about my experiences with waiting and admission of my family member.

CONSENT

I understand that the results of this research will be given to me if I ask for them. My signature below indicates that I agree to participate in the study. I will be given a copy of this consent form. I am still free to withdraw from this study even after signing this form. My questions about the research study will be answered at any time.

My signature on this consent form indicates that I have understood to my satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive my legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. I am free to withdraw from the study at any time, and/or refrain from answering any questions I prefer to omit, without prejudice or consequence. My continued participation should be as informed as my initial consent, so I should feel free to ask for clarification or new information throughout my participation.

Mary Meisner is the person to contact if there are any questions about the study or about the rights of the participant. Mary can be reached at . I can also contact the thesis chairperson, Dr. David Gregory, Faculty of Nursing, University of Manitoba at (204) 474-9201.

Date: _____ Participant's Signature: _____

Mailing Address: _____

Date: _____ Researcher Signature: _____

This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the

above-named persons or the Human Ethics Secretariat at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.