Individualized Care, the Preservation of Personhood, and the Degree of Family Orientation in Winnipeg Personal Care Homes

by

Lucia Trotta

A thesis submitted to the Faculty of Graduate Studies of
The University of Manitoba
in partial fulfillment of the requirements for the degree of

MASTER OF SOCIAL WORK

Faculty of Social Work
University of Manitoba
Winnipeg

THE UNIVERSITY OF MANITOBA

FACULTY OF GRADUATE STUDIES

*****

COPYRIGHT PERMISSION

Individualized Care, the Preservation of Personhood, and the Degree of Family Orientation in Winnipeg Personal Care Homes

BY

Lucia Trotta

A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of Manitoba in partial fulfillment of the requirement of the degree

Of

MASTER OF SOCIAL WORK

ABSTRACT

With the implementation of strategies to keep individuals in their home as long as possible, the result is that when they are admitted into a personal care home (PCH), most residents have multiple problems and complicated impairments. Often, family involvement is critical to ensure their relative's needs are properly assessed and to impart to staff the person behind the illness – her or his personhood. Family involvement is also often required if caregiving staff are going to provide individualized care. However, family involvement is strongly influenced by a facility's degree of family orientation. This research explored whether or not the personhood of residents is pursued and supported by caregiving staff and if family involvement is endorsed in Winnipeg personal care homes (PCHs). The importance that family members place on these issues was also explored. Questionnaires completed by forty-four family members whose relatives reside in six PCHs throughout the city revealed that there are clear differences between what takes place in the PCH and what families consider important. Overall, PCHs strive to be family oriented but they continue to fall short of family members' expectations and are often unsuccessful at meeting the family's needs. It is evident that barriers beyond the staff's control exist which raise some important policy implications. Meeting the family's needs and other implications for the practice of social work in long-term care are discussed.

ACKNOWLEDGEMENTS

I would first like to say thank you to my thesis advisor Dr. Sharon Taylor-Henley whose guidance was immeasurable and whose faith in me never waivered.

I also want to extend my sincere appreciation to Kathy McKnight for providing invaluable feedback when I felt stuck and for adding more to her already full schedule to see me through this until the end.

A sincere thank you is extended to Dr. Lorna Guse for both planting the seed which grew into this work and for making thoughtful suggestions that improved its quality.

I also want to say thank you to Dr. Carol Harvey for coming through at the very last minute – I sincerely appreciate it.

A big thank you goes to my fellow MSW graduate students and great friends Heidi, Maggie, and Betty. Without them it's quite likely that this task would have taken *much* longer to complete.

Finally, but most importantly, I want to say thank you to my husband and dearest friend Kurtis for never letting me lose sight of my goal. You were an endless source of support and encouragement and I thank you from the bottom of my heart.

TABLE OF CONTENTS

Appendices

List of Tables

List of Figures

CHAPTER 1

INTRODUCTION

It has been well documented that individualized care for personal care home (PCH) residents is a valuable part of quality care and as such has significant consequences on their quality of life. The acknowledgement and maintenance of one's personhood—features that make each of us unique—are also critical components of quality of life and should therefore guide the provision of formal care. Hence, as the literature brought forth in the following discussion will demonstrate, personhood and individualization of care should always be considered in concert in any discussion of care giving for residents in long-term care.

The provision of individualized care, however, is a manifestation of knowing and of being willing to acknowledge an individual's personhood. Consequently, only through the involvement and participation of those who are most knowledgeable about the individual in care, such as family members and close friends, can this level of quality care be achieved. However, the involvement of family is influenced and affected by several things, including facility policies, employee attitudes, and relationships with staff, to name only a few, and these are all symptomatic of the degree to which facilities are family oriented.

In the discussion to follow, the term 'family member' will be used to identify *any* individual with biographical expertise of the resident in care. In other words, any person who knows a PCH resident intimately enough to have an in-depth understanding of the facets of their personhood will be termed a 'family member' in this report. Also, the terms 'resident' and 'relative' will be used to identify the individual living in the PCH.

Over the years improvements in technologies and expanded home care services have made remaining in the community longer possible (Motiwala, Flood, Coyte & Laport, 2005). As a consequence, admission into a PCH is now occurring later in life than in the past (Pitters, 2002). In response to the widespread belief that staying in the community as long as possible is better than institutionalization (National Advisory Council on Aging; NACA, 2006), in January of 2006, Manitoba Health implemented the Aging in Place Policy (today, this is known as the Long Term Care Strategy). This policy or strategy virtually guarantees that all possible efforts to keep individuals in the community have been exhausted before admission into a PCH occurs in Manitoba. Therefore, when they *are* admitted, most PCH residents have more complicated impairments and often a diminished ability to communicate (Pitters, 2002; Davies & Nolan, 2006). Family involvement is therefore unarguably essential to ensure that one's needs are adequately assessed and met and to impart to staff the 'person' behind the illness.

It is important to note that although the Aging Place Policy or Long Term Care Strategy mentioned above applies locally, it is not addressing a concern exclusive to Manitoba but rather one that is Canada-wide. Accordingly, although this research is focused on Manitoba (and Winnipeg more specifically) family involvement to improve the lives of residents in care can also be seen as a Canada-wide issue with equally far reaching policy implications.

As the reader will learn, family involvement is not always endorsed or facilitated. In reality, the vast majority of studies on this subject report that quite often families are not encouraged to be highly involved or at the very least that there are clear restrictions on the degree of their involvement. With this in mind, the objectives of this study and the questions for which answers were sought were:

Study Objectives	*Research Questions*
To further explore the argument that the individualization of care and the maintenance of personhood are vital components of quality of life for PCH residents.	How are the individualization of care and the maintenance of personhood vital to the quality of life of residents in long-term care?
To investigate the argument that the individualization of care and the maintenance of personhood require family involvement.	How are individualized care and the maintenance of personhood impacted by family involvement or lack thereof?
To uncover the families' views regarding the present state of family orientation in PCHs throughout the city of Winnipeg.	What are the families' perceptions of opportunities for involvement in the care of their relative in a PCH?
To examine how important family involvement is to families in Winnipeg.	What are the families' perceptions of the importance of opportunities for involvement?
To ascertain the relationship between actual opportunities for family involvement and the importance placed on that involvement in Winnipeg PCHs.	What is the relationship between the opportunities for involvement and the importance families place on their involvement in PCHs in Winnipeg?
To contribute to the field of gerontological social work by calling attention to the fact that it is the PCH social worker's ethical obligation to evaluate and work toward the implementation of policies that endorse family involvement in long-term care.	How can this contribute to the field of gerontological social work; specifically in the area of long-term care?

The present study begins with a review of the literature examining family involvement in long-term care. The areas covered in Chapter 2 include: social work practice and the ecosystems perspective, the concept of personhood, families and the personal care home, family involvement and the preservation of personhood, the Canadian Council of Health Services Accreditation, family involvement and individualized care, facility policies and degree of family orientation, and social work and family involvement.

Following the literature review, chapter 3 describes the methodology used in this study. The participants and criteria for their participation, the procedures for recruiting PCHs and participants, the research design and instrumentation used are all discussed in detail. Also, the ethical considerations of this study are explored.

Chapter 4 outlines the results of this study and chapter 5 provides an extensive discussion of these results. Finally, in chapter 6, the implications of this research on social work practice and policy are discussed. In addition, the limitations of the present study are explored and some recommendations for future research are presented.

CHAPTER 2

LITERATURE REVIEW

Social Work and the Ecosystems Perspective

Setting social work apart from other disciplines which focus mainly on the individual is its inclusion of both the interpersonal and the social environment (or the micro and the macro) (Payne, 2005). Rather than looking at the individual and their environment as mutually exclusive groups, social work takes into account *all* of the influences on the individual that can affect their well-being; including their social connections and their environment (Payne, 2005). One of the social worker's main objectives is to improve the life of the individual and they do this not only through interpersonal work but also through exploring and changing one's social environment (Payne, 2005).

This psychosocial focus is the heart of the *ecosystems perspective*, because it highlights the *person in the environment* (Meyer & Mattiani, 1998). For precisely this reason Caron (1997) contends that the ecosystems perspective as a theoretical base is particularly useful within the PCH setting. Specifically, this perspective takes into consideration not only the individual resident, but it also situates them within the context of their surroundings which includes the interactions and interconnectedness within those surroundings. According to Payne (2005), by widening the focus of intervention to include families and the community, the ecosystemic social worker provides the necessary balance in a highly medical and patient-oriented field.

As defined by this perspective, the PCH environment is referred to as a large ecosystem comprised of several separate systems or subsystems each with its own patterned ways of interacting with one another (Caron, 1997). Within this larger ecosystem is the unique subsystem of the family of each resident. Through the resident, the family system and the facility system become linked and are therefore forced to co-exist (Caron, 1997; Maas, Buckwalter, Kelley & Stolley, 1991). Conflict can arise between these two systems as families may feel confused about their roles and responsibilities in the organization (Maas, et al., 1991). Alternatively, families who are satisfied and involved with the care their relative is receiving can be helpful to both their relative and the staff (Maas, et al., 1991). As Caron (1997) explains, the relationships that are formed between these systems "create a context that has a direct impact on the quality of life for residents and their families" (p. 238).

Caron (1997) further posits that the family system is a valuable resource and can in fact be the avenue through which positive changes within the PCH can result. This is possible because as a unique subsystem, the family has roots and exists on its own outside the facility and as such brings with it opportunities for transformation within the home (Caron, 1997). Highly compatible with the ensuing arguments that family involvement is vital to the quality of life of residents in care and is in fact a fundamental component of maintaining their personhood and individualizing their care, the ecosystems perspective provides an ideal theoretical frame.

Incorporating this framework, the discussion will centre on the interacting elements or subsystems within the larger ecosystem that is the facility itself. In particular, the subsystems are comprised of the individual resident, their family, the staff and the larger, institutional barriers such as attitudes and behaviours, and the structures, regulations, and policies that influence and shape them.

Apart from the resident and family, the macro, structural, or institutional barriers all speak to the degree of family orientation within the PCH which will be discussed later in greater detail. With regard to the ecosystemic perspective as the theoretical framework of this proposal, though perhaps not referred to directly, it will nevertheless guide the following discussion with the ultimate goal being the achievement of a goodness-of-fit between the resident and her/his environment.

The Concept of Personhood

Though often conceptualized as such, *personhood* is much more than a philosophical concept. In fact, some of the very tangible elements that comprise personhood include: relationships, social roles, personal triumphs and challenges, culture, values, self-identity, history, strengths, and weaknesses (Buzzell & Gibbon, 1991; Harrison, 1993). Buzzell and Gibbon (1991) pointed out that personhood entails a sense of personal control that, when not taken into account makes one feel vulnerable. Harrison (1993) further added that personhood is about preserving one's story as it happens over the course of a lifetime and appreciating that an individual is always that person with continuous, linked experiences which all contribute to their selfhood and personal identity.

The name Tom Kitwood is synonymous with the term *personhood.* Kitwood's primary objective was to bring awareness of the *person* into the discussion of dementia (Woods, 2001) and to separate cognitive ability and personhood (Kitwood & Bredin, 1992). Kitwood's efforts were very influential in helping researchers recognize that far too much emphasis is placed on the diagnosis of dementia and not enough on the person with the disease (Kitwood & Bredin, 1992; Kitwood, 1993; Woods, 2001; Nolan, Ryan, Enderby & Reid, 2002). According to Woods (2001), this shift away from pathology toward the person and their personhood was one of the most significant developments in the field of dementia care.

There is little dispute over the fact that when biological and/or neurological damage or deterioration is present, they will almost certainly pose challenges to the individual (Kitwood & Bredin, 1992). However, an important point made by Kitwood (1993) is that individuals are also affected by their social environment and that this environment can have dramatic effects on the clinical presentation of their illness. From this line of reasoning, it is argued that personhood should be separated from higher cognitive functioning and instead viewed as essentially social because its expression is strongly influenced by relationships and interactions with others (Kitwood & Bredin, 1992).

To reinforce this argument, in 1992, Kitwood and Bredin presented findings that suggest the social environment may not only be powerful enough to reverse dementia to a small, though nevertheless significant degree, but that it can also help to stabilize the progression of and possibly even regenerate some of the brain damage caused by the disease. The authors (1992) related evidence describing notable improvements—the term used is "rementia"— in social skills, independence, and continence when positive modifications in social conditions were experienced by some individuals with dementia (p. 278). They (1992) also reported on the occurrence of some individuals showing no signs of deterioration since diagnosis five to eight years earlier and again attribute this to a positive social environment. Finally, the researchers (1992) described the findings of experiments with 'geriatric' rats indicating that when taken out of an impoverished social environment and placed into one that was more lively and social, the brains of these geriatric rats underwent "considerable neurological development" (p. 279). Though Kitwood and Bredin (1992) conceded that the findings of the latter experiment could not yet be generalized to human beings, they argued that they were nevertheless powerful and worthy of further investigation and consideration within the human context.

In keeping with the above argument, Cohen-Mansfield, Golander and Arnheim (2000) also supported the need for greater recognition of the impact of the social environment on the individual. According to Cohen-Mansfield and associates (2000), institutionalization makes retention of identity very difficult and this is attributed in part to the changes in interactions, demands, and expectations that residents experience after they move into a personal care home. This argument is reminiscent of what Kitwood called “malignant social psychology” which refers to the milieu created by caregivers who try to be helpful, but instead quash or suppress the personhood of the individual to whom they are providing care because they lack insight (Kitwood & Bredin, 1992, p. 271). According to Kitwood and Bredin (1992), “‘Bad care’ involves this malignancy to a high degree. ‘Good care’’ conversely, is singularly free of this, and is highly respectful of personhood” (p. 271).

As several authors point out (e.g. Kitwood & Bredin, 1992; Kitwood, 1993; Harrison, 1993; Woods, 2001; Cohen-Mansfield, Parpura-Gill & Golander, 2006), this type of information is precisely what caregivers need to stay mindful of in order to provide and encourage interactions that promote a sense of self and to avoid unwittingly contributing to the destruction of personhood. It is therefore argued that one of the most important roles caregivers can perform is to persistently pursue, evoke and reassure one’s personhood and to provide personalized interventions to foster its expression (Kitwood & Bredin, 1992; Harrison, 1993). Indeed, literature continues to progress toward an emphasis on transcending the goals of care from mere maintenance to the promotion of a sense of security and individual value, which includes ensuring that one feels understood and personally known (Ory, 2000).

As noted earlier, another major contribution made by Kitwood was that he separated cognitive ability and personhood which were often erroneously conceptualized together (Kitwood & Bredin, 1992). In their pursuit to call attention to their conviction that cognitive deterioration did not necessitate the total loss of personhood, Kitwood and Bredin (1992) explored twelve indicators of relative well-being (which they argued applied to *all* human beings regardless of illness). Through several hours of observations of people with varying degrees of dementia in a variety of settings, their belief was confirmed as scores on cognitive tests were not accurate determinants of how well a participant was faring. In other words, some individuals with very low scores on cognitive tests were managing quite well whereas others with only moderately low scores were doing considerably worse (Kitwood & Bredin, 1992). Although some of these differences were undoubtedly associated with neurological decline, the authors (1992) maintained that enduring individual personalities or "psychological reserves" play a role as well (p. 284). Several years later, Cohen-Mansfield, Golander and Arnheim (2000) also discovered that even in the advanced stages of dementia, some sense of self-identity does indeed persist.

Though the discussion thus far has involved primarily the use of the word personhood, additional research in this area employ a broader range of terms that encompass what personhood entails. Some of these terms include: "selfhood", "self-identity", "self-concept", and "sense of self" and will therefore be used interchangeably with the term personhood in this paper hereafter. In addition, though a pioneer in the work on personhood, Kitwood's focus was primarily on the person with dementia. As indicated by Kenny (1990), however, losing touch with the links to one's past is a common occurrence wherever health is a focal point, including acute care facilities such as hospitals. Furthermore, Coker (1998) argued that in long-term care where health problems are not curable, the focus is often *only* on maintaining the physical condition. So although the discussion thus far has been limited to personhood and dementia, it is germane to individuals with any illness that leads to their institutionalization and accordingly renders them dependent upon formal caregivers.

According to Woods (2001), one's sense of identity is an important area of concern for residents of long-term care. However, as revealed by Cohen-Mansfield, et al., even in 2006, there is a paucity of research on the actual impact personalized interventions have on the self-identity of residents in care. To address this, the researchers (2006) embarked on a study which looked at precisely this issue and discovered that engaging individuals in activities aligned with lifetime role identities indisputably led to improved affect, higher levels of interest and involvement, decreased disorientation and agitation, and a greater awareness of their identity during the intervention. In fact, the researchers (2006) learned that for some participants the results were so significant that some families continued to provide the same interventions after the study was completed.

Earlier work by Cohen-Mansfield, et al. (2000) elucidated the fact that relocating to a nursing home meant no longer being in the familiar surroundings that prompt one to remember her/his identity roles. This was further confirmed by their discovery that being outside of the nursing home resulted in some residents experiencing an enhanced sense of self (Cohen-Mansfield, et al., 2000). Cohen-Mansfield and associates (2000) further explained that these excursions are usually beyond the facility's capacity or control implying that when residents *did* leave the facility, it was often with someone close to them such as a family member.

If one were to expand on what is considered 'familiar surroundings' as described by Cohen-Mansfield and associates (2000), it would not be unreasonable to include one's family as a primary component. By extension then, it is plausible that being in the presence of family members also has the potential to enhance one's self-identity. Furthermore, families are biographical experts and as such are equipped to support and maintain their relative's autobiographical memory (Bowers, 1988, p. 365). When taken together, this literature unequivocally suggests that familiarity can foster personhood and an increased sense of personal identity.

Families and the Personal Care Home

The impact of institutionalization on the new PCH resident can be very difficult, and for some, traumatic. According to Tobin (1995), even under the best circumstances, placement in a long-term care facility evokes feelings of abandonment for all involved—family and new resident alike. Through regular involvement, families can show their relative that they have not been abandoned and reduce the older person's distress associated with institutionalization (Bauer & Nay, 2003). Family members can help them engage in the nursing home community, cope with living in an institution, buffer them from the effects of the bureaucracy (Malench, 2004) and bring a general sense of order and control in a foreign environment (Bauer & Nay, 2003).

In fact, research suggests that families who visit their resident relative regularly make a significant contribution to their psychosocial well-being (Gladstone, 1995) and help them preserve their sense of self and personal identity (Tobin, 1995). Additionally, although sometimes it may seem as though the resident is not aware of their family's presence, evidence to the contrary exists (e.g. Tobin, 1995; Wright, 2000; Bauer & Nay, 2003).

The sense of abandonment referred to above has not been confirmed by the literature and in fact a wealth of research demonstrates the opposite (e.g. Bowers, 1988; Tobin, 1995; Rowles & High, 1996; Stull, Cosbey, Bowman & McNutt, 1997; Ross, Carswell, & Dalziel, 2001; Gaugler, Anderson & Leach, 2003). Furthermore, while it may be assumed that placement of a relative in care relieves stress and burden on the family this has also been proven to be a myth (Bauer & Nay, 2003). Quite to the contrary, many families continue to feel responsible for the physical and emotional well-being of their relative (Duncan & Morgan, 1994; Stull, et al., 1997) and sometimes this leads to even greater levels of stress than when they were caring for them in the community (Ross, et al., 2001).

As Tobin (1995) explains, when an elder is institutionalized due to dementia, the strain on families is at its peak. Long-term care facilities often worsen this strain because of their highly impersonal medicalized focus which in turn results in impersonal care (Tobin, 1995). No longer being in direct control of a relative's care places extra burden on families who feel that staff are not doing their jobs well or appropriately which in turn compels them to be more involved to ensure that tasks are done correctly (Stull, et al., 1997). Feelings of guilt, sadness, frustration, and uncertainty about their role within the facility only serve to further compound the stress associated with the adjustment to a relative's institutionalization (Ross, et al., 2001; Janzen, 2001).

Family Involvement and the Preservation of Personhood

Early research on family involvement with relatives in care was narrowly focused on the division of technical and non-technical tasks between family and care staff (e.g. Rubin & Shuttlesworth, 1983). Bowers' (1988) revolutionary work broke new ground by shifting the focus away from the division of tasks between families and staff toward the *type* of care families provide based on its purpose. According to Bowers (1988), the main purpose for family involvement in their relative's care is to provide and facilitate *preservative care.*

Preservative care is defined as "care which is engaged in to maintain the older person's self..." (Bowers, 1988, p. 362). According to Bowers (1988), families engage in four types of preservative care: "maintaining family connectedness, maintaining their relative's dignity, maintaining their relative's hopes (generally for recovery), and helping their relative maintain control of the environment" (p. 364). As indicated by Bowers (1988), 'the maintenance of family connectedness' is a responsibility that both staff and families agree belongs mostly to the family. Without the staff's cooperation however, successfully achieving the other three is virtually impossible (Bowers, 1988). Nevertheless, the families in Bowers (1988) work indeed felt that staff often did fail to cooperate (Bowers, 1988).

While families believe that most tasks are the staff's responsibility, they do feel personally responsible for monitoring and evaluating the quality of care. In fact, Duncan and Morgan (1994) ascertained that sometimes families gauge the care their own relative receives by monitoring the way staff treat other residents. Consequently, when families feel that the care staff is providing falls short of their expectations, they often feel compelled to compensate (Bowers, 1988).

Bowers (1988) also argued that of utmost importance to families is that their relative's identity and sense of self are acknowledged and that all caregiving tasks involve emotional or psychosocial (i.e., preservative) care. Families expect staff to care for their relative in a manner that is in no way demeaning, insulting or upsetting, but rather in ways that preserve their dignity and sense of self (Bowers, 1988). Bowers (1988) asserted that preservative care contributes to an individual's sense of control over themselves and their environment. In their quest to help their relative retain their personal identity and uniqueness, however, families often encounter roadblocks, including staff who continue to treat all residents alike (Bowers, 1988).

These findings are echoed by Duncan and Morgan (1994) who also discovered that their study participants tirelessly endeavoured to persuade staff to relate to their relative as a unique individual and not merely as an "object of care" (p. 239). As a matter of fact, the families in Duncan and Morgan's study evaluated quality of care based on the staff's ability to provide care that was both professional and respectful of whom the resident was as an individual. Clearly, families want to ensure that their relative is not only cared for in ways that make them feel safe and comfortable, but also in a manner that preserves their individual value, dignity, uniqueness and sense of competence— in other words, in ways that support their personhood (Bowers, 1988; Duncan & Morgan, 1994).

Bowers (1988) was also responsible for drawing attention to the fact that preservative care incorporates both the family's biographical expertise and the staff's technical expertise, and that this type of care necessitates collaboration between the two. In fact, Bowers (1988) argued that without the two working together, neither preservative care nor high quality care are possible. In their efforts to try to teach staff how to incorporate preservative care into their technical tasks, the families in Bowers' (1988) study used three informal strategies: (1) they told stories about their relative to illustrate her/his uniqueness and preferences; (2) they demonstrated the 'right way', and; (3) they explained the outcomes of poor care on her/his emotional well-being (Bowers, 1988). Other research confirms that many families indeed spend considerable time and effort forging relationships with staff as a way to ensure their relative is adequately cared for (Duncan & Morgan, 1994; Hertzberg & Ekman, 2000).

Furthermore, according to the families in Duncan and Morgan's (1994) study, building relationships with staff was even *more* important to families when their relative was unable to communicate their personhood on their own. In particular, the authors (1994) learned that "[i]n the face of such 'depersonalization,' efforts to get staff to relate to their resident as a person were often a major part of the role that family caregivers saw themselves performing in the nursing home" (Duncan & Morgan, 1994, p. 239-40). Ongoing relationships with staff therefore allows families to impart their own knowledge and expertise of what works best to meet the needs of their relative and also to help staff understand the resident as a person (Duncan & Morgan, 1994). In other words, consistent with the work of Bowers (1988), families seek out a shared commitment in not only *caring for*, but also *caring about* their relative (Duncan & Morgan, 1994).

The Canadian Council of Health Services Accreditation

The Canadian Council of Health Services Accreditation (CCHSA) is a non-profit, independent organization and its purpose is to assure high quality in health care services through an accreditation program (Young, 2002). Since 1978, the CCHSA has delineated standards for care delivery in long-term care in Canada. Through the accreditation process, long-term care organizations can maintain a level of good standing in the health care community by being accountable to their residents and to the public. In 1995, the CCHSA launched the client-centered accreditation program. The program's philosophy is based on a client-centred approach and the focus of care and service was shifted from measurement and evaluation to meeting needs and exceeding the expectations of clients as individuals (Young, 2002).

Family Involvement and Individualized Care

Nolan and Dellasega (1999) argued that partnerships between family members and staff should be seen as an important and legitimate part of life in nursing homes. Although families understand that they are no longer the primary caregiver, as part of the team with the most to offer by way of personal knowledge about their relative, they expect to have some influence on the caregiving provided (Duncan & Morgan, 1994). Yet, despite the passage of time and progress in the philosophies that guide caregiving (e.g. client or person-centred care), studies repeatedly reveal that care-giving staff continue to have little interest in the biographical information of residents, nor do they appear willing to see residents as individuals with unique personalities and care needs (Hertzberg & Ekman, 1996; Friedemann, Montgomery, Maiberger & Smith, 1997; Ryan & Scullion, 2000; Iwasiw, Goldenberg, Bol, & MacMaster, 2003).

As an example, in their investigation of the roles that families play in the nursing home, Ryan and Scullion (2000) learned that families are comfortable with being responsible for their relative's social care, for the personalization of their relative's room, and for providing their relative's biographical details however they continue to feel that individualized care is absent. What's more, they found that improvement in the provision of individualized care was one of the most important changes families in their study wanted to see come to fruition (Ryan & Scullion, 2000). Iwasiw and colleagues (2003) provide further support for this argument with their finding that the former roles that residents held, "through which they contributed to their families and society, were not acknowledged by staff…" (p. 52).

In addition, families recognize their value in facilitating individualized care for their relative, however PCH staff often does not acknowledge them as valuable resources (Ryan & Scullion, 2000; Iwasiw, et al., 2003). As an example, though only a group of ten, every family respondent in Ryan and Scullion's (2000) study assumed that their relative's care plan was strictly focused on nursing issues because they were never asked to be involved despite "see[ing] themselves as having an important role in providing information, particularly about their relative's likes, dislikes, hobbies and biographical details" (Ryan & Scullion, 2000, p. 631). In fact, the majority of participants in Iwasiw, et al.'s (2003) study felt more comfortable sharing concerns with the researchers than they did with the staff despite recognizing that their input was necessary to the perceptions staff would develop of their resident relative and to the care they would provide to them. These unequivocally echo the earlier findings of Rowles and High (1996) which showed that family members *often* feel completely excluded from *all* decisions pertaining to their relative in care.

Therefore, even with all the advancements in the field of long-term care, family involvement as a principle component of care that is personalized and individualized remains an unrecognized necessity (Hertzberg & Ekman, 2000; Ryan & Scullion, 2000; Wright, 2000; Gladstone & Wexler, 2000; Iwasiw, et al., 2003; Davies & Nolan, 2006). If welcomed to do so however, family members can provide the support their relative needs but cannot obtain from staff members either because they are too busy or they do not know the resident well enough (Rowles & High, 1996; Hertzberg & Ekman, 2000; Gladstone & Wexler, 2000; Davies & Nolan, 2006). In addition, knowing the individual intimately gives family members the ability to better recognize serious concerns before they become apparent to staff members, who may be busy attending to several residents (Hertzberg & Ekman, 1996; Rowles & High, 1996).

Propelled by the CCHSA, client or person-centred practice has gained much needed recognition as the approach which should now guide caregiving provided to residents of long-term care. However, it clearly can not surpass family involvement for the individualization of care and for the preservation of personhood. In other words, moving beyond person-centred care to recognize and incorporate the irreplaceable piece that is 'family' into the foundation of the Canadian long-term care industry is imperative. Building on this argument, the discussion will now turn to the topic of facility policies as a key consideration in the matter of family involvement and long-term care.

Facility Policies and Degree of Family Orientation

Policies shape the orientation and practices within facilities and as such also determine the extent of family involvement and the staff's willingness to accept and encourage it (Janzen, 2001). In effect, policies that do not endorse family involvement act as formidable institutional barriers that ignore both residents' and families' needs for their involvement and discount families as valuable resources in the care of their relative (Maas, et al., 1991). In other words, facility policies control whether families are treated as integral or peripheral to the care system (Montgomery, 1983, as cited by Janzen, 2001).

Over time in the literature, the *degree of family orientation* has become an indicator of administration and staff attitudes regarding family involvement which directly affect the way family are treated and the relationships that form between family and staff (Janzen, 2001). Montgomery (1983) writes: "The degree of family orientation of a facility's care policy is measured by: (1) the extent to which services are extended to the residents' families; (2) the extent of inclusion of families in activities and events of the institution, and; (3) the degree to which rules and regulations are made with the family's well-being in mind" (Montgomery, 1983, as cited by Janzen, 2001, p. 39). In essence, nursing homes with a high degree of family orientation promote family involvement and the opposite is true of facilities with low family orientations.

Using a social work perspective, Wright (2000) raises the issue of disempowerment through exploring the roles that family members try to assume in the nursing home. Among several interesting findings, Wright (2000) learned that even when managers actively encourage family involvement, sometimes front line staff does not. Wright (2000) recounts a specific example about a spouse who told interviewers that although she was encouraged to stay during mealtimes to assist her husband by a facility manager, as she was obtaining his food, front line staff members made remarks that clearly demonstrated their opposition to her doing so. Another account presented by Wright (2000) is of a resident's wife who was successfully discouraged from seeing her husband on a daily basis in spite her blatant "overwhelming" desire to do so (p. 654). Only two examples of likely many, these stories nevertheless effectively illustrate that there is an irrefutable need for administrators and managers to adopt and endorse 'relative friendly' policies and to ensure that all facility staff members are sending the same message.

In their study, Friedemann and associates (1997) examined patterns of family involvement, the interactions between family and staff, and factors about the nursing home itself which families feel help or hinder their active involvement in the formal nursing home system. Family policies and practices were also explored by having administrators of 143 nursing homes complete a survey about their family oriented practices (Friedemann, et al., 1997). Through family interviews, the authors (1997) learned that family orientation does indeed have a significant impact on how families feel about the care their relative receives and about their own involvement in that care. Specifically, families whose relative resided in nursing homes that were highest in family orientation were relatively relaxed whereas those associated with homes ranked lowest in family orientation were highly concerned with maintaining control over the care their relative was receiving (Friedemann, et al., 1997). The unfortunate irony is that family members of residents living in low family oriented homes are *discouraged* from visiting and from being actively involved (Friedemann, et al., 1997).

Paradoxically, Gladstone, Dupius and Wexler (2006) add that higher family orientation which encourages family involvement sometimes leads to visiting less because family are comfortable with the care their relative is receiving. According to Friedemann and others (1997), this can be explained by the formation of relationships between family and staff so that families can entrust the care of their relative to the caregivers. By having trust and confidence in those who provide direct care to a relative, fear of neglect and maltreatment is considerably diminished or nonexistent.

The unfortunate reality however is that "the desire on the part of families and residents for staff with good attitudes who provide personal care and promote positive family-staff interactions is likely to conflict with the demands on the nursing home industry for cost-reduction and efficiency" (Ejaz, Noelker, Schur, Whitlatch, Looman & Rose, 2002, p. 380). In reality, as Foner (1995) illustrates, sometimes nursing assistants are reprimanded for spending too much time on 'emotional work' with residents. Nevertheless, Ejaz and associates (2002) assert that facilities that encourage and train staff to be more relative-friendly and to provide personalized care are also going to be dealing with more satisfied customers. This is supported by several authors (e.g. Wright, 2000; Finnema, de Lange, Dröes, Ribbe & van Tilburg, 2001; Janzen, 2001) who argue that 'relative friendly' facilities are those that families are more apt to choose as a home for their relative, and for proprietary homes in particular, this could be very valuable information.

As part of a larger study, Marquis, Freegard and Hoogland (2004) explored the factors that influence positive family involvement in 'aged care' facilities by presenting a facility in Australia known for its exceptional reputation for encouraging family involvement. Family members in this study report extremely high levels of satisfaction with every aspect of the facility. These results are not surprising as many authors have found a strong correlation between satisfaction and encouragement of family involvement (e.g. Friedemann, et al., 1997; Wright, 2000; Janzen, 2001; Marquis, et al., 2004; Gladstone, et al., 2006). Furthermore, quality of care is ranked higher when the nursing home is considered a "relational environment" endorsing quality interactions between relatives, residents, and staff as is the one described here (Marquis, et al., 2004).

According to Marquis and colleagues (2004), the staff's interaction style was also found to be integral to satisfaction with care. The authors (2004) report that employees in this facility have an unreserved willingness to communicate with families and that they possess qualities like kindness and cheerfulness which, in turn, make families feel welcome and comfortable. Continuity of contact with relatives was strongly influenced by the staff's ability to form relationships with family (Marquis, et al., 2004) and these relationships gave families a greater sense of security about the quality of care their relative was receiving which is aligned with the earlier noted findings of Friedemann, et al. (1997) and Gladstone and associates (2006).

What is particularly distinctive about the employees in the facility studied by Marquis and associates (2004) is that they view families as a *unit*. Accordingly, care staff provide emotional support for families during the stressful post-placement period and they include relatives (particularly spouses) "in the circle of care" by recognizing their need for frequent contact with their relative (Marquis, et al., 2004). In contrast to the earlier discussion, staff in this facility are described by families as being skilled, gentle and compassionate and as "'having a genuine liking for' and 'respect for the person they once were'" which, for families, instils a sense of confidence that their relative is safe and secure (Marquis, et al., 2004, p. 181). Family members are encouraged to be part of the caring team and their value as important providers of information and contributors to care is acknowledged and fostered (Marquis, et al., 2004).

In line with Nolan and Dellasega's (1999) argument regarding the need for families and staff to form partnerships, the Marquis and associates (2004) found that in this facility, that is precisely the case. In fact, families are encouraged to be part of the caring team, even when the past relationship between the resident and relative was not always positive. Marquis, et al. (2004) write: "Partnerships between relatives and staff help relatives to find meaningful roles in aged care by concentrating on caregiving roles that only family members can provide such as personal continuity with family identity, reinforcement of past life roles, contact with extended family and resolution of personal issues" (p. 182). It is evident that this facility places great value on safeguarding a resident's personhood and that the individualization of care through family involvement is perceived as essential to quality of life.

Overall, the satisfaction ratings of families associated with this particular facility are very high and they are attributed mostly to the quality of relationships between relatives and staff (Marquis, et al., 2004). Facilities that foster positive relationships between families and personnel, the authors (2004) write, allow families to feel at ease so they can move into playing supportive roles within the formal caregiving environment. By do so, they are able to concentrate on preserving their relative's identity and maintaining continuity with past life roles (Marquis, et al., 2004). This depth of family involvement also helps staff care for residents as it provides them with the knowledge and expertise that only relatives have about their relative (Marquis, et al., 2004). As Marquis, Freegard and Hoogland (2004) argue therefore, the relational environment between staff, residents, and families is vital to both the provision of and the perception of high quality care.

Social Work and Family Involvement

As is now well understood, during the process of admission into a personal care home, families are often in a state of crisis (Greene, 1982; Tobin, 1995; Toye, Percival, & Blackmore, 1996). Consistent with Tobin's (1995) position, Levine and Kuerbis (2002) maintain that social workers are the health care system's helping professionals who are best equipped to provide information, support and advocacy for family caregivers. This is further reinforced by the fact that the desired outcomes of the social worker and the family are the same—"the best care possible for the care recipient and the most sustainable plan for the caregiver" (Levine & Kuerbis, 2002, p. 7).

The ability to spend time with the facility social worker may also help the family work through feelings of guilt, anger and abandonment (Greene, 1982). A social worker's contribution can be vital to the family's ability to resolve the emotional and symbolic challenges associated with the decision to place a relative in care (Levine & Kuerbis, 2002). Furthermore, Greene (1982) adds that if the PCH social worker is able to spend time with the family and the resident in the early stages of the transition, the negative impact of institutionalization can be diminished for both.

An important observation is made by Levine and Kuerbis (2002) regarding "who the client is" in long-term care. In particular, sometimes clients are without any sources of support and when this is the case, it is clear that the focus is only on the needs of one person. However, when family caregivers are involved, "there is a blurring of boundaries" (Levine & Kuerbis, 2002, p. 5). In other words, although policies often dictate that the only client is the care recipient, the fact remains that the family may also be part of the unit of care.

An important objective for long-term care social workers according to the National Association of Social Workers (NASW; 2003) is to "strengthen communications among residents, families, and the program or facility staff" (p. 9). As a liaison between residents, families and staff, the social worker can help to promote and sustain good relationships between these groups (Gaugler, et al., 2003). Furthermore, Levine and Kuerbis (2002) assert that in the care home, social workers can bridge the gap between the viewpoints of family caregivers and nursing home personnel. In particular, social workers can and should encourage staff to recognize the family as an integral part of who the resident is and as a valuable source of support and information for the care of that resident (Levine & Kuerbis, 2002).

The promotion and maintenance of psychological, physical and social functioning and an "optimal quality of life" are guiding principles of long-term care social workers according to the NASW (2003, p. 9). In light of the preceding discussion, social workers must stress that family involvement is imperative to achieve this objective. Accordingly, as a primary advocate for residents, the social worker has the responsibility to evaluate whether or not the facility encourages family involvement and advocate for the implementation of facility policies that do (Greene, 1982; Wright, 2000).

As one of the first employees families deal with at the nursing home, it is even more critical that social workers not only work in relative-friendly facilities, but that they also unambiguously represent that orientation (Levine & Kuerbis, 2002). In other words, in PCHs that are not highly family oriented, the social transformation that social workers need to strive to achieve is the adoption of 'relative friendly' policies and the endorsement of family involvement (Wright, 2000). The need to do so is poignantly underscored by Rowles and High (1996) who write that "...the quality and significance of their contribution serves to highlight the comparative disadvantage and sense of alienation that is likely experienced by those residents who do not have family" (p. 25).

Concluding Remarks

In the 1980s Bowers argued that family involvement served two main purposes: (1) to maintain their relative's sense of identity and sense of self, and (2) to monitor and evaluate the quality of care their relative was receiving. Similar findings continued to emerge thereafter (e.g. Duncan & Morgan, 1994; Hertzberg & Ekman, 2000) and almost two decades later, this exact sentiment still resonates (e.g. Gladstone, et al., 2006; Davies & Nolan, 2006). In fact, relatives feel that their personal contributions to care are essential and yet presently, there is little information on how such family involvement can be facilitated (Davies & Nolan, 2006).

Despite the wealth of research on family involvement in care, only one article in this extensive literature review describes a PCH that actively encourages family involvement and recognizes the value of this involvement for the quality of life of its residents (i.e., Marquis, et al., 2004). This facility, however, exists in Australia. Although the argument that family involvement is both valuable and necessary has been studied at length, given the scarcity of literature indicating that families are in fact highly involved, it is clear that more still needs to be learned. This research is intended to build upon the findings of previous studies by investigating the degree of family orientation and family involvement from the family's perspective. The overall goal was to learn if individualized care that preserves the personhood of residents *through family involvement* is endorsed and carried out in PCHs within the city of Winnipeg, Manitoba.

CHAPTER 3

METHODOLOGY

Participants

The participants of this study were family members or significant friends of residents living in PCHs in Winnipeg, Manitoba. As noted above, the term 'family member' was used to describe any individual whose relationship with the person in care makes them a biographical expert of that person (Bowers, 1988). In other words, all participants had extensive knowledge of the resident's history, personality, preferences and habits.

Criteria for Participation

Minimal criteria for participants was outlined as follows: Participants: (1) were 18 years of age and older; (2) visited their relative resident at least twice per month, and; (3) have had any type of contact with facility staff members on various levels.

Procedure

When this research was conducted there were a total of 39 PCHs with approximately 5600 beds in Winnipeg, Manitoba (Winnipeg Regional Health Authority; WRHA, 2007). The size of facilities ranged from 55 to 314 beds. Appendix B provides a complete listing of Winnipeg PCHs categorized for the purposes of this study as small, medium or large based on the number of beds in each.

As outlined in Appendix B, there are fifteen facilities in the small category (55 - 110 beds) with an average bed number of 85, fourteen facilities in the medium category (111 - 184 beds) with an average bed number of 142, and ten facilities in the large category (195 - 314) with an average bed number of 236. Categorization by size was one measure taken to ensure that all PCH sizes were represented as it was recognized that size of PCH could have an influence on family involvement.

In an additional effort to promote representation, a simple random sampling procedure was used for facility selection as follows: As illustrated in Appendix B, within the separate size categories all PCHs have a corresponding number. For each category, pieces of paper with a corresponding PCH number were placed in a box. Two PCHs from the small category, two from the medium category, and two from the large category were drawn randomly (approximately 15% from each category). After selection, the Executive Directors (EDs) or Administrators were contacted through a letter (Appendix C). Components of the letter included: (1) the purpose of the study; (2) how the researcher proposed to obtain participants; (3) an invitation to meet with the researcher; (4) a request to attend one or two Family Council meetings (if applicable), and; (5) a request for their participation. It also included assurance that in no way will results identify or refer to any specific facility. The ED was also given a participant information letter as well as a consent form to review in advance. A copy of the Family Involvement and Importance of Family Involvement questionnaire (Appendix D; F-Involve and F-Important) was also provided as well as the rationale behind why, in the future, this type of questionnaire may prove to be advantageous to them and beneficial to their residents (Reid, Chappell & Gish, 2007).

> Briefly, this argument put forth by Reid and associates (2007) is that although research has established that families are more satisfied when they know their relatives are being treated as individuals with sensitivity and dignity, there are problems associated with focusing on satisfaction. First of all, it has been found that there is a clear difference in what families are willing to report and what they actually perceive to be true about the care their relative receives. In other words, fear of negative repercussions for their

relative leads to reporting higher levels of satisfaction with care. Ross, Carswell and Dalziel (2001) have termed this the *social desirability bias* and argue that artificially high satisfaction responses threaten the reliability of satisfaction surveys.

Secondly, there may be issues unrelated to the care a relative is receiving that influence satisfaction (Reid, et al., 2007). In their research, Reid and colleagues (2007) learned that a variety of things can impact satisfaction responses, including: one's general opinion of PCHs, the emotions generated by placing a relative in a PCH, the degree of their involvement with care, positive and negative interactions with staff, and the frequency with which they visit their relative. Together, these support the fact that another method to get this information is necessary (i.e., that a focus on satisfaction is not working) (Reid, et al., 2007).

Furthermore, as Reid and associates (2007) point out, responses to the items on the F-Involve and F-Important questionnaire can give facilities valuable information about where they are unsuccessful in their involvement of families and what needs to be improved from the family's perspective. Although not the explicit aim of this research, the tool was designed with this purpose in mind. Accordingly, it may prove to be a valuable resource for EDs and Administrators who are themselves looking for a way to improve the rate of return on satisfaction questionnaires and to reduce the social desirability bias associated with satisfaction questionnaires in long-term care (Ross, et al., 2001; Ejaz, Noelker, Schur, Whitlatch & Looman, 2002; Reid, et al., 2007).

Approximately five days after mailing the letters, the researcher contacted EDs and Administrators by telephone to discuss the project further and to verbally request their involvement. If the invitation was declined, the researcher returned to the list (see Appendix B) and selected the next available PCH that followed the one that declined. The same procedure for contacting the facility described above was then carried out.

If the invitation to participate was accepted, the ED or Administrator was asked to designate an individual such as the social worker to assume responsibility for: (1) displaying a poster (Appendix E) in a location where visitors were certain to see it, (2) facilitating the distribution of packages to participants, and; (3) providing any pertinent information to interested family members. In addition to the poster, this individual was given a letter describing the study as well as the researcher's contact information in the event that further clarification became necessary (see Appendix F).

Sealed participant packages were delivered to PCHs (by the researcher) containing the following: (1) an information letter (Appendix G); (2) two consent forms with the researcher's contact information and details of the study—one to keep and one to return to the researcher signed (Appendix H); (3) the questionnaire (see Appendix D), and; (4) a stamped return envelope with the researcher's mailing address so that consent forms and questionnaires could be sent directly to the researcher with no further PCH involvement. The number of packages distributed to each facility was the closest approximation of 25% of the number of beds in the participating facility (see Appendix B).

For the purpose of identifying the size category to which the questionnaire belonged, all questionnaires were coded with the appropriate letters indicating the size of facility: *sm, mdm, lrg*. Upon receiving signed consent forms and questionnaires, the two documents were separated immediately and the consent forms were placed in a separate envelope. These steps were thoroughly described in the information given to participants as it was the researcher's intention to assure confidentiality and to take all possible measures to reduce the social desirability bias (see Appendix G).

The Recruitment Process of PCHs

The anonymity of both participants and PCHs was assured by the researcher in both the family letter and the consent form (see Appendices F and G). Therefore the following discussion will provide an overview of the recruitment process with the exclusion of any information that may reveal the identity of either.

The first set of letters went out to six randomly selected PCHs on June 22, 2007. As proposed, the researcher mailed letters to the EDs or Administrators (in some cases CEOs) of two PCHs per each size category. Few problems and obstacles were encountered by the researcher for the recruitment of the medium and large PCHs however this was not the case for the small category. In fact, the recruitment of two small PCHs entailed mailing out letters on four separate occasions: June, 22, 2007, July 6, 2007, July 16, 2007, and July 20, 2007.

The ED of one small PCH declined to participate because they were in the process of conducting their own satisfaction surveys and did not want to have another survey confound responses. An explanation given for declining to participate by the EDs of two other small PCHs was that they only employed one part-time social worker. Upon hearing this, the researcher was quick to assure that very little effort and time would be required of the PCH Designate. Interestingly, however, this was not the source of the apprehension. Instead, their concern revolved around the possibility of certain items on the questionnaire leading to an expectation of delivery of service they were not equipped to provide. The items on the questionnaire that evoked this concern were: *r. Staff have helped me to plan for the death of my family member*, and *s. Staff have helped me to plan for the handling of my family member's estate upon his or her death.*

The involvement of the third small PCH originally invited to participate was circumvented by the need to first go through their own governing body's research ethics board. It was unlikely that their ethics board would convene over the summer for this matter alone and as the study was well under way at other PCHs, waiting was not an option. Accordingly, the researcher made the decision to pursue another small PCH.

The distribution of questionnaires to participating PCHs officially began on July 10, 2007. The PCH Designate was asked to distribute questionnaires for approximately one month and specific deadline dates were given. All PCH Designates received a phone call on the deadline date asking the Designate to return the phone call should they require the researcher to pick up any left over packages. Only the Designate of one large PCH asked the researcher to do same.

The deadline for picking up the packages that were not distributed by last participating PCH was September 17, 2007. The date that the last questionnaire was received by the researcher was Monday, September 24, 2007. In total, 237 questionnaires were distributed to PCHs. Based on the 10% distribution rate, this resulted in 25 questionnaires going to each of the small PCHs, 44 and 40 to the medium PCHs, and 53 and 50 to the large PCHs.

The Research Design

This was an exploratory study with a cross-sectional design entailing the completion of one questionnaire at one single point in time. Through the responses on the questionnaire, the researcher hoped to glean a better understanding of the degree of family orientation in PCHs in Winnipeg. Though lacking the rigor of the experimental design, the cross-sectional method has advantages in that it has the potential to result in a substantial amount of data from several participants in a relatively short time frame (Leedy & Ellis Ormrod, 2001). Additionally, attrition is also not a significant concern with this design because involvement is brief and relatively effortless (Leedy & Ellis Ormrod, 2001).

Furthermore, as it is understood that the social desirability bias often leads to a reluctance to raise concerns or draw attention in ways that could be perceived as criticism (Grau, Teresi, Burton & Chandler, 1995), it was anticipated that recruiting participants would be a challenge. Consequently, although random sampling is the ideal method of participant selection, (Leedy & Ellis Ormrod, 2001), it was not feasible for this study.

Instead, the recruitment of participants involved a combination of purposive and convenience sampling procedures. Purposive sampling, as described by Leedy and Ellis Ormrod (2001), involves targeting a specific group of individuals who are believed to be typical or average of the population under study—though true representation of the population is never known. It is primarily limited to exploratory research therefore it suited the purpose of this research well. The 'targeted' individuals were the involved family members (or any biographical expert) of residents currently residing in Winnipeg PCHs.

Convenience sampling is also limited in its potential to identify a representative sample however it permits the involvement of individuals who show a special interest in the study (Leedy & Ellis Ormrod, 2001). As all participating PCHs complied with the researcher's request to display posters, participants were also given the opportunity to pursue their own involvement.

Once considered interchangeable by Patton (1980), used together, these two sampling procedures likely enhanced the representation of the group, improved the recruitment of participants, and created more opportunities for involvement. Specifically, the purposive sampling procedure allowed the PCH Designate to approach families and request their participation. The convenience sampling method, on the other hand, gave family members who expressed an interest in getting involved the chance to do so. Although there is no way to guarantee that participants of this study were in fact representative of the actual population, using both methods may have helped to widen the scope of participants. Furthermore, *only* having participants who were "hand-picked" by facilities was undoubtedly circumvented.

Instrumentation

As mentioned above, the instrumentation for this study was the Family Involvement (F-Involve) and Importance of Family Involvement (F-Important) questionnaire developed by Dr. Colin Reid, Dr. Neena Chappell, and Jessica Gish (Ph.D. Student) (see Appendix D) and employed in this research with permission. This questionnaire contains two scales each with 20 items: (1) The F-Involve which pertains to the *presence of family involvement* in the facility from the family's perspective, and (2) the F-Important which addresses the *importance of family involvement* from their perspective. The F-Involve scale asks respondents to rate on a scale of one to four (one = strongly disagree; four = strongly agree) the presence of each item in the facility. The F-Important scale asks families to rate how important each item is to them on a scale from one to four (one = unimportant; four = extremely important).

The development of this questionnaire involved a three-stage process. The first stage consisted of a literature review of family involvement in long-term care. The second stage, or phase one, involved collecting observational data in PCHs in both Victoria and Sidney, British Columbia. Phase two entailed conducting analyses to determine the reliability of the F-Involve and the F-Important scales. The data for these analyses were collected in Victoria and Sidney as well as in Kelowna and Vernon, British Columbia.

All scale items were developed by an expert panel consisting of three PCH managers, three registered nurses experienced in long-term care, and the researchers. Until an acceptable level of face and content validity was achieved, items for each scale were repeatedly scrutinized by the panel, revised, and pilot-tested with family members. The "items were only retained if they received unanimous endorsement from the panel" (Reid, et al., 2007, p. 93).

In the spring and summer of 2004, the scales were subjected to test-retest reliability with families of residents in four PCHs in the Victoria region and four in the interior of British Columbia (Kelowna and Vernon). The time between the first and the second administration was approximately 25 days. Strong test-retest reliability was found for both scales. Specifically, 56 family members responded to the F-Involve scale at time 1 and time 2, and a Pearson's r of 0.93 (p < .001) was obtained. For the F-Important scale, a total of 65 individuals responded at time 1 and time 2 and the outcome was a Pearson's r of 0.89 (p<.001). In addition, a Cronbach's alpha of 0.93 on the F-Involve and of 0.85 on the F-Important indicated excellent internal consistency for both scales.

"Construct validity…is based on the degree to which the newly developed scales reflect logical hypotheses based on the construct" (Streiner & Norman, 1995 as cited in Reid, et al., 2007, p. 97-99). Reid and associates (2007) have in fact conducted factor analyses to determine construct validity however the objective for doing so was to learn whether the scale items would indeed measure family satisfaction. These analyses are therefore inconsequential for the purposes of this research.

To review, the study was designed to gain an understanding of the degree of family orientation in Winnipeg PCHs. As previously indicated, the degree of family orientation speaks to the extent to which a facility is willing to allow family members to be involved with the care of their resident relative. If the degree of family orientation is high, families are encouraged to be involved, in turn fostering the facilitation of individualized care and the maintenance of personhood. Conversely, a low degree of family orientation is more likely to result in the prohibition of these outcomes.

Reid, Chappell and Gish (2007) state that the purpose of the F-Involve and F-Important items "was to measure the extent to which facilities involved family members in the care of their loved ones and to measure the extent to which family members placed importance on that particular facility-provided involvement opportunity" (p. 93). This purpose is clearly consistent with the objective of this research as the degree of family orientation in Winnipeg PCHs was gauged by uncovering the similarities and differences between actual family involvement and the importance placed on that involvement.

Delving further, according to Reid, et al. (2007), the items on the questionnaire are derived from and reflect the content of an extensive literature review. This content was condensed to nine themes:

> 1. Family members provide information to staff about the life history, coping styles, strengths and weaknesses, and the care needs of residents with dementia; 2. Staff help family members meaningfully interact with their relative; 3. Family members are included in decision-making and care activities; 4. Facilities have in place formal and informal support systems in the form of regular meetings and support groups; 5. Educational opportunities for family members are present so that they can learn about how best to communicate with persons with dementia and about how the nature of the disease process progresses so that they will be able to make sense of the changes that they observe taking place in their relative; 6. Family members are offered assistance with planning for the future eventualities of death and estate management; 7. Family members are encouraged to participate in the life of the facility (i.e., volunteering, social engagements); 8. Family members are oriented to the rules and regulations and how things work in the facility; 9. Administrators seek out perceptions and opinions about the quality of care provided from family members (Reid, et al., 2007, p. 93).

These themes are unequivocally relevant to the matter of family involvement in long-term care and as such are also clearly associated with degree of family orientation. In particular, the higher the responses on the F-Involve scale (which pertains to an item's presence in the facility) the greater the family involvement and/or opportunity for involvement. Additionally, the higher the scores on the F-Important scale, the greater the importance families place on that item. These responses, in turn, will shed light on both the degree of family orientation and the importance of that orientation from those who are impacted directly—the family. Also, for the purpose of this research, added to the end of the questionnaire are a total of six questions (see Appendix D). Responses to these questions provide both demographic data as well as information on family involvement prior to institutionalization.

Ethical Considerations

Prior to the commencement of this study, this thesis research was submitted to the Psychology/Sociology Research Ethics Board (PSREB) of the University of Manitoba and as such met the criteria of the PSREB as well as those of the Faculty of Social Work and the Faculty of Graduate Studies. All materials used in this research were included in the proposal of this research. Data collected for this study was for the sole purpose of completing this Masters thesis and will not be used for any other purpose.

In compliance with the guidelines of the PSREB, confidentiality will be maintained at all times and at no time will there be disclosure of any personal or identifying information. In the interest of obtaining responses with minimal bias, participants were not required to include their names on the questionnaires. However, to uphold the standards of the PSREB, signed consent forms were required from all participants. As outlined in the proposal and in all participant correspondence, the researcher separated the consent forms from the completed questionnaires *prior to* looking at the questionnaires for the purpose of maintaining confidentiality and to reduce the bias associated with this type of study involvement (i.e., the social desirability bias). For the duration of the research, all correspondence was stored in a locked filing cabinet in the researcher's home of which she is the sole key holder. Immediately upon completion of the project and acceptance of this thesis, all documents were shredded.

Included in the consent form was a section where participants could provide their e-mail or home address so that upon completion of the study, the researcher can forward the final results to them should they wish to receive them. A total of 27 participants provided their address for this purpose. As the contact information of the researcher and faculty advisor was provided, participants were also offered the opportunity to learn more about the study and/or to discuss the final results over the telephone, however neither individual was contacted. As promised, upon completion of this project and acceptance of the thesis, a summary of the findings were delivered to all participating PCHs.

CHAPTER 4

RESULTS

Introduction

This research was conducted to investigate the degree of family orientation and family involvement from the family's perspective. The overall goal was to learn if individualized care that preserves the personhood of residents *through family involvement* is endorsed and carried out in PCHs within the city of Winnipeg, Manitoba.

This chapter presents the results of this study. The data was obtained using a questionnaire distributed within six PCHs in Winnipeg, Manitoba. The family members of PCH residents were the participants in this study.

In the early part of this chapter, the analyses conducted will be explained, the characteristics of the sample will be described and the response rate will be outlined. Following this, the mean responses of the two scales will be provided. Finally, the response frequencies and correlations of the items on both scales will be described.

Procedures for Analysis

Analyses of the data included calculating the measures of central tendency and frequency of responses for each item on the Family Involvement and Importance of Family Involvement questionnaire (Reid, et al., 2007; see Appendix D). This questionnaire contains two scales – The F-Involve scale and the F-Important scale. Responses on the F-Involve scale were analyzed for the purpose of learning about the families' views regarding the present state of family orientation in Winnipeg PCHs. Responses to items on the F-Important scale were analyzed to explore the importance placed on that orientation.

To ascertain the relationship between actual opportunities for family involvement (F-Involve scale) and the importance placed on that involvement (F-Important scale), a comparison of responses on the two scales was carried out for each of the twenty items. The correlation or strength of association between these responses was examined using the Kendall's Tau rank correlation coefficient (Kendall's Tau; τ) (Kendall, 1962). The higher the correlation, the better the fit between what exists in the PCH and what families consider important.

Although it may be argued that non-parametric testing does not share the rigor of its parametric counterparts (Field & Hole, 2003) use of the Kendall's Tau was necessary for several reasons. First, the ordinal nature of the scales necessitated the ranking of responses. Second, the same individuals completed both scales. As a result, there were no independent groups nor were there changes in condition which could be compared (Siegel & Castellan, 1988; Field & Hole, 2003). The use of a non-parametric test was also necessary because the researcher was unable to satisfy the random sampling component and consequently the assumption of a normal distribution could not be made – both requirements of parametric testing (Siegel & Castellan, 1988).

Characteristics of the Sample

The following demographic information is based on the six questions added by the researcher to the end of the questionnaire (see Appendix D).

1. Of the 44 participants, there were 15 males (34%) and 29 females (66%).
2. The average time the participants' relatives had been living in a PCH was 2.36 years. Responses ranged from less than one year to more than six years, with the mode being two years.

3. One participant indicated that they visited “frequently”. This response could not be quantified and therefore had to be excluded from the analysis. Based on the remaining questionnaires, the average number of visits per week was 4.35 with a range of one day to seven days per week. The mode was seven days per week.
4. The number of participants who were and who were not the primary caregiver prior to admission into PCH was equal with 22 in both categories.
5. The average time spent caregiving prior to admission into PCH was three years. The range was less than one year to more than six years. The mode was two years.
6. When asked if another family member provided the primary care to their relative prior to admission into PCH, four participants indicated “yes” and 18 indicated “no”.

Response Rate

A total of 237 questionnaires were distributed to six PCHs (two from each of the three categories based on size). Using a 10% distribution rate, 25 questionnaires were distributed to each of the small PCHs, 44 and 40 to the medium PCHs, and 53 and 50 to the large PCHs. The total number of questionnaires returned was 44 – a response rate of approximately 19%. Returned questionnaires per size category are described in Table 1.

Table 1 PCH Distribution & Response

Size of PCH	**Small**	**Medium**	**Large**
Packages Distributed	50	84	103
Packages Returned	13	5	26
Return Percentage	26%	6%	25%

F-Involve Scale Responses

As shown in Table 2, the "Missing" row denotes the total number of responses to the F-Involve items that could not be included in the analysis either because none was provided or because the response given did not correspond with the scale response options. An example of this type of response is: "don't know". The actual number of responses for each item on the F-Involve scale included in this analysis is noted in the "Valid" row. Overall, 28 participants provided a response for *every* item on *both* scales of the questionnaire.

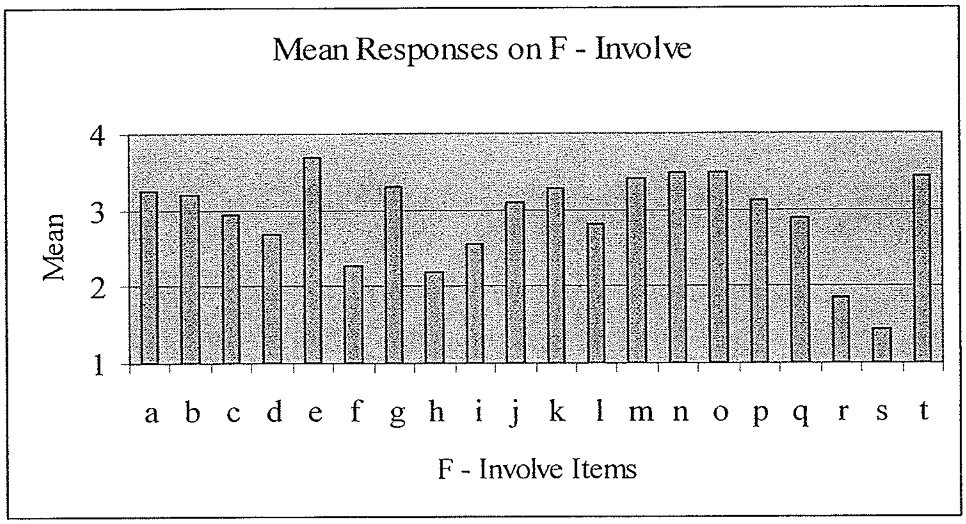
Table 2 F-Involve Item Response Overview

		a1	**b1**	**c1**	**d1**	**e1**	**f1**	**g1**	**h1**	**i1**	**j1**	**k1**	**l1**	**m1**	**n1**	**o1**	**p1**	**q1**	**r1**	**s1**	**t1**
N	**Valid**	43	43	43	33	42	43	43	37	37	40	41	43	44	43	43	43	40	41	40	43
	Missing	1	1	1	11	2	1	1	7	7	4	3	1	0	1	1	1	4	3	4	1

F–Involve Scale: Measures of Central Tendency

To uncover the general or average opinion held by families regarding the present state of family orientation in PCHs in Winnipeg, measures of central tendency for each response on the F-Involve scale were calculated. The choice of responses for the F-Involve scale were: 1 - strongly disagree; 2 - somewhat disagree; 3 - somewhat agree, and; 4 - strongly agree. The overall mean response on the F-Involve scale was 2.95 or "somewhat agree". The median was 3.00 or "somewhat agree" and the range was 3.00. In reality, there was a fair amount of variation in response choices. Figure A provides an overview of the mean responses for each item however a more detailed discussion of these results will follow.

Figure A



F-Important Scale Responses

The "Missing" row in Table 3 denotes the responses to F-Important items that could not be included in the analysis. The number of applicable responses for each of the 20 items on the F-Important scale is noted in the "Valid" row. Again, only 28 participants responded to *all* items on *both* scales of the questionnaire.

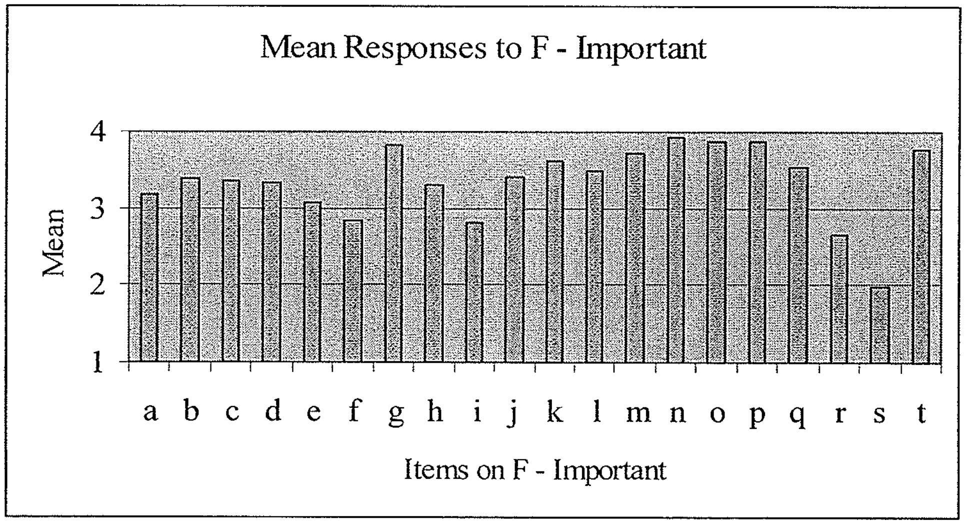
Table 3 F-Important Item Response Overview

		a2	**b2**	**c2**	**d2**	**e2**	**f2**	**g2**	**h2**	**i2**	**j2**	**k2**	**l2**	**m2**	**n2**	**o2**	**p2**	**q2**	**r2**	**s2**	**t2**
N	**Valid**	44	44	42	35	43	43	43	36	39	41	41	42	43	44	44	44	41	41	40	43
	Missing	0	0	2	9	1	1	1	8	5	3	3	2	1	0	0	0	3	3	4	1

F–Important Scale: Measures of Central Tendency

The average opinion held by participants regarding the importance of family involvement was assessed by the measures of central tendency for all responses on the F-Important scale. The choice of responses for the F-Important scale were: 1 - unimportant; 2 - somewhat important; 3 - quite important, and; 4 - extremely important. As depicted in Figure B, the large majority of responses for items on the F-Important scale were on the higher end of the scale. Specifically, the mean was 3.35 or "quite important"; the median was 4.00 or "extremely important" and the range was 2.00. A quick glance suggests that the majority of items were of high importance to participants.

Figure B



F-Involve and F-Important Questionnaire - Response Frequencies and Correlations

The frequencies of responses to the F-Involve and the F-Important scale items were calculated to learn about the presence of family orientation in Winnipeg and to examine how important their involvement is to families in Winnipeg. In addition, to ascertain the *relationship* between actual opportunities for family involvement and the importance placed on that involvement in Winnipeg PCHs, a Kendall's Tau rank correlation coefficient (τ) was calculated for each scale item. The strength of this correlation is determined by the correspondence of responses on both scales. For example, the number of "*strongly agree*" *(4)* responses on the F-Involve Scale will be compared to the number of "*extremely important*" *(4)* responses on the F-Important scale; the number of "*somewhat agree*" *(3)* responses on the F-Involve scale will be compared to the number of "*quite important*" *(3)* responses on the F-Important scale, and so forth. The correlation can range from 1.00 to -1.00 with a 1.00 indicating that the correspondence between scales is equal, and a -1.00 reflecting exact opposite opinions on one scale versus the other. The closer the correlation is to 1.00, the higher the congruence between opportunities for involvement and the importance families place on them. The following section will provide the results of responses to each of the items on both scales, as well as the results of the Kendall's Tau for each.

Item A: *Staff have created opportunities for me to meaningfully participate in my family member's day.*

Of the 43 participants who responded to Item A on the F-Involve scale, 17 participants (39.5%) *strongly agreed*, 21 participants (48.8%) *somewhat agreed*, four participants (9.3%) *somewhat disagreed*, and one participant (2.3%) *strongly disagreed* that opportunities for meaningful involvement are created by PCH staff (M = 3.26).

Of the 44 participants who provided a response on the F-Important scale for this item, 19 participants (43.2%) selected *extremely important*, 17 (38.6%) chose *quite important*, five participants (11.4%) indicated that opportunities for meaningful involvement were only *somewhat important*, and three participants (6.8%) indicated that this was *unimportant* to them ($M = 3.18$).

A very strong statistically significant correlation exists between responses on the two scales for this item ($\tau = .608$; $p = .01$; one-tailed). Combined, these results show that not only it is important to families, but that at least the majority of PCHs do offer opportunities for their meaningful involvement.

Item B: *I have been asked about my family member's personal history.*

Twenty one participants (48.8%) indicated that they *strongly agree* while fourteen participants (32.6%) stated that they *somewhat agree* with the item. Four (9.3 %) participants chose the response *somewhat disagree* and the remaining four participants (9.3%) indicated that they *strongly disagree* ($N = 43$; $M = 3.21$).

Twenty-six participants (60.5%) considered being asked about their family member's personal history *extremely important* and 11 participants (25.6%) deemed it to be *quite important*. Five participants (11.6%) indicated that this was only *somewhat important* and one (2.3%) relayed that it was *unimportant* to them ($N = 43$; $M = 3.39$).

The Kendall's Tau revealed a moderate significant positive correlation between families being asked about their family member's personal history and the importance families place on this ($\tau = .242$; $p = .05$; one-tailed).

Item C: *I have been asked about my family member's preferences and values.*

Twelve participants (27.9%) indicated that they *strongly agree* while 21 participants (48.8%) *somewhat agreed* that they were asked about their family member's preferences and values. A total of six (14.0%) participants *somewhat disagreed* and four (9.3 %) *strongly disagreed* with the item ($N = 43$; $M = 2.95$).

Half of the participants expressed that this was *extremely important* to them and 15 (35.7%) indicated that it was *quite important.* The remaining six participants (14.3%) conveyed that being asked about their family member's preferences and values was *somewhat important.* No participants indicated that this was *unimportant* to them (*N* = 42; *M* = 3.36).

A moderate positive correlation was found ($\tau = .352$; $p = .01$; one-tailed) indicating that families *are* being asked about preferences and values and that this is important to them.

Item D: *Staff have helped me to understand how dementia affects my family member.*

Six questionnaires contained notations that this item did not apply for both scales. In addition, five participants left this item blank on the F-Involve scale, and three left it blank on the F-Important scale. Of the remaining responses on the F-Involve scale, eight participants (24.2%) *strongly agreed* and 13 (39.4%) indicated that they *somewhat agree.* Five (15.2%) *somewhat disagreed* while seven participants (21.2%) *strongly disagreed* that staff helped them understand how dementia affects their family member (*N* = 33; M = 2.67).

Twenty-one participants (60.0%) indicated that staff's help with understanding their relative's behaviour was *extremely important* to them and seven participants (20.0%) indicated that it was *quite important.* Five participants (14.3%) chose *somewhat important* and two participants (5.7%) conveyed that it was *unimportant* (*N* = 35; *M* = 3.34).

No significant association exists between the two scales indicating that there *is* a difference between the presence of being helped to understand how dementia affects a family's relative in Winnipeg PCHs and the importance that families place on this help.

<u>Item E:</u> *I am able to dine with my family member if I want to.*

Forty-two responses were calculated for this item on the F-Involve scale as one questionnaire contained no response and another the words: "don't know". The most prevalent response on the F-Involve scale was *strongly agree* with 34 or 81.0%. The next highest response chosen by five participants (11.9%) was *somewhat agree* while one participant selected *somewhat disagree* and two *strongly disagree* ($N = 42$; $M = 3.69$).

On the F-Important scale, one participant left this item blank. Seventeen participants (39.5%) chose *extremely important* and 15 (34.9%) chose *quite important.* Eight participants (18.6%) felt that being able to dine with their family member was only *somewhat important* while three (7.0%) indicated that it was *unimportant* to them ($N = 43$; $M = 3.07$).

The results of the Kendall's Tau showed a strong positive correlation ($\tau = .421$; $p = .01$; one-tailed) between being able to dine with resident relatives and the importance of this to family members.

<u>Item F:</u> *I have been asked to bring in pictures, letters, and other personal items to teach staff about my family member.*

On the F-Involve scale, a total of seven participants (16.3%) *strongly agreed* with this item and twelve participants (27.9%) indicated that they *somewhat agree.* Nine participants (20.9%) *somewhat disagreed* while 15 participants (34.9%) revealed that they *strongly disagree* that they were asked to bring in personal effects about their relative to teach staff about them ($N = 43$; $M = 2.26$).

On the F-Important scale, eleven participants (25.6%) selected *extremely important* and 17 (39.5%) selected *quite important.* Twelve participants (27.9%) felt that being asked to bring in their relative's personal items was only *somewhat important* and three participants (7.0%) considered this *unimportant* ($N = 43$; $M = 2.84$).

A highly statistically significant positive correlation ($\tau = .545$; $p = .01$; one-tailed) exists between being asked to bring in personal items to teach staff about relative resident and the importance of being able to do so.

Item G: *I feel like I am involved in decision-making about my family member's care when he or she cannot make decisions for themselves.*

Twenty three participants (53.5%) *strongly agreed* and eleven participants (25.6%) *somewhat agreed* with feeling involved in decision-making about their relative's care. Eight participants (18.6%) indicated that they *somewhat disagree* while one participant *strongly disagreed* with this item on the F-Involve scale ($M = 43$; $M = 3.30$).

The large majority of participants on the F-Important scale (36; 83.7%) indicated that feeling involved in their family member's care was *extremely important.* Six participants (14.0%) felt this was *quite important* and one participant identified it as *somewhat important.* There were no participants who felt that this type of involvement was *unimportant* ($N = 43$; $M = 3.81$).

There is a moderate positive correlation between the actual involvement in decision-making about care and the importance of this involvement ($\tau = .322$; $p = .05$; one-tailed).

Item H: *Staff have taught me how to communicate with my family member as the disease has progressed.*

The analysis of this item excludes responses from seven participants as five indicated that the question did not apply to them and two left the item blank. Out of the remaining questionnaires, five participants (13.5%) *strongly agreed* and ten participants (27.0%) responded with *somewhat agree.* Nine participants (24.3%) indicated that they *somewhat disagreed* with this item and the most frequent response was *strongly disagree* (13 participants or 35.1%) (N = 37; M = 2.19).

The F-Important results excludes responses from eight participants as five conveyed that this item was not applicable to them and three left the item blank. Of those who did respond, 50% of participants indicated that this was *extremely important*, 12 participants (33.3%) believed this to be *quite important* and five (13.9%) felt that it was *somewhat important.* One participant reported that being taught how to communicate with their family member as the disease progressed was *unimportant* to them (N = 36; M = 3.31).

Although there is no significant correlation between responses on the F-Involve and the F-Important scales, the result is a negative value ($\tau = -.092$). This result is suggestive of a discrepancy between staff teaching family how to communicate with relatives as their illness progress and the importance that families place on receiving this education. This will be further discussed in the next chapter.

Item I: *The facility has a support group.*

Responses on the F-Involve scale were as follows: Six participants (16.2%) *strongly agreed*; 16 participants (43.2%) *somewhat agreed*; seven participants (18.9%) *somewhat disagreed*, and; eight participants (21.6%) *strongly disagreed.* A total of 37 participants responded to this item as four indicated that they did not know if the PCH had a support group and three left this item blank (N = 37; M = 2.54).

The F-Important scale responses were as follows: Eleven participants (28.2%) conveyed that a support group was *extremely important* and 15 (38.5%) considered it to be *quite important.*

Ten participants (25.6%) indicated that it was *somewhat important* to them while three (7.7%) felt that it was *unimportant*. One participant conveyed that they did not know if the facility had a support group and four participants left the item blank ($N = 38$; $M = 2.87$).

The Kendall's Tau analysis found no statistically significant correlation between the presence of support groups in Winnipeg PCHs and the importance of them to families.

Item J: *I was introduced to the different staff members at the facility when my family member was admitted.*

A total of 40 participants provided a response to this item on the F-involve scale (one left it blank, two wrote "not applicable", and one reported that they did not know). The majority of responses were positive as 17 participants (42.5%) chose *strongly agree* and 14 (35.0%) responded with *somewhat agree*. A total of nine participants responded on the negative end of the scale with five (12.5%) choosing *somewhat disagree* and four (10.0%) choosing *strongly disagree* ($N = 40$; $M = 3.10$).

A total of 41 responses were included in the analysis of this item as two participants wrote "not applicable" and one left the item blank. Of the remaining responses, the majority of participants (23 or 56.1%) believed that being introduced to staff members upon their relative's admission was *extremely important* and 29.3% felt that it was *quite important*. Six participants (14.6%) indicated that this was *somewhat important* to them and there were no participants who felt that being introduced to staff was *unimportant* ($N = 41$; $M = 3.41$).

There is a strong statistically significant relationship between families being introduced to staff and its importance to them ($\tau = .434$; $p = .01$; one-tailed).

Item K: *Staff explained to me the rules and procedures at the facility upon admission.*

Two participants indicated that the item did not apply to them and one participant wrote the words "don't know" on the F-Involve scale. The majority of responses fell within the positive range with 18 participants (43.9 %) choosing *strongly agree* and 18 (43.9%) choosing *somewhat agree*. Three participants (7.3%) *somewhat disagreed* and two (4.9%) *strongly disagreed* with this item ($N = 41$; $M = 3.27$).

Three responses were excluded as two participants conveyed that this item did not apply to them and one left it blank on the F-Important scale. Of those who did respond, the majority of participants (26 or 63.4%) felt that being explained the rules and procedures upon admission was *extremely important* and 14 (34.1%) considered this *quite important*. The remaining participant deemed this to be *somewhat important*. None of the participants considered this item *unimportant* ($N = 41$; $M = 3.61$).

There is a highly statistically significant correlation ($\tau = .560$) between staff having explained the rules and procedures to families upon admission and the importance of doing so from the perspective of families ($p = .01$; one-tailed).

Item L: *Administrators have asked my opinions about the quality of care provided at this facility.*

One participant left this F-Involve item blank. The majority of responses were positive with the *strongly agree* and *somewhat agree* categories each containing 32.6% of the responses. The remaining responses were distributed fairly equally between *somewhat disagree* (eight participants or 18.6%) and *strongly disagree* (seven participants or 16.3%) ($N = 43$; $M = 2.81$).

Two participants left this item blank on the F-Important scale. Of the remaining participants, 23 (54.8%) chose *extremely important* and 17 (40.5%) selected *quite important.*

One participant indicated that having the administrator ask their opinion about the quality of care provided was only *somewhat important* and one felt that it was *unimportant* ($N = 42$; $M = 3.48$).

A moderate correlation between being asked by Administrators the opinion about the quality of care and the importance of being asked this by Administrators was found ($\tau = .290$, $p = .05$; one-tailed).

Item M: *The facility holds family information meetings.*

All 44 participants responded to this item on the F-Involve scale. The majority (65.9%) of participants chose *strongly agree* and the next highest response was *somewhat agree* with nine participants (20.5%). One participant (2.3%) *somewhat disagreed* and five (11.4%) *strongly disagreed* with this item ($N = 44$; $M = 3.41$).

The large majority of participants who responded to this F-Important item (34 or 79.1%) felt that having family information meetings was *extremely important*. Seven participants (16.3%) indicated that the meetings were *quite important* while one participant considered family information meetings to be only *somewhat important*. One participant deemed these meetings *unimportant* ($N = 43$; $M = 3.72$).

A statistically significant positive correlation between the presence of family information meetings and the importance of these meetings was found ($\tau = .358$; $p = .01$; one-tailed).

Item N: *I feel like my family member has been well cared for.*

The majority of participants (26 or 60.5%) chose *strongly agree* and thirteen participants (30.2%) selected *somewhat agree* on the F-Involve scale. Three participants (7.0%) *somewhat disagreed* and one participant disclosed that they *strongly disagree* that their relative has been well cared for ($N = 43$; $M = 3.49$).

All participants responded to this item and the large majority (41 or 93.2%) conveyed that this was *extremely important*. The remaining three participants indicated that this was *quite important*. There were no *somewhat important* and *unimportant* selections ($N = 44$; $M = 3.93$).

The Kendall's Tau analysis revealed no significant relationship between responses on the two scales.

Item O: *I trust the staff members at this facility.*

On the F-Involve scale, 58.1% of participants indicated that they *strongly agreed* with this item. The second highest response was *somewhat agree* (32.6%). Three participants (7.0%) indicated that they *somewhat disagreed* and one disclosed that they *strongly disagreed* with this item. One participant left this item blank ($N = 43$; $M = 3.47$).

All 44 participants responded to this item on the F-Important scale. Thirty-eight (86.4%) indicated that being able to trust the staff was *extremely important* and the remaining six (13.6%) identified this as *quite important*. None of the participants felt that trusting the staff was neither *somewhat important* nor *unimportant* ($N = 44$; $M = 3.86$).

There is no significant correlation between the participants' trust of staff members and the importance placed on this.

Item P: *I am informed about changes in my family member's care plan.*

One participant left this item blank on the F-Involve scale. Eighteen participants (41.9%) *strongly agreed* while 15 (34.9%) *somewhat agreed* that they are informed about changes to their relative's care plan. Seven participants (16.3%) *somewhat disagreed* and three (7.0%) indicated that they *strongly disagreed* with this item ($N = 43$; $M = 3.12$).

On the F-Important scale, the large majority (40 or 90.9%) of participants indicated that this item was *extremely important*. Three participants conveyed that being informed about changes in their relative's care plan was *quite important* while one participant revealed that it was *unimportant* ($N = 44$; $M = 3.86$).

There was no significant correlation between responses on the F-Important and F-Involve scales.

Item Q: *Staff have helped me understand the difficult behaviours that my family member sometimes has.*

Two participants conveyed that the item did not apply to them and two left the item blank. The number of *strongly agree* and *somewhat agree* responses were equal with 13 participants choosing (32.5%) each. Ten participants (25.0%) *somewhat disagreed* and four (10.0%) *strongly disagreed* that staff have helped them understand their relative's difficult behaviours ($N = 40$; $M = 2.88$).

On the F-Important scale, two participants left the item blank and one indicated that it was "not applicable". Of those who did respond, 27 (65.9%) conveyed that the help of staff to understand difficult behaviours was *extremely important* and 10 (24.4%) felt that it was *quite important*. Three participants (7.3%) felt it was *somewhat important* while one indicated that it was *unimportant* ($N = 41$; $M = 3.54$).

No significant correlation between the F-Involve and the F-Important scales were found for this item.

Item R: *Staff have helped me to plan for the death of my family member.*

One participant left this F-Involve scale item blank. Ten participants selected positive responses as five (12.2%) chose *somewhat agree* and five (12.2%) chose *strongly agree.* Ten participants (24.4%) *somewhat disagreed* while almost half of the participants (21 or 51.2%) *strongly disagreed* ($N = 43$; $M = 1.85$).

Responses on the F-Important scale were as follows: 12 (29.3%) chose *extremely important*, 11 (26.8%) chose *quite important* and 10 (24.4%) selected *somewhat important.* Eight participants (19.5%) indicated that being helped to plan for the death of one's family member was *unimportant* to them and three participants left this item blank (N = 41; M = 2.66).

A moderate significant positive correlation was found between these two scale items ($\tau = .322$; $p = .01$; one-tailed).

Item S: *Staff have helped me to plan for the handling of my family member's estate upon his or her death.*

Three participants left this item blank and one made a note that it did not apply to them on neither the F-Involve nor the F-Important scale. One participant *strongly agreed* and two *somewhat agreed* with this item. Eleven participants (27.5%) indicated that they *somewhat disagreed* but the majority of responses (26 or 65.0%) were found in the *strongly disagree* category ($N = 40$; $M = 1.45$).

On the F-Important scale, three participants (7.5%) felt that this was *extremely important.* Eleven participants (27.5%) considered this to be *quite important* while eight (20.0%) deemed it to be *somewhat important.* The majority of participants (18 or 45.0%) considered the help of staff to plan for the handling of their relative's estate *unimportant* ($N = 40$; $M = 1.98$).

The responses on the two scales are strongly correlated ($\tau = .434$; $p = .01$; one-tailed). This does not come as a surprise as the majority of respondents indicated that this service is not available, nor is it important to families.

Item T: *I feel comfortable phoning staff members and talking to them about how my family member is doing.*

On the F-Involve scale, the majority of participants responded positively to this item as 25 (58.1%) chose *strongly agree* and 13 (30.2%) selected *somewhat agree*. However, four (9.3%) participants *somewhat disagreed* and one participant *strongly disagreed* with this item ($N = 43$; $M = 3.44$). One participant left this item blank resulting in a total of 43 valid responses.

On the F-Important scale, 36 (83.7%) believed that feeling comfortable phoning staff members to discuss their family member was *extremely important* and five (11.6%) felt that it was *quite important*. One participant indicated that it was *somewhat important* and one stated that it was *unimportant* ($N = 43$; $M = 3.77$).

A highly statistically significant correlation was found between families feeling comfortable phoning staff and the importance of being able to do so ($\tau = .539$; $p = .01$; one-tailed).

Summary and Concluding Remarks

The family members of PCH residents were asked to complete the Family Involvement and Importance of Family Involvement questionnaire (Reid, et al., 2007; see Appendix D). The reader will recall that this questionnaire contains two scales: the F-Involve scale and the F-Important scale. In this study, the F-Involve scale was used as a tool to explore whether or not family involvement is in fact endorsed and encouraged in Winnipeg PCHs. In other words, the degree of family orientation in Winnipeg PCHs was gauged by responses to the items on this scale.

While the mean response ($M = 2.95$ or *somewhat agree*) does support the notion that PCHs involved in this study are in fact family oriented to some degree, there is not absolute agreement among respondents and some responses actually suggest otherwise. The F-Important scale was used to learn the importance that families place on opportunities for their involvement in Winnipeg PCHs. Compared to that of the F-Involve scale ($M = 2.95$), the mean of the F-Important scale is 3.35 or *quite important* suggesting that the actual involvement opportunities are not as high as the importance placed on those opportunities.

A Kendall's Tau rank correlation (τ) was calculated for each of the items. This was done to learn whether or not a relationship between the opportunities for involvement and the importance placed on those opportunities exists and to ascertain the strength of that relationship. Thirteen of the 20 items were found to be statistically correlated however there is a fair amount of variability in the strength of the correlations (see Appendix I).

This chapter reported the results of the data collected during the course of this study. The responses on the Family Involvement and Importance of Family Involvement questionnaire as well as the results of the Kendall's Tau rank correlation were examined and explained. The next chapter presents an in-depth discussion of these findings. The following discussion will also address the objectives of this research.

CHAPTER 5

DISCUSSION

Introduction

It is well documented that family involvement both supports individualized care and promotes the preservation of personhood. A goal of this study was to explore whether or not families feel comfortable and are indeed encouraged to be involved in the lives of their resident relative. Understanding the importance families place on this involvement was another goal. The overall degree of family orientation in Winnipeg PCHs was examined as well. This chapter presents a discussion of the findings of this research.

The following discussion has been organized according to these five themes: 1. General Opportunities for Family Involvement; 2. Personhood and Individualized Care; 3. Family Involvement in Care; 4. Degree of Family Orientation, and; 5. Family – Staff Relationships. The order in which the questionnaire items and their responses will be examined will correspond with these themes. The purpose for doing so is to provide a structured and comprehensive discussion that plainly addresses the objectives of this research. Consistent with the outline of the previous chapter, the frequencies of both scales and the results of the Kendall's Tau Rank Correlation (when germane) will be discussed.

GENERAL OPPORTUNITIES FOR FAMILY INVOLVEMENT

Item A: Staff have created opportunities for me to meaningfully participate in my family member's day.

Item E: I am able to dine with my family member if I want to.

Admission to a PCH can be very difficult. In fact, newly admitted residents often feel as though they have been abandoned by their families (Tobin, 1995; Bauer & Nay, 2003). Family involvement has been shown to effectively diminish the distress experienced by residents in care (Bauer & Nay, 2003), and research has also found that with regular family involvement psychosocial well-being can improve and a sense of personal identity can be retained (Gladstone, 1995). In fact, even when the resident appears to be unaware of their family's presence, there is evidence to suggest that their presence has an effect (Tobin, 1995; Bauer & Nay, 2003). *Items A* and *E* will be discussed in this section as they relate to general opportunities for family involvement.

Item A

The results of *Item A* on the F-Involve scale suggest that the staff in Winnipeg PCHs do, for the most part create opportunities for family members to meaningfully participate. However, as evidenced by the 11.6% of participants who *disagree* that staff have created opportunities for meaningful participation there continues to be room for improvement. Although this result is not surprising given the literature, of particular note are the results of the F-Important scale.

In keeping with the literature, most participants feel that opportunities for family involvement are of high importance. Of particular interest, however is that five participants perceive this to be only *somewhat important* and three not important at all. Although learning that some families are dissatisfied with the level of opportunities for involvement created by staff was expected, it is surprising to learn that some family members actually do not place high importance on this. This was an unanticipated finding as other studies found much higher agreement among families regarding their desire to be involved (e.g. Duncan & Morgan, 1994; Stull, et al., 1997; Hertzberg & Ekman, 2000; Wright, 2000).

An in-depth review of the responses to *Item A* on the two scales shows that the presence of this item in the facility is consistent with the degree of importance they place on it. Indeed, the Kendall's Tau further supports this conclusion as a very high correlation between the responses on the two scales was found ($\tau = .608$). In fact, only one participant indicated that they *strongly disagree* yet considered it *extremely important*. Therefore, the opportunities for family involvement are comparable to the importance families place on those opportunities. In other words, just as there are family members who disagree that this is available in some PCHs, there are a comparable number of family members who do not feel that this is important.

Given that the average length of time relatives of participants in this study have resided in a PCH is 2.36 years with some over six years, the family's degree of involvement has likely by now been established. Therefore, although there is no way to determine this for certain, one possible explanation is that family members who both disagree and who maintain it is only somewhat or not important at all have experienced a scarcity of opportunities created *by staff* which has in turn led to a reduction in its importance. Phrased differently, if it is important to them, families may be creating *their own* opportunities for involvement without the staff's help. It is also possible that given the level of comfort in the PCH, families no longer look to staff to create opportunities for their involvement. Again, this is also unknown, but definitely a possibility as the staff's encouragement of general family involvement is really only *most* important to families in the first year after admission (Gladstone, et al., 2006).

Item E

The second scale item falling under the theme of General Family Involvement is *Item E (I am able to dine with my family member if I want to).* Dining with a relative in care is one way for families to continue to be involved in their lives in a common, yet meaningful way. It can promote a sense of normalcy in an often medical setting and it can be a way for all individuals – resident and family members alike – to spend time with one another in a way that is not care focused.

The majority of families in this study feel comfortable dining with their relative, however once again some responses indicate that this is not the case in all PCHs or at least for all families. Interestingly, these negative responses are also not limited to one or two facilities. In fact, three participants from three *different* PCHs responded negatively. What is more is that size does not seem to be part of the equation as a negative response was chosen by participants whose relatives reside in a small, a medium, and a large PCH.

In addition, one participant reported that they "did not know" if they could dine with their relative if they wanted to. This is an interesting finding because although this was the response of only one participant, it intimates that opportunities for involvement are not always well communicated to families. Another finding worth mentioning is that one participant *strongly disagrees* that staff create opportunities for meaningful involvement (*Item A*) yet *strongly agrees* that they can dine with their relative if they want to (*Item E*). In addition, this participant indicated that both of these items are *extremely important.* Again, it is impossible to know what precipitated the drastic difference in responses on the two items, however once again what comes to mind is that family members may initiate and create opportunities for their involvement *on their own* and dining with their relative is one way they do this. In other words, families may not view dining with their relative as an opportunity created by staff which further contributes to the conjecture offered for the responses to *Item A* (i.e., that families may create their own opportunities for involvement without the staff's help).

Apart from a few participants whose responses on the two scales do not correspond, the strong significant correlation between the two scales for this item indicates that most of the responses on the two scales do indeed coincide ($\tau = .421$). In other words, there is high correspondence between the ability of family members to dine with their relative and the importance they place on being able to do so. In general, the opinion of families is that most PCHs in this study endorse this and it is also quite important to them.

PERSONHOOD AND INDIVIDUALIZED CARE

Item B: I have been asked about my family member's personal history.

Item C: I have been asked about my family member's preferences and values.

Item F: I have been asked to bring in pictures, letters, and other personal items to teach staff about my family member.

It has been well established that many families work very hard to have their relative treated as a unique individual with distinctive needs (Bauer & Nay, 2003). The unfortunate reality however is that families often report feeling that staff see and treat all residents in a stereotypical fashion (Bauer & Nay, 2003). Family is a fundamental means by which to learn about a resident's personhood but it is also very often a vital component of one's personhood. Furthermore, as biographical experts, not only can family members impart essential information about their relative but they are also best equipped to support and promote their personhood and sense of identity (Bowers, 1988). Families are able to provide the necessary information essential for care that is individualized and as such have much to contribute to the quality of care received by their relative. In essence, their involvement should be unambiguously endorsed in all PCHs as it is assumed that high quality care and quality of life are foundational pieces of all PCH philosophy. *Items B*, *C*, and *F* pertain specifically to the personhood and individualization of care and will therefore be discussed in this section.

Item B

Item B pertains to family members being asked by PCH staff to provide information about the resident's personal history. As already argued, this is extremely valuable for both the individualization of care and the maintenance of personhood. The majority of participants (81.4%) chose a response on the positive end of the scale (i.e., *strongly agree* or *somewhat agree*). At first glance, this appears to suggest that obtaining the personal history of a resident from family is a component of care for most of the PCHs in this study, but a closer look at the questionnaires reveals that there are inconsistencies even within the same PCHs. In other words, not all families who participated from the same PCH had the same experience. Accordingly, one can neither conclude that there are PCHs with staff members who consistently ask families about their relative's personal history nor that some PCHs are superior to others at doing so. Instead, this result suggests that there may be other explanations. For example, it is quite conceivable that some staff members may simply be better at engaging the family and soliciting this information from them than others (within the same PCH).

Additionally, a total of 18.6% of participants do not agree that PCH staff have asked them about their family member's personal history. Although these results are not entirely negative, they nevertheless suggest that at least some families feel that something continues to prevent some PCH staff from wanting to learn and inquiring about the personal history of their residents. This is not surprising given the similar findings of other researchers (Rowles & High, 1996; Hertzberg & Ekman, 1996; Ryan & Scullion, 2000; Iwasiw, et al., 2003).

Based on these results it may seem logical to conclude that the personal history of residents is not an essential component of resident care for all PCH staff, but other explanations may exist. As Rowles and High (1996) point out, there are definite restrictions that prohibit the exchange of information about the personal histories of residents. For example, although all participants in this study are family members or close enough friends to have biographical expertise (and therefore to qualify), it can not be known if other family members were involved in providing information to staff. As the Personal Health Information Act (PHIA) prohibits the exchange and dialogue of personal information with just anyone who has a relationship with a resident, it *is* possible that the participant pool includes individuals who were not involved in the formal information gathering process.

Apart from this, one of the qualifications to participate in this study was having biographical expertise so it would stand to reason that all participants are sources of valuable information. This information can be imparted to staff even if done so informally as long as staff members are willing and able to listen. In fact, informal methods are often the way families communicate information about their relative to care giving staff (Bowers, 1988).

Moreover, given the abundance of evidence demonstrating that families are dissatisfied with what appears to be the staff's unwillingness to get to know their relative resident, it is very probable that these results are merely further evidence of same (Friedemann, et al., 1997; Nolan & Dellasega, 1999; Hertzberg & Ekman, 1996; Hertzberg & Ekman, 2000; Wright, 2000; Davies & Nolan, 2006). As identified by Ejaz, et al. (2002) however it is also possible that workplace demands such as staff shortages, cost-containment, and efficiency are to blame for what appears to be an unwillingness to spend extra time with residents and their families. These factors may also help to explain the variation in responses from families within the same PCH as discussed above.

The mean response on the F-Important scale indicates that families in Winnipeg consider imparting personal history information to staff *quite important.* Although more than half of the participants believe that being asked about their family member's personal history is *extremely* *important*, in truth a much higher number was expected. In addition, one participant feels that this is *unimportant*.

One possible explanation for the lower than expected degree of importance placed on this item may be related to the ability of the resident. Specifically, it is quite probable that the cognition of some participants' relatives remains intact and that their ability to relate who they are to staff is unaffected by the illness that has rendered them in a PCH. In other words, these residents do not depend on their family members to impart this information for them. Although this can not be confirmed it would nevertheless provide a reasonable explanation for why most participants did not choose *extremely important* as was expected given the findings of related studies (Bowers, 1988; Duncan & Morgan, 1994; Friedemann, et al., 1997; Nolan & Dellasega, 1999; Hertzberg & Ekman, 2000; Wright, 2000; Davies & Nolan, 2006).

Upon further investigation, it was noted that of the four participants who *strongly disagree* that they were asked about their family member's personal history, two consider this *extremely important*, one feels it is *quite important*, and one deems it to be *somewhat important*. In other words, of the participants who took note of the fact that they were definitely <u>not</u> asked about their relative's personal history, none of them consider being asked altogether *unimportant*. Nevertheless, in spite of the variation in the actual presence of this item in the PCH, clearly not all family members in this study share the same opinion regarding its degree of importance. Once again, this finding is surprising given that research has repeatedly found that families feel that communication with staff regarding the personhood of their relative is extremely important (Duncan & Morgan, 1994; Hertzberg & Ekman, 1996; Friedemann, et al., 1997; Ryan & Scullion, 2000). However, as research has also found, families place even greater importance on this when their relative is unable to do so on their own (Duncan & Morgan, 1994) and these results may very well be a reflection of the fact that some residents are indeed able to.

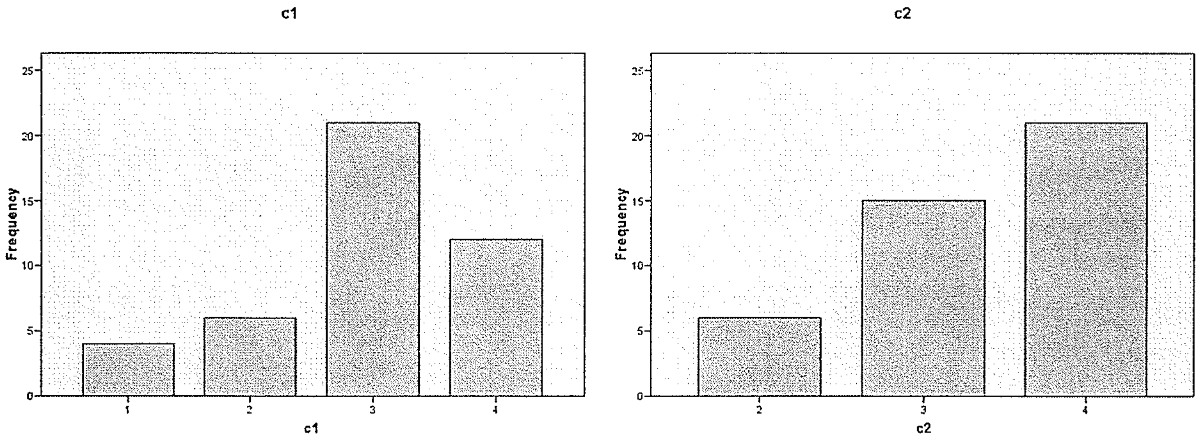
Item C

It is well documented that family members spend a great deal of time helping staff understand these preferences and values of their relative (Duncan & Morgan, 1994; Hertzberg & Ekman, 1996; Hertzberg & Ekman, 2000; Ryan & Scullion, 2000). It is also well understood that if staff and family do not work together, the quality of care received by residents is compromised (Duncan & Morgan, 1994; Hertzberg & Ekman, 2000; Ryan & Scullion, 2000). However, research also shows that families often feel that staff do not recognize their value and overlook them as important resources (Rowles & High, 1996; Ryan & Scullion, 2000; Iwasiw, et al., 2003).

Item C asks families to respond to being asked about their family member's preferences and values. The overall responses suggest that while there has been progress in this area, there continues to be room for improvement. Only one third of participants *strongly agreed* that they were asked about their family member's preferences and values. The highest response was *somewhat agree* demonstrating that although there may be an effort made by PCHs to incorporate details of the resident's person into their caregiving strategy in order to provide individualized care, it continues to fall short of what families feel is adequate. This is further reinforced by the fact that a quarter of the participants *disagree* with this statement.

The above conclusion is supported in several ways. First, as illustrated in Figure C, a greater number of participants chose *extremely important* (shown as 4) on the F-Important Scale than *strongly agree* (shown as 4) on the F-Involve Scale. This reveals an unmistakable disparity between what is present in PCHs and the level of importance families place on this. Second, there are no participants who consider being asked about their relative's preferences and values *unimportant*. This is very much in keeping with the literature on this subject as families feel very strongly about ensuring their relative is cared for in ways that correspond with their preferences and values. In addition, of the four participants who *strongly disagree*, all of them feel that this is *extremely important.* Moreover, unsatisfactory responses came from all sizes of PCHs. They are also not limited to one or two of the participating facilities suggesting that this is a widespread issue and not specific to one or two facilities.

Figure C



F-Involve **F-Important**

Item F

Also salient to a discussion on personhood is *Item F* as the elements fostering the preservation of personhood are described plainly (i.e., "*...pictures, letters, and other personal items to teach staff about my family*"). The maintenance of personhood is a critical component of quality of life but PCH residents are not always able to communicate or convey their personhood on their own. When one's personhood is not acknowledged however, the individual can be left feeling vulnerable and powerless (Buzzell & Gibbon, 1991). Furthermore, when caregivers do not understand the person to whom they are providing care, they often unknowingly create a malignant social psychology which can also have a damaging effect on the resident (Kitwood & Bredin, 1992).

Over half of the participants in this study chose a negative response. These results are consistent with the results of many previous studies (e.g. Bowers, 1988; Duncan & Morgan, 1994; Hertzberg & Ekman, 1996; Friedemann, et al., 1997; Ryan & Scullion, 2000; Ory, 2000). These findings suggest that most family members are not consistently asked to provide effects to help the staff get to know their relative. Given the literature and the results of the previous item, one may infer that generally family members do not feel that PCH staff strive to develop an understanding of the person they are caring for and that they are dissatisfied with this.

Further exploration of the responses on the two scales however demonstrates that the families in this study are not as resolute as those in other studies about the importance of this process. For example, consistent with the literature the highest number of responses to this item on the F-Involve scale are found in the *strongly disagree* category ($n = 15$). However, in contrast to the literature, of those 15 participants only two feel that this is *extremely important*. Six of these participants consider it *quite important* and the remaining seven indicate that being asked to bring in items to teach staff about their relative is either *somewhat important* or entirely *unimportant*. Once again, the size of the PCH appears to have no impact on the responses as the range of responses applies to PCHs of all sizes.

Studies in this area repeatedly show that families expect staff to care for their relative in ways that preserve their personhood and sustain continuity with their personal histories. However the unanimity of participants that was expected has not been found here. While these results do lend further support to the knowledge that PCH staff are disinclined to understand the uniqueness of the residents they are caring for, the variation of the importance families place on this was not anticipated.

These results are also noteworthy when the discussion encompasses the expectations of the CCHSA. As the reader may recall, the CCHSA is the non-profit, independent body that regulates the quality of health care services in Canada through the accreditation process. In order to become accredited, all PCHs have to meet certain standards of care and since 1995 this has meant adhering to a client-centred approach. At the heart of this approach is the emphasis on viewing clients as *individuals* and meeting their individual needs while exceeding their *individual* expectations (Young, 2002).

FAMILY INVOLVEMENT IN CARE

Item G: I feel like I am involved in decision-making about my family member's care when he or she cannot make decisions for themselves.

Item P: I am informed about changes in my family member's care plan.

Family involvement in decisions related to care is considered essential by families (Bowers, 1988; Duncan & Morgan, 1994). Involving families in decisions about their relative's care and acknowledging them as important resources when developing care plans is also a frequent recommendation made by researchers. This is a necessity not only to provide individualized care but also to promote a family oriented environment. This theme addresses this very matter and accordingly the results of the *Items G* and *P* will be discussed.

Item G

Item G on the F-Involve scale asks participants about the family's involvement in decision-making about the care of their resident relative when they are unable to make decisions for themselves. Overall, the findings show that for the most part, staff in Winnipeg PCHs do involve families in the decision making process as it relates to care. However, some families are still not satisfied with their level of involvement. Furthermore, when compared to the results of Rowles and High (1996) over a decade earlier, it becomes evident that barriers to their involvement continue to be present.

Specifically, in this study 79.1% of participants *agree* that they are involved in decision making about their relative's care when their relative is unable to make her or his own decisions (53.5% *strongly agree*; 25.6% *somewhat agree).* However, a total of nine participants (20.9%) indicated that they are not involved (18.6% *somewhat disagree*; 2.3% *strongly disagree*). In comparison to 34.9% of the family members in Rowles and High's (1996) study who felt left out of all care decisions about their relative, this reflects an approximate 15% improvement. However, given the fact that 12 years have passed since their (1996) study was conducted, these findings suggest that family involvement in the care of PCH residents remains an area of concern.

The results of the F-Important scale show that the large majority of participants (83.7%) feel that their involvement in care decisions is *extremely important.* There are also no participants who considered it entirely *unimportant.* Of interest, however, is that one participant identified this as only *somewhat important* possibly demonstrating that they have a great deal of confidence in the care staff. While this is not known for certain, as this item was phrased using these words: "*when he or she cannot make decisions for themselves*", the researcher can not surmise that this response was made because of the resident's ability to make her or his own decisions.

Although the response on the F-Involve scale shows some improvement from earlier research (e.g., Rowles & High, 1996), when examined more closely and compared to the results of the F-Important scale, it becomes clear that some families remain dissatisfied with their level of involvement in this area. Specifically, 53.5% of participants *strongly agree* that this is carried out in the PCH yet 83.7% of participants consider this *extremely important.* This represents a difference of nearly 20%. In other words, in spite of a slight improvement from the findings of Rowles and High (1996), overall these results remain consistent with those of other studies in that they show that the degree of importance placed on family involvement in this area is not matched by what actually takes place in the PCH.

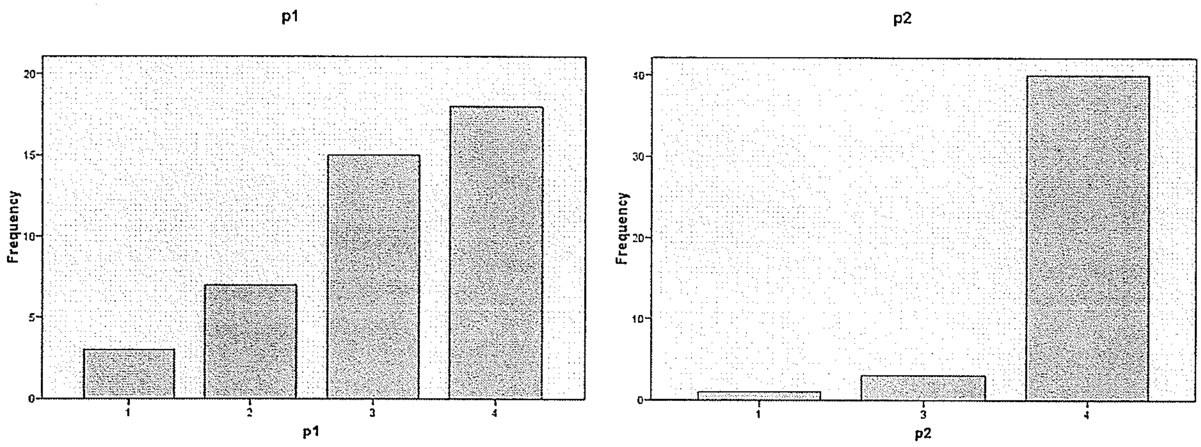
Item P

In the same vein as above, *Item P* asks family members to provide a response to the following: *I am informed about changes in my family member's care plan.* In comparison to the study of Ryan and Scullion (2000) who found that all participants assumed that their relative's care plan dealt with only nursing matters (because they were completely excluded from participating in them) the findings for this item suggest that there has been an improvement in this area. Specifically, 33 participants agree that they are indeed informed of changes to their relative's care plan (41.9% *strongly agree;* 34.9% *somewhat agree*).

In spite of these results being an improvement over those of previous research, 10 out of 43 participants (22.7%) expressed dissatisfaction. Moreover, out of these 10, three participants *strongly disagree* that they have been kept informed of changes to their relative's care plan. Furthermore, these negative responses are derived from questionnaires from both the large and the small PCHs and were not confined to a specific facility within either of the size categories. In other words, participants in both of the small and both of the large participating PCHs have had similar experiences in this matter.

The F-Important graph depicted in Figure D serves to highlight the importance that families place on this. As revealed by the high response choice of *4* or *extremely important* the participants in this study show the family's unmistakable expectation of the PCH when it comes to being informed of changes to a relative's care plan. Specifically, 90.9% of participants indicate that this is *extremely important.* As Figure D also reveals however in comparison to *p2* (F-Important), *p1* (F-Involve) has much greater variation in responses. This further reinforces the finding that there are inconsistencies in this area. In addition, the Kendall's Tau analysis uncovered no correlation between responses on the two scales which also stresses the difference between what families are actually experiencing in the PCH and what they want to – again suggesting that this is an area PCHs in Winnipeg need to work on.

Figure D



F-Involve

F-Important

DEGREE OF FAMILY ORIENTATION

Item D: *Staff have helped me to understand how dementia affects my family member.*

Item H: *Staff have taught me how to communicate with my family member as the disease has progressed.*

Item I: *The facility has a support group.*

Item J: *I was introduced to the different staff members at the facility when my family member was admitted.*

Item K: Staff explained to me the rules and procedures at the facility upon admission.

Item L: Administrators have asked my opinions about the quality of care provided at this facility.

Item M: The facility holds family information meetings.

Item Q: Staff have helped me understand the difficult behaviours that my family member sometimes has.

It is well understood that there is a strong correlation between resident and family satisfaction and family involvement (Friedemann, et al., 1997; Wright, 2000; Janzen, 2001; Marquis, et al., 2004; Gladstone, et al., 2006). As delineated by policies, family orientation defines how much and in what ways families are encouraged to be involved (Janzen, 2001). The PCHs with a high degree of family orientation promote family involvement and the opposite is true of those with a low degree of family orientation. Additionally, a PCH environment that fosters and initiates interaction among staff, families, and residents is one that family members perceive to be most family oriented (Marquis, et al., 2004). As such, a high degree of family orientation has been found to have a positive impact on the opinions that families have about the PCH and its staff (Montgomery, 1983; Janzen, 2001; Gladstone, et al., 2006).

The mean response on the F-Involve scale for these eight items is $M = 2.86$. This figure represents an opinion between *somewhat agree* and *somewhat disagree*. In other words, though not entirely absent, the family orientation in these PCHs is not exceptional from the perspective of family members. In contrast, the mean response on the F-Important scale for these items corresponds with a sentiment that lies between *quite important* and *extremely important* ($M =$ 3.41). These two figures demonstrate a clear difference between what is present and what families expect and want. In other words, although the sample size does not allow for broad inferences to be made, the difference in mean responses suggests that family members are not satisfied with the state of family orientation in some Winnipeg PCHs.

As a collective, *Items D, H, I, J, K, L, M, Q* address the matter of degree of family orientation. To facilitate the discussion, the eight items have been divided into three sections based on the similarity of their content. The first two to be explored will be *Items I* and *M* as they both deal with the provision of events or programs offered specifically to families.

Items I and M

The highly family oriented care facility in Australia studied by Marquis and colleagues (2004) gained its exceptional reputation in part because of the staff's unquestionable interest in the family. Known for its staff members' sincere willingness to recognize the family as an integral part of the resident's life, employees provide support to families and promote the inclusion of family members in the care of residents as they understand and appreciate that family involvement results in a high quality of care (Marquis, et al., 2004). The active involvement and encouragement of family can take many forms, including offering support groups and family information meetings. By providing these to families, PCHs convey that they are valued, that their input and knowledge is important, and that they want to support them.

In this study, when asked if the facility had a support group (*Item I*) four participants indicated that they "did not know" and three participants provided no response. While discerning precisely why some of these participants left the item blank is impossible, the fact that four were unaware of a support group suggests that communication with families may not be paramount. In addition, close to half of the participants *disagree* that a support group is offered. Together, these findings do little to support a finding of a high degree of family orientation.

In comparison to those of the F-Involve, the responses on the F-Important scale suggest that many families feel that support groups would be beneficial. In fact, only three participants indicate that they are *unimportant* and the majority consider them either *extremely important* or *quite important.* Furthermore, of those who *strongly disagree* that a support group is offered, half considered it *extremely important* and no one feels that it is altogether *unimportant.* In addition, the Kendall's Tau analysis reveals no significant correlation between the responses on the two scales which further confirms the difference between what is present in the PCH and the importance placed on this by families.

Item M

Item M is related to *Item I* as it also pertains to services or activities offered to families. *Item M* refers to the availability of family information meetings and in contrast to the low number of participants who responded to *Item I* ($N = 37$), all 44 participants provided a response to *Item M.* This indicates that in contrast to being informed of whether or not support groups are offered, families are definitely aware and informed of family information meetings. Also very different from the responses to *Item I* is that only six participants (13.7%) *disagree* that family information meetings are available in the PCH. Combined, these findings suggest that although support groups are not regularly offered in Winnipeg PCHs, family information meetings are. At first glance one might consider this a noteworthy finding but in all probability families have interpreted "family information meetings" as events such as Resident Care Reviews (which are mandated by Manitoba Health) and Family Council Meetings (which are often provided in accordance with PCH policy). In light of this, the dissimilarity of responses for *Items I* and *M* (i.e., *Item I*: 16.2% = *strongly agree* vs. *Item M*: 65.9% = *strongly agree*) is not as surprising as it initially appears.

Items D, H, and Q

Marquis and associates (2004) explain that the staff employed at the highly family oriented facility in Australia demonstrate a consistent willingness to communicate with families. They strive to make families feel comfortable and welcome, and seemed to have an understanding of what families needed by way of support (Marquis, et al., 2004). Using this facility as a point of reference, the following discussion of *Items D, H,* and *Q* will explore the matter of PCH staff in Winnipeg taking the time to help families cope with and understand the illness of their relative. This, in turn will contribute to a larger understanding of the degree of family orientation in Winnipeg PCHs.

The mean of the three items on the F-Involve scale is $M = 2.58$. This figure reflects an average response that rests between *somewhat agree* and *somewhat disagree*. In contrast, the mean of these items on the F-Important scale is $M = 3.40$ – positioned between *quite important* and *extremely important.* The discussion to follow will further explore the results of each of these items separately, however the overall difference in responses to these three items points to a degree of family orientation that does not meet the satisfaction of families.

Item D

Item D asks families if staff have helped them understand how dementia affects their family member. Given the disparity between the average response on the two scales ($M = 2.67$; $M = 3.34$) it is apparent that what is present does not match the importance placed on it. To further reinforce this, only 24% of participants *strongly agree* in comparison to 60% who indicate that it is *extremely important.* In addition, no significant correlation was found between the two scales to provide further support for the argument that there is a distinctive difference between what families are getting and what they need with respect to understanding their relative's illness.

Item H

Item H asks families to provide a response to the following statement: *Staff have taught me how to communicate with my family member as the disease has progressed.* Once again, the extreme differences between the mean responses on the two scales ($M = 2.19$; $M = 3.31$) strongly suggests that families are not getting what they want or feel they need from the PCH staff in this area. In fact, 59% of the group *disagree* that this is available to them, yet 50% indicate that it is *extremely important*, and 33% state that it is *quite important.* In addition, while no significant correlation between responses on the F-Involve and the F-Important scales was found, the result is a negative value ($\tau = -.092$) further lending support to the argument that there is a discrepancy between staff teaching family how to communicate with relatives as their illnesses progress and the importance that families place on receiving this education.

Item Q

Item Q refers to staff helping family members understand the difficult behaviours that their relative in care sometimes has. The differences in the means on the two scales ($M = 2.88$; $M = 3.54$) shows that once again a gap exists between what is present and what families feel is important in the PCH. Although the number of positive responses on the F-Involve scale ($n = 26$) is an improvement from those of the previous two items, there are still a total of 14 participants who *disagree.* In addition, when placed alongside the findings of the F-Important scale, this result is also somewhat less noteworthy.

To further explain, on the F-Involve scale, 65% of responses are found in the *somewhat agree* and *strongly agree* response options combined. In comparison, on the F-Important scale a total of 90.3% of responses are found in the *quite important* and *extremely important* categories. Once more, this suggests that while helping family members understand the difficult behaviours that their resident relative sometimes has is very important to family members, this importance is not matched by what is actually being offered in Winnipeg PCHs.

Once again, the findings of Ejaz and colleagues (2002) demonstrating that PCH staff are often forced to work short with high demands may in part explain why these items are not regular occurrences in PCHs. Nevertheless, these are very important findings because they unambiguously illustrate where PCHs are falling short from the family's perspective. For PCH administration, this information is valuable as it is a concrete area to work on to improve the satisfaction of families and to bolster the degree of family orientation in their PCH.

Items J, K, and L

It has been well documented that staff members in facilities that are family oriented encourage family involvement (Janzen, 2001; Bauer & Nay, 2003; Marquis, et al., 2004). Also, a high degree of family orientation creates an inclusive atmosphere causing family members to feel comfortable spending time with their relative – especially important while residents adjust to their new environment (Janzen, 2001; Gladstone, et al., 2006). This, in turn, also allows families to observe and assess care – something they often feel the need to do (Friedemann, et al., 1997; Bauer & Nay, 2003).

Additionally, family oriented practices usually result in greater contact between families and staff and often in families being treated as an integral part of the care team (Gladstone, et al., 2006). In fact, for some family members, a high degree of family orientation often leads to a reduction in frequency of visits as family members feel confident that their relative will be properly cared for and treated well (Friedemann, et al., 1997; Gladstone, et al., 2006). The opposite it true for PCHs with a low degree of family orientation (Friedemann, et al., 1997).

Promoting a high degree of family orientation takes time and effort however and must be set in motion at the administrative level. In a general sense, the items in this section pertain to both the administration's and staff's attitudes regarding family orientation as reflected by the inclusiveness of the admission process (i.e., introducing families to staff and explaining the rules and procedures to families) and the opinions garnered from the families (by the Administrator) thereby imparting that they are valued. The following discussion with explore the results of *Items J*, *K*, and *L* which pertain to the above and therefore further contribute to an understanding to the degree of family orientation in Winnipeg PCHs.

The mean of the F-Involve scale for these three items corresponds with a response of *somewhat agree* ($M = 3.06$). In contrast, the F-Important scale responses suggest that families consider these items *quite important* or *extremely important* ($M = 3.50$). As expected, these results are different. Given that all of these items require PCH employees to take time out of their already very busy schedules and make the effort to engage the family, these results are not surprising.

Item J

Item J asks family members to reflect back on when their relative was admitted to try to recall if they were introduced to various staff members. The majority of participants chose a response on the positive end of the scale (42.5% chose *strongly agree*; 35.0% chose *somewhat agree*). In addition, the mean response on the F-Involve scale for this item corresponds with *somewhat agree* ($M = 3.10$). This suggests that for the most part families are being introduced to staff upon admission in Winnipeg PCHs but not all family members shared a similar experience. In fact, a total of nine participants conveyed that they were not introduced to staff. Although this latter group is the minority, it nevertheless comprises almost 25% of this study's participants.

Spending time helping residents and families adjust to a new facility is one way that staff can promote the involvement of family. However, as discussed the shortage of staff is a concern that plagues the health care field in most provinces and so it is not surprising to learn that there are shortfalls in this area. In addition, as Foner (1995) and Ejaz, et al. (2002) demonstrate care givers are regularly chastised for spending too much time on 'emotional work' with residents as the priorities are often cost containment and efficiency.

Participants were not given the opportunity to provide further explanations regarding the introductions they received, so the staff to whom families were introduced remains unknown. However, according to the literature the primary individuals families have the most contact with are the Health Care Aides (HCAs) (Duncan & Morgan, 1994). Therefore it is unknown if all participants perceived this item the same way. For example, it is possible that some family members are dissatisfied by not being introduced to staff other than the HCAs causing them to choose a negative response but it is equally possible that some participants are satisfied with *only* meeting HCAs. In other words, these results may be compounded by varying expectations. Despite this uncertainty, what is certain is that overall families consider being introduced to staff *important*. In fact, there are no participants who deem being introduced to staff unimportant and in reality the majority of participants feel that it is *extremely important*.

As an aside, there appears to be no association between the size of the PCH and the dissatisfaction of participants. Specifically, all sizes of PCHs had at least two families who *disagree* with this item (i.e., 5 large, 2 small, and 2 medium). Nevertheless, there is correspondence between what occurs in Winnipeg PCHs and the degree of importance placed on this by families as indicated by the strong statistically significant association between responses on the two scales ($\tau = .434$). In other words, all in all what does occur in the PCH appears to be consistent with the value families place on it.

Item K

Problems can arise when family members are not clear on their roles and responsibilities in the PCH. Maas and colleagues (1991) add that families often feel confused about where they stand in the organization which is frequently a sign of their lack of familiarity with the facilities procedures. In addition, according to Bauer and Nay (2003), "[c]onfusion about family and staff responsibilities…exist because these roles are often non-negotiated. Families usually have to learn 'the ropes'…by trial and error" (p. 49). Moreover, family members will often base their expectations of PCH staff on what they experienced in the hospital which can be unrealistic in the long-term care setting (Nolan & Dellasega, 1999). To explore this matter further, participants in this study were asked to consider the following: *Staff explained to me the rules and procedures at the facility upon admission.*

On the whole, the findings suggest that families are indeed explained the rules and procedures upon their relative's admission to a PCH. However, while the majority of participants chose a positive response there are once again some participants who did not. Out of 41 responses, five were negative. Reviewing the questionnaires led to the discovery that once again, negative responses were found in all sizes of PCHs which communicates that size does not have an effect on this process.

Worth mentioning is that the participants who provided a negative response all considered it important. In fact, of the participants who responded to this item ($N = 41$), all but one indicated that it was either *quite important* or *extremely important* and no one felt that it was *unimportant.* This finding is commensurate with those of previous studies demonstrating that families expect and feel the need to be shown "the ropes" (Bauer & Nay, 2003, p. 49).

Despite the five negative responses on the F-Involve scale, nearly 95% of participants indicated that PCH staff in Winnipeg do explain the rules and procedures at the facility upon admission. Furthermore, the strong significant association between responses on the two scales ($\tau = .560$) suggests that for the most part families are being given the information they need upon their relative's admission. This does suggest that in general during the time of admission the staff in Winnipeg PCHs are making time for the families.

Item L

Item L states: *Administrators have asked my opinions about the quality of care provided at this facility.* The mean responses on the two scales show a difference between what families have experienced and what they consider important ($M = 2.81$; $M = 3.48$). Despite the obvious difference in mean responses however they are moderately associated on the two scales ($\tau = .290$). This may be explained by the fact that although this item is more important to families than is realized in the PCH overall, there are some PCH Administrators who do ask families for their opinions about the quality of care and there are some families who do not consider this effort important.

Interestingly, however, the negative responses on the F-Involve scale were found in questionnaires from all sizes of PCHs. One possible explanation for this is that not all family members receive correspondence from the PCH. In fact, only the main contacts or those with legal authority do and if Administrators solicit this type of information from families via questionnaires (i.e., through the mail), the opinions about the quality of care would indeed not be solicited from all family members.

As mentioned, these results also suggest that it should not be assumed that all families value the Administrator's inquiry of this matter. Certainly, as Foner (1995) has shown, the PCH staff families are most concerned with are the HCAs because they provide the direct care to their relative. Duncan and Morgan (1994) concur with this finding and further add that families frequently express frustration regarding the constraints placed on the time HCAs can spend with each resident and the lack of respect shown to them within the organization. Like Foner (1995), Duncan and Morgan (1994) discovered that this was a source of stress because of the direct impact it has on the care received by their relatives.

Although some family members do not share the opinion that the Administrator asking about the quality of care is important and instead may focus on the direct care providers, it nevertheless remains that the Administrator is the one who can resolve the problem. In other words, the HCAs are indeed those who provide the hands-on care, but often the quality of care is directly impacted by factors beyond their control, such as short staffing and time and cost constraints (Duncan & Morgan, 1994; Ejaz, et al., 2002). This finding therefore serves to highlight the need for the Administrator's involvement because not only do they hold the most power to effect change (within the facility) but the degree of family orientation has to be initiated and maintained at the Administrative level.

In addition, if a high degree of family orientation and family involvement are indeed recognized as valuable components of care to Administrators, then it becomes even more important to obtain the opinions of families. This is emphasized by Wright (2000) whose study results incorporated actual examples from families describing events showing that even when managers encourage family involvement, front line staff members sometimes do not. Therefore, asking families for their input could lead to the disclosure of occurrences contradicting the facility goals that management may not be aware of. This will expose the divergence of staff's attitudes and behaviours from the Administration's goal of creating a high degree of family orientation and provide the focus for staff education.

FAMILY – STAFF RELATIONSHIPS

Item N: I feel like my family member has been well cared for.

Item O: I trust the staff members at this facility.

Item T: I feel comfortable phoning staff members and talking to them about how my family member is doing.

There is no objective dedicated to this theme, however it is a frequently debated issue in the literature. This matter is also plainly addressed by three items on the questionnaire. As such, the following section will discuss items *N*, *O*, and *T* which all pertain to the theme of Family-Staff Relationships.

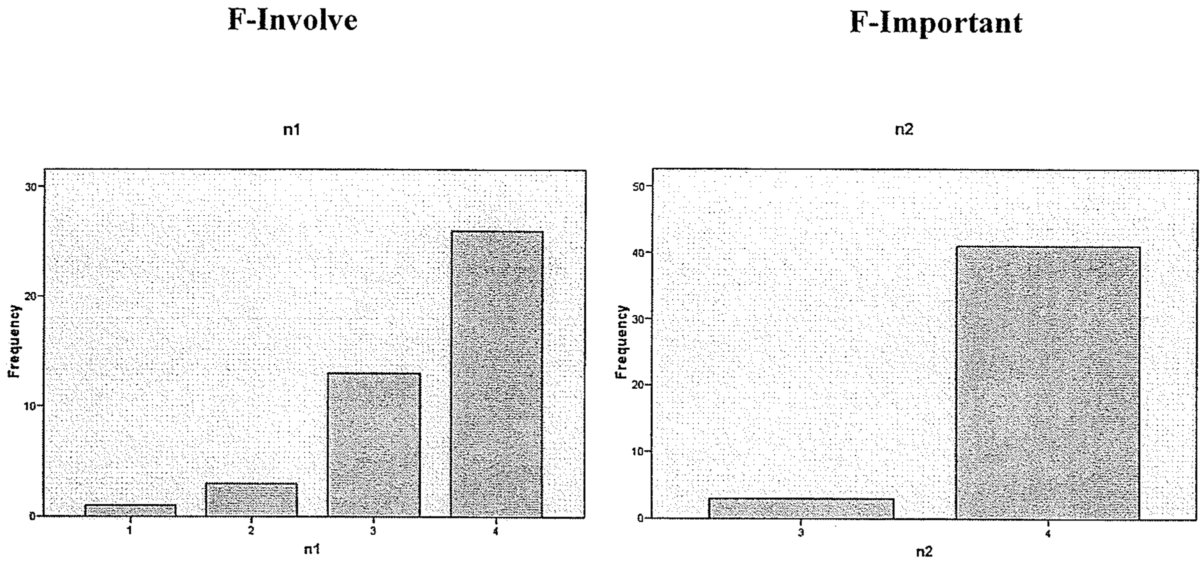
Establishing good relationships with staff, getting recognition as a valuable resource, and feeling accepted as part of the care team are extremely important to families (Bowers, 1988; Duncan & Morgan, 1994). Families spend a considerable amount of time and energy developing relationships with staff with the hope that this will lead to better care for their relative (Duncan & Morgan, 1994). In addition, families feel that conflict between staff and families is best avoided by building relationships with staff (Duncan & Morgan, 1994). Finally, Nolan and Dellasega (1999) argue that partnerships between family members and staff should be seen as an important and legitimate part of life in nursing homes.

Item N

Overall, the results of *Item N* suggest that the majority of participants feel their relatives are well cared for. This conclusion is based on the finding that the large majority of participants (n = 90.7%) chose a response on the positive end of the F-Involve scale. However, as the negative responses on the F-Involve scale show, it is also apparent that some family members do not share this opinion.

Figure E illustrates the distinctive differences in the responses on the F-Involve scale compared to those on the F-important scale. As expected, there are no participants who chose *somewhat important* or *unimportant* on the F-Important scale, yet 9.3% *disagree* that their relative is well cared for in the PCH. In addition, one participant indicates that they do not feel their relative is well cared for (i.e., *strongly disagree*) but considers this item *extremely important*. In addition, no statistically significant correlation was found between the responses on the two scales which also serves to highlight a disparity between what exists and what families consider important. In actual fact, as the discussion deals with being well cared for versus not well cared for, it is not only important to know that families are satisfied but also that PCH residents are receiving high quality care. Indeed, the variation in responses on the F-Involve scale alone suggests that at the very least the care provided in Winnipeg PCHs is not consistent and from some families' perspectives is less than exemplary.

Figure E



F-Involve

F-Important

Additionally, one participant left this item blank on the F-Involve scale and what is particularly noteworthy is that this same individual chose *extremely important* on the F-Important scale. Given that participants did not have the opportunity to qualify their responses, the reason for this participant's decision to leave this item on the F-Involve scale blank can not be known. Based on her/his response on the F-Important scale however it is plausible that they are displeased with the care provided in the home but are uncomfortable indicating so. This line of reasoning is consistent with the social desirability bias observed by Ross and colleagues (2001) in their research. The reader will recall that the social desirability bias is a tendency for families to report high levels of satisfaction even when they are not highly satisfied (Ross, et al., 2001). In fact, following this line of reasoning, it is also plausible that some of the high positive responses are a consequence of this bias as families often feel compelled to rate satisfaction artificially high because of the belief that low scores may negatively impact the care a relative receives (Ross, et al., 2001). Again, this can not be confirmed within the confines of this study however it is a conceivable possibility and warrants further research.

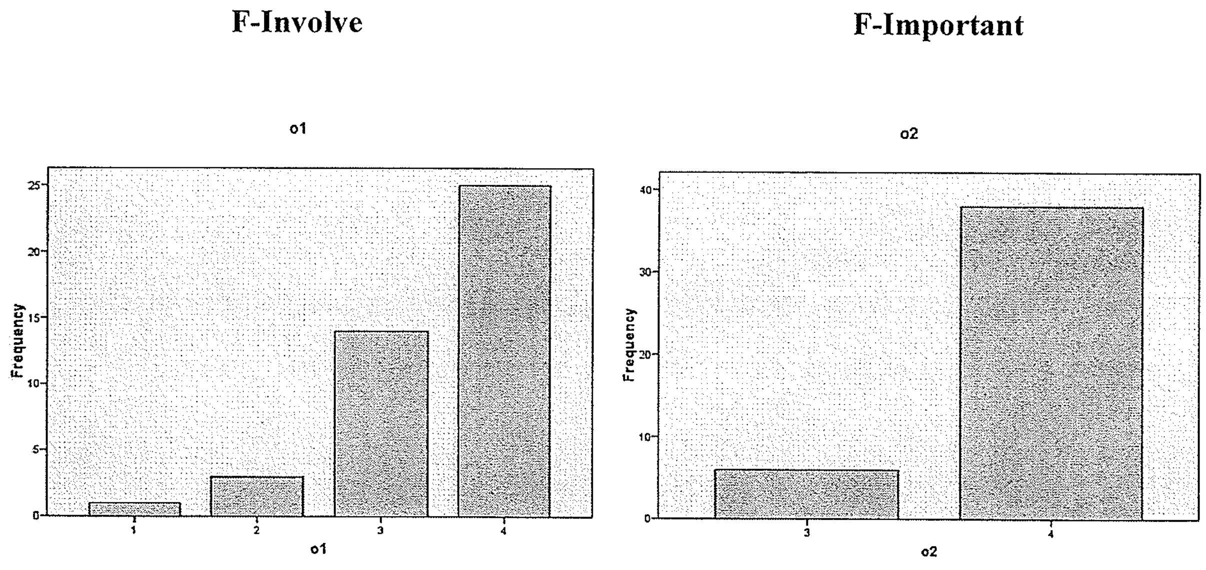
Item O

Item O asks participants to respond to the following statement: *I trust the staff members at this facility.* Once again, the overall findings suggest that families do trust the care staff in the PCH. However, similar to the responses to *Item N* above, there are a few participants who have indicated otherwise (9.3%). Also analogous to the findings of the above item is the fact that one individual left this item blank on the F-Involve scale yet chose the *extremely important* response on the F-Important scale.

Also worth mentioning is that the participants who responded negatively to *Item N* are the same participants who responded negatively to this item. Although this is an interesting finding, it is not a surprising one as the two items are highly interconnected. However, what this finding does is provide further support to the conclusion that these participants have indeed had negative experiences rendering them incapable of feeling confident in the care staff. This is further supported by the fact that these same participants identified this item as being *extremely important*.

Once again, none of the participants deemed this item *somewhat important* or *unimportant.* However, similar to the responses on *Item N* (as shown in Figure F), the responses on the F-Involve scale in comparison to those on the F-Important scale illustrates that what exists is quite different from what is important to the family. Further evidence of this is provided by the absence of a correlation between responses on the two scales. Once again, the social desirability bias may also have played a role in the results of the F-Involve scale however this can not be confirmed at present. In other words, from this speculative point of view, it is quite possible that some family members chose a response that paints a better picture than what actually exists.

Figure F



F-Involve

F-Important

In Hertzberg and Ekman's (2000) study *uncertainty* and *distrust* were two sentiments that families expressed about the staff. The authors (2000) also learned that to combat these feelings and to assure the quality of care for their relative, families often remain highly involved. This is consistent with the findings of Stull and associates (1997). Therefore, although there is once again no way to confirm it, this *could* nevertheless be an explanation for why almost 15% of participants did not choose *extremely important* on the F-Important scale. In other words, it is quite plausible that participants have remained highly involved in the care of their relative or at the very least remained active advocates who ensure that staff carry out tasks correctly.

Item T

The final item under the Theme of Family-Staff Relationships asks participants about their degree of comfort phoning staff for the purpose of inquiring about their relative. Unlike the responses on the previous two items, there is a high statistically significant correlation between those of the two scales for this item ($\tau = .539$). This confirms that there is strong correspondence between this item's presence in the PCH and its degree of importance to families.

However, also unlike the previous two items, the responses on the F-Important scale for this item include *somewhat important* and *unimportant.* Therefore, while the findings show that the majority of participants do feel comfortable phoning staff to discuss their relative and that they feel it is equally important to be able to do so, there are also some participants who do not consider this important.

In addition, a total of five participants revealed that they do not feel comfortable phoning staff. Of these five participants however only two indicated that this is *extremely important.* The remaining three participants do not consider being able to do so nearly as consequential or important. Again, it is only conjecture but it is possible that the three latter family members are able to communicate directly with their relative to ascertain the information they may be seeking (i.e., via the telephone). It may also be possible that they have simply never phoned the staff to discuss their relative and therefore have no frame of reference on which to base their response or to contemplate its importance.

Interestingly, the five participants who chose a negative response on the F-Involve scale are all associated with a large PCH. Given that PCH staffing levels are determined by governing bodies and not the PCH itself, one can not conclude that staff in large PCHs have a higher number of residents to care for and therefore have less time to address family concerns over the phone. However, it is a well-known fact that staff shortages are a problem in health care (Ejaz, et al., 2002) and indeed may have some influence on the time and willingness of staff to respond to telephone calls. In addition, although there is no way to determine this at present, it stands to reason that the smaller the PCH the higher the likelihood of families establishing relationships with staff and accordingly feeling more comfortable phoning them. By the same token, these relationships may also influence the staff's commitment to the family perhaps leading to a heightened sense of obligation to return family phone calls.

Items R and S

The two items on the questionnaire that have not been included in this discussion are *Item R* (*Staff have helped me to plan for the death of my family member*) and *Item S* (*Staff have helped me to plan for the handling of my family member's estate upon his or her death*). All participants in this study were involved in this research because during the recruitment phase they had a living relative residing in a PCH. Both of these items are relevant to events that occur when an individual is either very near death or is already deceased. If a resident was deceased their family member would not have been involved in this study. Also, although it is improbable that a family member would have participated if their relative was near death (as the findings were not promised until at least one year after the study had begun and would lose its relevance), it was brought to the researcher's attention by the social worker of a PCH who declined to participate that these are not services Winnipeg PCH staff are able to offer. It was their concern (and subsequent reason for declining) that the inclusion of these items could lead to an expectation of delivery of service they are not equipped to provide.

From a social work perspective, this is a warranted concern as these are tasks that would indeed be most appropriate for a PCH social worker. However, although there are no specific standards for long term care in Manitoba (according to the Manitoba Association of Social Workers/Manitoba Institute of Registered Social Workers [MASW/MIRSW, 2006), the Canadian Association of Social Workers (CASW, 2002) recommends one full-time social worker for every 60-70 residents. Certainly if this recommendation was adhered to in the PCH, these items would have been included in this discussion. However, this ratio is merely an ideal that in no way reflects reality thereby making the undertaking of these tasks impossible.

Finally, it is the researcher's experience and understanding that the estates of most PCH residents are usually dealt with before they pass away and often early after admission to a PCH if not beforehand. In addition, family members, Powers of Attorneys or Committees are responsible for handling these matters. In fact, the PCH staff's involvement may even be considered a conflict of interest. While the responses to these items have not been discussed, they nevertheless remained on the questionnaire as their implications only came to light after the distribution process had begun. The results can be found in the previous chapter for review.

Summary - Research Objectives and Questions

1. Objective: *To further explore the argument that the individualization of care and the maintenance of personhood are vital components of quality of life for PCH residents.*

Question: *How are the individualization of care and the maintenance of personhood vital to the quality of life of residents in long-term care?*

It is abundantly clear that the quality of life of PCH residents is highly affected by the type of care they receive. Specifically, care that is individualized to meet a resident's personal preferences, etc. and care that fosters the maintenance of their personhood improves their quality of life. Care that does not on the other hand, leaves them feeling vulnerable and without a sense of personal control (Buzzell & Gibbon, 1991).

Furthermore, the presentation of one's illness can be highly affected by their social environment (Kitwood, 1993). Relocation from one's familiar environment (i.e. their home) to an institution that is entirely foreign makes retaining one's personal identity very difficult, in particular when dementia is a diagnosis as is often the case in the PCH (Cohen-Mansfield, et al., 2000). This difficulty is compounded by being surrounded and cared for by virtual strangers.

If the interactions between residents and their caregivers are not supportive of their personhood, this can quite quickly result in a diminished sense of self and an increased sense of vulnerability (Buzzell & Gibbon, 1991; Kitwood, 1993; Cohen-Mansfield, et al., 2000). On the other hand, if the staff is informed and given insight into what makes the resident an individual, and if they incorporate these into the care they provide, the sense of loss and vulnerability can be circumvented and their personhood can be supported (Buzzell & Gibbon, 1991; Kitwood & Bredin, 1992; Harrison, 1993; Kitwood, 1993). In turn, a higher quality of life in the PCH is the result.

2. <u>Objective:</u> *To investigate the argument that the individualization of care and the maintenance of personhood require family involvement.*

<u>Question</u>: *How are individualized care and the maintenance of personhood impacted by family involvement or lack thereof?*

Families are often highly involved with their relative in the PCH and often work very hard to ensure they are being treated as an individual with unique needs and preferences (Duncan & Morgan, 1994). This is especially true when residents are unable to communicate their personhood on their own (Duncan & Morgan, 1994). Indeed, it has been shown that residents who receive regular visits from family members have an improved sense of psychosocial well-being and a preserved sense of self and personal identity (Gladstone 1995; Tobin, 1995).

In addition, families often spend considerable time and energy building relationships with staff for the purpose of teaching them about their relative in an effort to prevent staff from seeing and treating them the same as other residents (Bowers, 1988; Duncan & Morgan, 1994). This is a formidable task because often caregiving staff *do* treat all residents alike (Bowers, 1988; Duncan & Morgan, 1994). In the words of Rowles and High (1996), "...the quality and significance of [family members'] contribution serves to highlight the comparative disadvantage and sense of alienation that is likely experienced by those residents who do not have family" (p. 25).

3. <u>Objective</u>: *To uncover the families' views regarding the present state of family orientation in PCHs throughout the city of Winnipeg.*

<u>Question</u>: *What are the families' perceptions of opportunities for involvement in the care of their relative in a PCH?*

This study found that the degree of family orientation in Winnipeg PCHs is not outstanding from the family's perspective. It is evident that overall families assign more value to a high degree of family orientation than do PCHs. Nevertheless, not all families are dissatisfied with the degree of family orientation and this was found to be the case even within the *same* facilities. In other words, families involved with the same PCH had varying opinions about its degree of family orientation.

This suggests that there are other factors at play. For example, the expectations and interest in this orientation may differ from one family to another. In addition, it is also quite possible that some staff members help to cultivate this orientation while others may serve to discourage it even within the walls of the same PCH.

4. Objective: *To examine how important family involvement is to families in Winnipeg.*
Question: *What are the families' perceptions of the importance of opportunities for involvement?*

In this study, it was learned that families continue to be very involved in the lives of their relatives and that many families spend time with them daily. It is unknown whether this is a consequence of feeling less than confident in the staff providing care, however consistent with the literature, it is clear that understanding the preferences, values, and history of residents continues to be a low priority for PCH staff. This, in turn, also compromises the maintenance of the resident's personhood. It is quite possible therefore that some families feel the need to be highly involved to ensure their relative is receiving care that is congruent with their preferences, values, and personal history in order to support and preserve their personhood.

However, unexpectedly, there were also some family members in this study who do not share the opinion that sharing this information with staff is important. Specifically, not all families share the opinion that being asked to bring in items to teach staff about their relative is highly important. In fact, there were participants from a few PCHs who felt this way. As explained, it is possible that their relatives are able to communicate this information on their own and do not need their families to do so for them. However, it is equally possible that some families simply do not consider this important, or they may have other reasons or explanations that remain unknown.

5. *Objective: To ascertain the relationship between actual opportunities for family involvement and the importance placed on that involvement in Winnipeg PCHs.*

Question: What is the relationship between the opportunities for involvement and the importance families place on their involvement in PCHs in Winnipeg?

Overall, this study has found that *general* opportunities for family involvement created by staff (such as dining and visiting with their relative) are consistent with the importance families place on this. This suggests that families are either satisfied with opportunities that staff create for them or they do not rely upon the staff to do so and instead initiate these opportunities on their own.

However, when it comes to family involvement in *care* and in particular to decision-making related to care, it is evident that there is disparity between what actually goes on and what families consider important. In fact, as many as 20% of the families in this study have felt excluded from contributing to decisions related to care. In addition, over 20% of participants felt completely excluded from the development of their relative's care plan.

Recognizing that these are the very individuals who know and understand their relatives best, it only seems logical for them to be *highly* involved in care related decisions and the care planning process, however this remains a fight that families have yet to win. Unfortunately, the real losers are the residents themselves because without the family's input, care that is individualized and that promotes their personhood remains virtually unachievable.

6. <u>Objective</u>: *To contribute to the field of gerontological social work by calling attention to the fact that it is the PCH social worker's ethical obligation to evaluate and work toward the implementation of policies that endorse family involvement in long-term care.*

<u>Question</u>: *How can this contribute to the field of gerontological social work; specifically in the area of long-term care?*

This objective/question will be addressed in the next and final chapter of this work.

Concluding Remarks

This chapter presented a discussion of the findings of this study. Also, five of the six research questions and objectives were addressed. The following chapter will address the final research question by examining the implications of this research. In addition, the limitations of the study and recommendations for future studies will be explored.

CHAPTER 6

CONCLUSIONS AND IMPLICATIONS

Introduction

The purpose of this study was to examine a sample of family members whose relatives reside in a Winnipeg PCH to learn whether or not families are made to feel comfortable remaining involved in the lives of their relatives after they are admitted to a PCH. This purpose was derived from the extensive body of literature which unequivocally demonstrates that family involvement is a vital component of quality of life and quality of care for PCH residents. This was explored by asking the following research questions: 1. How are the individualization of care and the maintenance of personhood vital to the quality of life of residents in long-term care? 2. How are individualized care and the maintenance of personhood impacted by family involvement or lack thereof? 3. What are the families' perceptions of opportunities for involvement in the care of their relative in a PCH? 4. What are the families' perceptions of the importance of opportunities for involvement? 5. What is the relationship between the opportunities for involvement and the importance families place on their involvement in PCHs in Winnipeg? 6. How can this research contribute to the field of gerontological social work; specifically in the area of long-term care?

Research questions one through five were addressed in the previous chapter and question six will be addressed here. Specifically, this section will be dedicated to answering the question: How can this contribute to the field of gerontological social work; specifically in the area of long-term care?

Summary of the Findings

The findings of this study show that, in general, the importance families place on their involvement tends to be higher than what they experience in the PCH. In other words, families are not always made to feel that their involvement is as important to staff as it is to them and their involvement is not consistently endorsed. In addition, the overall degree of family orientation is lower than families expect it to be and as a consequence, there is a lack of support for the families of residents. In addition, the attention paid to the personhood of residents is also not an exceptional level, from family members' perspectives. Despite these seemingly negative findings, 13 of the 20 items on the two scales are positively correlated. Although some of these correlations are stronger than others, this nevertheless suggests that for these 13 items, what is present in the PCH is indeed consistent with what families consider important at least to some degree.

The finding of contradictory responses within the *same* PCHs is especially interesting however. This finding suggests that there may be factors beyond overall PCH operations influencing the opinions and satisfaction of families. Without further study, the reasons remain unknown, but as Reid and colleagues (2007) pointed out there are a myriad of possible explanations for why some families feel more involved and satisfied than others even within the PCH. Some explanations include: preconceived expectations (e.g. of staff; of PCHs; of care), experiences both within the PCH and leading up to admission, family and staff personality factors and relationship dynamics, as well as varying levels of resident care needs (Reid, et al., 2007). It is also possible that the care and attention provided by some staff members within the same PCH is more satisfactory to families than that of others. Again, further research is needed to understand this finding more fully.

Social Work Practice Implications

Social workers who practice in the PCH setting understand that families and new residents are often in a state of crisis during the admission process (Tobin, 1995; Toye, et al., 1996). It is also well understood that social workers are the best equipped to provide support to residents *and* families both during the time of transition and as illnesses progress (Levine & Kuerbis, 2002). According to Greene (1982), the social worker can help families work through many emotions associated with placing a relative in care and often they can help diminish the negative impact of institutionalization. Peak (2005) found that families who were offered support learn to deal more effectively both with their resident relative's needs as well as their own. In addition, Peak (2005) stresses that providing support "is a way for a facility to communicate to family members that it cares" (p. 109).

The general approach of social work in long-term care includes the understanding that the family is an integral component of the resident's life and should therefore be valued and treated as equally important (Levine & Kuerbis, 2002). Meyers (2006) writes: "…relationships are the building blocks of life, and they must be alive and vigorous. Relationships are the stimulus for growth, as we draw nourishment from one another" (p. 274). Levine and Kuerbis (2002) also emphasize that in the PCH the boundaries are blurred and care and attention needs to be given to not only the resident but also to their relatives.

However, as this study has shown, there are serious shortcomings in this area in Winnipeg PCHs. For example, five of the questionnaire items (i.e. D, H, I, M, Q) pertain specifically to ways that families can be educated and supported in the PCH. Overall, the responses to these items indicate that families want and need to be provided education and support but that these needs are not being met. The implication this has for social work practice in long-term care is that it provides an irrefutably important area for improvement.

To provide what the CASW (2002) describes as "adequate core services" such as these however, the resident-to-staff ratio should be 60-70 residents for every one full-time social worker (CASW, 2002). The unfortunate reality is that in the PCH, staff shortages are a constant problem as is the focus on controlling costs (especially in privately run facilities). Consequently, the importance of family involvement is overlooked or viewed as an inconvenience and the provision of services to the family is compromised (Ejaz et al., 2002). Nevertheless, this research shows that families are asking for what social workers are best equipped to offer but in all likelihood have insufficient time and resources to provide. Acknowledging the need for and recognizing the value of the PCH social worker is the first step toward giving what families are asking for and showing them that they do indeed matter.

Another implication for practice is the need for social workers to promote policies that endorse family involvement in long-term care; policies that are based on the establishment and maintenance of an environment that is highly family-oriented. According to the NASW (2003), maintaining and promoting the psychological, physical and social functioning and an "optimal quality of life" for residents in care is a guiding principle for social workers (p. 9). As this research has demonstrated, the involvement of the family has been unambiguously shown to support all of these. It is therefore the social worker's ethical obligation to evaluate and work toward the implementation of policies that endorse the highest degree of family involvement possible.

Policy Implications

Based on a variety of factors Canadian seniors are living longer and are therefore more dependent upon the services of long-term care (Havens, 2002). In 1995, only one percent of Canada's total population lived in long-term care facilities. According to projections by Statistics

Canada (1999) however, the number of beds required in long-term care could rise from 184, 300 in 1996 to over 565, 000 in 2031. In addition, due to new technologies that support seniors in their homes longer than in the past, admission into care facilities now occurs later in life than it used to (Pitters, 2002). Consequently, most PCH residents have multiple problems and often more complicated impairments (Pitters, 2002).

However, as Ejaz and colleagues (2002) stated, the need to reduce costs and increase efficiency is of principal concern to industry leaders and staff are often discouraged from engaging emotionally. Instead, Hertzberg and Ekman (2000) argued that staff should actually be motivated to communicate with families. Recognizing the importance of doing so, the authors (2000) also stressed that caregiving staff should not only be encouraged to, but also given credit for inquiring about residents' life histories from family members. By doing so, staff and management are setting a tone within the facility that both fosters family involvement and expresses the understanding of the value that family involvement has for the quality of life of their relatives. However, staff shortages and a subsequent need to be efficient often preclude this even if the PCH does indeed endorse family involvement (Ejaz, et al., 2002).

It is abundantly clear therefore that there needs to be a strategy to meet the demands and needs of a growing population and recently one was announced. According to Manitoba Health Minister Theresa Oswald, the Provincial Government is going to invest $40 million in Manitoba PCHs to improve quality of care. This money will be spent to hire 250 nurses, 100 health care aides, and 50 allied health care professionals, such as social workers. Of particular note is that Oswald explained that this strategy is aimed at increasing the hours of direct care, strengthening the work environment for staff, and providing dementia education to staff and families (Oswald, personal communication, November 29, 2007). In other words, while the need for this education has been shown through this study, it is clearly a concern that has been raised in other, larger forums.

Increasing staffing levels is only one step toward improving care and recognizing the need for both staff and family education and support, but it is in the right direction. Not only does it confirm that staff are in need of education, but it also shows that they need more time to be able to spend with residents to provide quality care. In addition, this supports the value of the PCH social worker who must be afforded time to provide the support and education that families are seeking.

The social worker's role should also include working with other PCH management and staff to achieve a highly family oriented facility. In turn, it is possible that the overall degree of family orientation in Winnipeg PCHs can advance. The reader will recall that a high degree of family orientation is conveyed by offering services directly to the family of residents, by including families in the events of the facility, and by taking into consideration the well-being of the family when establishing policies (Janzen, 2001).

The fact is that families feel more secure with the care provided by staff in family friendly facilities (Friedemann, et al., 1997; Gladstone, et al., 2006). Instead of experiencing a sense of security that comes with knowing that a relative is receiving proper care, in PCHs with a low family orientation, families feel the need to maintain control over their relative's care which in turn increases their stress (Friedemann, et al., 1997). Interestingly, Gladstone and associates (2006) add that higher family orientation which encourages family involvement sometimes leads to visiting less because families are comfortable with the care their relatives are receiving. In light of this, the fact that the large majority of family members in this study visit daily becomes particularly noteworthy.

Theoretical Implications

The results of this research indicate that some families feel more positively than others about the majority of items referred to on the questionnaire. In fact, almost all of the items had some participants who responded favourably and some who responded negatively. It therefore seems that individual experiences play a large role in the way they responded. This could be explained, in part, by the ecosystems perspective as it is quite possible that some families are able to 'fit' into the PCH system better than others. However, it is also evident that none of the PCHs in this study were able to satisfy all of the participant family members entirely. This may also be explained by the ecosystems perspective as it may be indicative of issues related to the larger or macro system such as institutional barriers (i.e. staff attitudes, behaviours, and the policies which drive them).

As Caron (1997) explained, the family and the facility ecosystems are linked and required to co-exist through the resident. The relationships that are formed between these two systems have a direct impact on the quality of life of residents and the family system should be looked upon as a valuable resource (Caron, 1997). Caron's (1997) assertions are certainly aligned with the premise of this research as it is clear that without the family's involvement, the resident's personhood is likely to be lost, care that is individualized is impossible, and their quality of life, harmed.

However, what this research also shows is that although the degree of family orientation in Winnipeg PCHs is not at an exceptional level, it is present to varying degrees. Yet there are clearly systemic barriers which preclude the uninhibited involvement of families, influence the time staff are able and willing to spend learning about a resident's personhood and then incorporating this information into their care plan, and to nurturing the family to the extent they need to be. While the staff attitudes and behaviours as systemic barriers can not be confirmed within this study, it remains quite plausible that these do indeed play a role. However, what *has* been determined is that macro barriers in the form of policies and staff shortage issues do indeed exist and that they play a fundamental role in the manner in which the family is welcomed into and supported in the PCH.

The ecosystems framework has proven to be appropriate for this type of research; however, it is evident that any concepts of personhood and long-term care have not been emphasized in the social work literature. Long-term care social work is a well established profession with its own set of standards and guidelines (outlined by the CASW and NASW). In addition, in Manitoba alone, the Manitoba Association of Personal Care Home Social Workers (MAPCHSW) is dedicated to the practice of long-term social work. Furthermore, personhood appears intrinsically related to the practice of social work in long-term care. However, the two have yet to be discussed together within the social work literature. It is evident that the concept of personhood of residents in a PCH is a very important issue and there needs to be a bridge made between this and the practice of social work in the PCH. It is the researcher's hope that this study will make a contribution toward this end; however more work is required.

Limitations of the Study and Recommendations for Future Research

Six limitations were identified in this study; they are: 1. the response rate; 2. the distribution of questionnaires during the summer months; 3. the use of only a single method by which to obtain data; 4. the sampling technique; 5. the social desirability bias, and; 6. an absence of more detailed demographic information.

1. Response Rate

As described in a previous chapter, a total of 237 questionnaires were distributed to six PCHs. The total number of questionnaires returned was 44 – a response rate of approximately 19%. Although the relatively low response rate is a limitation of this study, the results nevertheless align with a wealth of literature on this subject which suggests that it is a valuable project with important implications. However, as Rubin and Babbie (1997) indicate, a low response rate does increase the chances of a response bias and it also affects how representative of the larger population the sample is.

Many measures were taken in the preparation of this study to promote participation. Specifically, as recommended by Rubin and Babbie (1997) the researcher provided a self-addressed stamped envelope, the questionnaire was short and concise, and the anonymity of participants and their relative was assured. Furthermore, as Hager, Wilson, Pollak, and Rooney (2003) contend, the salience of the topic to the individuals completing the questionnaire should also improve response rates – this was certainly the case in this study. Nevertheless, given that the number of packages distributed by PCH Designates was much higher than the number returned, it is clear that many participants who took a package did not complete and return the questionnaire. Suggestions to improve the response rate for future research include:

a. Offering a stipend for participation.
b. Sending the questionnaire (with a stamped return envelope) through PCH billing to target one family member of *all* PCH residents (excluding those with no or uninvolved family).
c. Supplying a locked drop-off box for completed questionnaires within the facility rather than asking participants to mail them back.

d. Having participants complete the questionnaire while the PCH Designate waits and retrieves it immediately upon its completion (within a sealed envelope to ensure confidentiality).

2. Summer Distribution

Although the precise reasons for the low response rate will never be known, given that the questionnaires were distributed during the months of July and August, it is possible that this was a factor in the rate of response. These are the peak summer months in Winnipeg, Manitoba, consequently a popular time for holidays. Accordingly, it is very likely that potential participants were away on summer holidays and not available to participate. For future research, it is recommended that the study be conducted during a different time of the year.

3. Methodology

The use of only the questionnaire proved to be somewhat of a limitation in this study. Some participants provided additional information on their questionnaires that was very interesting and informative. However as the use of this information was not presented to the Research Ethics Board prior to commencement of the study it could not be incorporated into this work.

In addition, participants were not actually assigned an area on the questionnaire for this additional information and so not all participants did so. Nevertheless, it was clear by the comments of some participants that a section for additional information would have been beneficial to the researcher. Providing this area on the questionnaire or perhaps incorporating another forum for a discussion, such as a focus group is therefore a recommendation for future research. The information garnered during a group conversation would likely have been an interesting complement to what was learned through the questionnaires alone.

4. Sampling Technique

The participant sample in this study was obtained through a combination of purposive and convenience methods. Without the use of a random selection process, the true representation of the group can not be known (Rubin & Babbie, 1997; Leedy & Ellis, 2001). The generalizability of results is also uncertain as a consequence of not having a large random sample (Rubin & Babbie, 1997). It is recommended, both for the generalizability of the results and to improve the sample's representativeness, that a random sampling methodology be employed.

In addition, the number of participants from the three size categories was disproportionate. Specifically, the percentage of completed questionnaires returned to the researcher from the small and large PCHs were comparable at 26% and 25% respectively, however from the medium sized PCHs, only 6% of the questionnaires were returned. This also impacts how representative the sample is. It is recommended that future researchers plan for and strive to achieve a more balanced picture if the size of PCHs is a factor. In addition, only six of 39 (now 40) PCHs were involved. A broader depiction may be achieved by involving more PCHs.

5. The Social Desirability Bias

One of the objectives for using the Family Involvement and Importance of Family Involvement questionnaire was to circumvent the social desirability bias that is well understood to exist in this type of research (Grau, et al., 1995; Ross, et al., 2001; Ejaz, et al., 2002; Reid, et al., 2007). While Reid and associates (2007) developed this questionnaire to address this very bias, it is still possible that it influenced the responses and/or decision to participate for some individuals.

A suggestion made by Finnema, et al. (2001) that may be a valuable consideration for this type of research is to seek out the opinions of family members of residents who have passed away. The authors (2001) propose that this is likely to result in more honest answers as families no longer have an interest in doing all they can to keep their relationships with staff positive. This would certainly help to reduce the social desirability bias and/or fears associated with participating in a study such as this one where some may feel that mere participation could be interpreted as negative.

6. Detailed Demographic Information

In this study little information about participants was obtained so beyond meeting the criteria for participation, it remains unknown who they were and what their relationships with the residents in care were (e.g. sibling, spouse, friend, etc.). While it was determined that 66% of the participants were female and 34% were male, it may have been advantageous to learn more. For example, it is known that spouses tend to visit much more frequently and regularly than other relatives (Wright, 2000) and it would have been interesting to learn if this was the case in this study as well. Therefore, for future research, it is recommended that more is gleaned about the participants in order to contribute to the existing picture of who family members of residents in long-term care are.

Conclusion

This study has further contributed to the existing body of knowledge which shows: 1. that the maintenance of personhood is paramount for quality of life in long-term care; 2. that families are best equipped to support the personhood of their relative in care; 3. that care that is individualized to match preferences and values leads to greater satisfaction; 4. that families also need support and need to feel welcome to be as involved as they wish, and yet; 5. that families still are not made to feel as comfortable being involved as they want and need to.

It is abundantly evident that the medical focus which merely sustains the life of a resident in long-term care is not enough. Instead, true quality of life is only possible if what the resident needs and desires are provided and nourished, and only those who are closest to them know what these are. However, if family members are not supported and their involvement not fostered, the relationship with their relative can be irreparably affected (Friedemann, et al., 1997). In effect, the family may spend less time with their relative and eventually even perhaps become entirely alienated and disengaged especially as diseases progress.

These findings have important implications for improving the quality of care of residents in the PCH. In fact, these results support what social work practice in long-term care has always sought to incorporate – the nurturing and caring for both the resident *and* their family. It is the researcher's hope that this study not only contributes to social work literature but also that it contributes to an understanding of and appreciation for the valuable role that social workers in the PCH play for both the residents and their families.

References

Abdi, H. (2007). The Kendall Rank Correlation Coefficient. In N. Salkind (Ed), *Encyclopedia of measurement and statistics.* Thousand Oaks, CA: Sage Publications.

Bauer, M., & Nay, R. (2003). Family and staff partnerships in long-term care: A review of the literature. *Journal of Gerontological Nursing, 29*(10), 46-53.

Bowers, B. J. (1988). Family perceptions of care in a nursing home. *The Gerontologist, 28*(3), 361-368.

Buzzell, M., & Gibbon, M. (1991). Personhood: What's the point of long-term care if the person doesn't feel cared for? *The Canadian Nurse, 87*(6), 32-33.

Canadian Association of Social Workers (2002). *Position Paper on Social Work in Long-Term Care*. Approved by the CASW Board, May 2002.

Caron, W. A. (1997). Family systems and nursing home systems: An ecosystemic perspective for the systems practitioner. In T. D. Hargrave & S. M. Hanna (Eds.), *The aging family: New visions in theory, practice, and reality* (pp. 235-258). New York: Brunner/Mazel.

Cohen-Mansfield, J., Golander, H. & Arnheim, G. (2000). Self-identity in older persons suffering from dementia: Preliminary results. *Social Science & Medicine, 51*, 381-394.

Cohen-Mansfield, J., Parpura-Gill, A., & Golander, H. (2006). Utilization of self-identity roles for designing interventions for persons with dementia. *Journal of Gerontology, 61B*(4), 202-212.

Coker, E. (1998). Does your care plan tell my story? Documenting aspects of personhood in long-term care. *Journal of Holistic Nursing, 16*(4), 435-452.

Davies, S., & Nolan, M. (2006). 'Making it better': Self-perceived roles of family caregivers of older people living in care homes: A qualitative study. *International Journal of Nursing Studies, 43*, 281-291.

Duncan, M. T., & Morgan, D. L. (1994). Sharing the caring: Family caregivers' views of their relationships with nursing home staff. *The Gerontologist, 34*(2), 235-244.

Ejaz, F. K., Noelker, L. S., Schur, D., Whitlatch, C. J., Looman, W. J., & Rose, B. (2002). Family satisfaction with nursing home care for relatives with dementia. *The Journal of Applied Gerontology, 21*(3), 368-384.

Field, A., & Hole, G. (2003). *How to design and report experiments.* Thousand Oaks, CA: Sage Publications.

Finnema, E., de Lange, J., Dröes, R.-M., Ribbe, M., & van Tilburg, W. (2001). The quality of nursing home care: Do the opinions of family members change after implementation of emotion-oriented care? *Journal of Advanced Nursing, 35*(5), 728-740.

Foner, N. (1995). Relatives as trouble: Nursing aides and patients' families. In J. N. Henderson & M. D. Vesperi (Eds.), *The culture of long term care: Nursing home ethnography* (pp. 165-178). London: Bergin & Garvey.

Friedemann, M. L., Montgomery, R. J., Maiberger, B., & Smith, A. A. (1997). Family involvement in the nursing home: Family oriented practices and staff-family relationships. *Research in Nursing & Health, 20*, 527-537.

Gaugler, J. E., Anderson, K. A., & Leach, C. R. (2003). Predictors of family involvement in residential long-term care. *Journal of Gerontological Social Work, 42*(1), 3-26.

Gladstone, J. W. (1995). The marital perceptions of elderly persons living or having a spouse living in a long-term care institution in Canada. *The Gerontologist, 35*(1), 52-60.

Gladstone, J. W., Dupuis, S. L., & Wexler, E. (2006). Changes in family involvement following a relative's move to a long-term care facility: *Canadian Journal on Aging, 25*(1), 93-106.

Gladstone, J., & Wexler, E. (2000). A family perspective of family/staff interaction in long-term care facilities. *Geriatric Nursing, 21*(1), 16-19.

Grau, L., Teresi, J., Burton, B., & Chandler, B. (1995). Family members' perception of the quality of nursing home care. *International Journal of Geriatric Psychiatry, 10*, 787-796.

Greene, R.R. (1982). Families and the nursing home Social Worker. *Social Work in Health Care, Spring, 7*(3), 57-67.

Hager, M. A., Wilson, S., Pollak, T. H., & Rooney, P. M. (2003). Response rates for mail surveys of nonprofit organizations: A review and empirical test. *Nonprofit and Voluntary Sector Quarterly.* Retrieved on October 1, 2007 from: http://nvs.sagepub.com/cgi/content/abstract/32/2/252

Harrison, C. (1993). Personhood, dementia and the integrity of a life. *Canadian Journal on Aging, 12*(4), 428-440.

Hertzberg, A., & Ekman, S. L. (1996). How the relatives of elderly patients in institutionalized care perceive the staff. *Scandinavian Journal of Caring Sciences, 10*(4), 205-211.

Hertzberg, A., & Ekman, S.-L. (2000). 'We, not them and us?' Views on the relationships and interactions between staff and relatives of older people permanently living in nursing homes. *Journal of Advanced Nursing, 31*(3), 614-622.

Iwasiw, C., Goldenberg, D., Bol, N., & MacMaster, E. (2003). Resident and family perspectives: The first year in a long-term care facility. *Journal of Gerontological Nursing, 29*(1), 45-54.

Janzen, W. (2001). Long-term care for older adults: The role of the family. *Journal of Gerontological Nursing, 27*(2), 36-43.

Jarrett, C. (2005). Caroline's corner: Survey response rates? 2% is not good enough. Retrieved on October 1, 2007 from: http://www.usabilitynews.com/news/article2528.asp.

Kendall, M. G. (1962). *Rank Correlation Methods.* London: Griffin.

Kenny, T. (1990). Erosion of individuality in care of elderly people in hospital:.An alternative approach. *Journal of Advanced Nursing, 15*, 571-576.

Kitwood, T. (1993). Towards a theory of dementia care: The interpersonal process. *Aging & Society, 13*, 51-67.

Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing and Society, 12*, 269-287.

Leedy, P. D., & Ellis Ormrod, J. (2001). *Practical research: Planning and design, 10th ed.* New Jersey: Prentice-Hall, Inc.

Levine, C., & Kuerbis, A. (2002). Building alliances between Social Workers and family caregivers. *Journal of Social Work in Long-Term Care, 1*(4), 3-17.

Maas, M. L., Buckwalter, K. C., Kelley, L. S., & Stolley, J., M. (1991). Family members' perceptions: How they view care of Alzheimer's patients in a nursing home. *The Journal of Long-Term Care Administration, Spring, 19*(1), 21-5.

Malench, S. S. (2004). Family and social work roles in the long-term care facility. *Journal of Gerontological Social Work, 43*(1), 49-60.

Marquis, R., Freegard, H., & Hoogland, L. (2004). Influences on positive family involvement in aged care: An ethnographic view. *Contemporary Nurse, 16*, 178-186.

Meyer, C. H., & Mattiani, M. A. (1998). The ecosystems perspective: Implications for practice. In M. Mattiani, C. Lowery & C. Meyer (Eds.), *The foundations of social work practice, 2nd ed.,* Washington: NASW Press.

Meyers, S. (2006). Role of the social worker in old versus new culture in nursing homes. *Social Work, 51*(3), 273-277.

Motiwala, S. S., Flood, C., M., Coyte, P. C., & Laport, A. (2005). The First Minister's Accord on Health Renewal and the future of home care in Canada. *Longwoods Review, 2*(4), 2-9.

National Advisory Council on Aging. (2006). *The National Advisory Council on Aging demands improvements to Canada's long-term care institutions.* Retrieved on January 5, 2007 from: http://www.naca-ccnta.ca/expression/18-4/pdf/exp18-4-insert_e.pdf

National Association of Social Workers (2003). *NASW standards for social work in long-term care facilities.* Washington: NASW Press.

Nolan, M., & Dellasega, C. (1999). 'It's not the same as him being at home': Creating caring partnerships following nursing home placement. *Journal of Clinical Nursing, 8*, 723-730.

Nolan, M., Ryan, T., Enderby, P., & Reid, D. (2002). Towards a more inclusive vision of dementia care practice and research. *Dementia, 1*(2), 193-211.

Ory, M. G. (2000). Dementia caregiving at the end of the 20th century. In M. P. Lawton & R. L. Robertson (Eds.), *Interventions in dementia care: Towards improving quality of life* (pp. 173-179). New York: Springer.

Oswald, T. (2007). News Release: Province invests more than $40 million for recruitment strategy to increase personal-care home nursing care and supports. Retrieved on January 10, 2008 from: http://news.gov.mb.ca/news/index.html?archive=2007-11-01&item=2707

Patton, M. Q. (1980). *Qualitative evaluation methods.* Thousand Oaks, CA: Sage Publications.

Payne, M. (2005). *Modern social work theory, 3rd ed.,* Chicago: Lyceum Books.

Peak, T. (2005). Support for families in the nursing home environment: Family caregiving, social support, and support group benefits of The Family Project. In J. Gaugler (Ed.), *Promoting family involvement in long-term care settings: A guide to programs that work* (pp. 93-112). Baltimore: Health Professions Press.

Pitters, S. (2002). Long-term care facilities. In M. Stephenson & E. Sawyer (Eds.), *Continuing the care: The issues and challenges for long-term care* (pp. 163-201). Ottawa: CHA Press.

Reid, R. C., Chappell, N. L., & Gish, J. A. (2007). Measuring family perceived involvement in individualized long-term care. *Dementia: The International Journal of Research and Practice, 6*(1), 89-104.

Ross, M. M., Carswell, A., & Dalziel, W. B. (2001). Family caregiving in long-term care facilities. *Clinical Nursing Research, 10*(4), 347-363.

Rowles, G. D., & High, D. M. (1996). Individualizing care: Family roles in nursing home decision-making. *Journal of Gerontological Nursing, 22*(3), 20-25.

Rubin A., & Babbie, E. (1997). *Research methods for social work, 3rd ed.*, California: Wadsworth.

Rubin, A., & Shuttlesworth, G. E. (1983). Engaging families as support resources in nursing home care: Ambiguity in the subdivision of tasks. *The Gerontologist, 23*(6), 632-636.

Ryan, A. A., & Scullion, H. F. (2000). Family and staff perceptions of the role of families in nursing homes. *Journal of Advanced Nursing, 32*(3), 626-634.

Siegel, S., & Castellan, N. J. (1988). *Nonparametric statistics for the behavioral sciences, 2nd ed.*, New York: McGraw-Hill.

Stull, D. E., Cosbey, J., Bowman, K., & McNutt, W. (1997). Institutionalization: a continuation of family care. *Journal of Applied Gerontology, 16*, 379-403.

Tobin, S. S. (1995). Fostering family involvement in institutional care. In G. C. Smith, S. S. Tobin, E. A. Robertson-Tchabo & P. W. Power (Eds.), *Strengthening aging families: Diversity in practice and policy.* Thousand Oaks, CA: Sage Publications.

Toye, C., Percival, P., & Blackmore, A. (1996). Satisfaction with nursing home care of a relative: Does inviting greater input make a difference? *Collegian, 3*(2), 4-11.

Woods, R. T. (2001). Discovering the person with Alzheimer's disease: Cognitive, emotional and behavioural aspects. *Aging & Mental Health, 5*(Supplement 1), S7-S16.

Winnipeg Regional Health Authority (WRHA) (2007). *WHRA Long Term Care Strategy.* Retrieved on March 13, 2008 from: http://www.wrha.mb.ca/ltc/strategy/index.php

Wright, F. (2000). The role of family care-givers for an older person resident in a care home. *British Journal of Social Work, 30*, 649-661.

Appendix C - Letter to Executive Director

UNIVERSITY OF MANITOBA | Faculty of Social Work

521 Tier Building
Winnipeg, Manitoba
Canada R3T 2N2
Telephone (204) 474-7050
Fax (204) 474-7594
Social_Work@UManitoba.CA

The Degree of Family Orientation in Winnipeg Personal Care Homes

Dear Executive Director,

My name is Lucy Trotta and I am a Master's student in the Faculty of Social Work at the University of Manitoba. I am presently working toward completion of my degree and as part of my program I am conducting a study of personal care homes (PCH) in Winnipeg. Through a random selection process, your facility was chosen so I am writing to request your help by participating in this study. Participation will require minimal effort from one or two of your employees (for large PCH, 2 may be required) and the procedure is designed to result in minimal disturbance to your facility's daily activities. Though the study will have no direct impact on any specific facility, participation in the study may be of interest and benefit to you, your staff, your residents and their families.

The focus of my research is on the individualization of care, the maintenance of personhood, and the degree of family orientation of PCHs in Winnipeg. Literature suggests that *individualization* is essential to providing high quality care and that family involvement is a key component to being able to provide care that is individualized. Also, a resident's *personhood*—the qualities, preferences, history, etc. that make one an individual—often cannot be fully understood without the help of family members. Finally, a facility's *degree of family orientation* relates to the extent to which families are encouraged to be involved and are taken into consideration with regard to facility activities, rules, and policies.

In addition to helping me gain a better understanding of these issues, another reason you may be interested in participating pertains to the present manner in which you obtain your measures of resident and family satisfaction. In particular, while satisfaction questionnaires are the primary method used by PCHs, it has been argued that this method is flawed and that it often leads to inaccurate levels of satisfaction for two major reasons.

First, it has been found that there is a clear difference in what families are willing to report and what they actually perceive to be true about the care their relative receives. Specifically, fear of negative repercussions for their relative leads to reporting artificially high levels of satisfaction with care; this is called the *social desirability bias*. Second, there may be issues unrelated to care that influence satisfaction. Among these, for example, are their own personal opinions of PCHs, the emotions generated by placing a relative in a facility, the degree of their involvement with care, positive and negative interactions with staff, and the frequency with which they visit. Though they have little or nothing to do with the actual care their relative is receiving, all of these can impact how families rate satisfaction.

The questionnaire used in this study addresses these very concerns because it does not focus on family satisfaction, but rather on their involvement. This is an important piece because it has been found that the more families are encouraged to be involved, the greater the overall level of satisfaction (even if family members choose *not* be very involved). This questionnaire can be the ideal tool to determine if and where your facility does in fact foster family involvement and where you may consider making improvements *from the family's perspective*. It may also prove to be a valuable alternative to the satisfaction questionnaire because without the social desirability bias, families are more likely to complete and return them and responses are likely to be more truthful.

I am requesting your permission to deliver participant packages to your facility and to display one (11" x 14") poster about the study (example enclosed). I am also asking that you designate one individual to let families know about the study and to give a package to those who are willing to participate. If your facility holds Family Council meetings, I also request your permission to attend a meeting so that I may inform family members about the study and answer any questions that may arise. If you agree to participate, the total number of packages delivered to your facility will be based on 25% of your resident population (approximately # packages) however under no circumstances is your facility obligated to ensure that all packages are distributed. If all packages are not distributed by the deadline date (to be determined), I simply ask that you call me and I will pick up the remaining packages.

There are minimal criteria for participation: (1) participants will be at least *18 years of age*; (2) they visit their relative resident *at least twice per month*, and; (3) have had *any type of contact* with facility staff members on various levels. Please note that all participation is entirely voluntary and it must be emphasized that there are no consequences for withdrawing from the study or declining to participate.

Each package will contain the following: an information letter, consent form, questionnaire (copies of each are enclosed) as well as an envelope for returning the completed questionnaire and consent form directly to the researcher. Upon completion of the project, I will send you a summary of the overall findings (they will not be facility-specific) and if you would like, I would gladly attend another Family Council meeting and/or meet with you and your staff to discuss the findings. I also ask that I may leave a few copies of the study findings at your facility for interested individuals to have.

Your participation is essential to obtain an accurate picture of the level of family involvement in personal care homes throughout the city of Winnipeg. What is being sought is an understanding of family orientation and the importance that families place on their involvement in PCHs in Winnipeg. By agreeing to participate in my study, you will not only be helping me achieve my goal, but you will also be demonstrating your commitment to the quality of life of residents in your care.

This research project is being supervised by three faculty members at the University of Manitoba – Dr. Sharon Taylor-Henley and Kathryn McKnight (Faculty of Social Work) and Dr. Lorna Guse (Faculty of Nursing). The project has been approved by the University of Manitoba Psychology/Sociology Research Ethics Board. If you have any questions or concerns about this research project, please feel free to contact me, my advisor Dr. Sharon Taylor-Henley; (thenley@ms.umanitoba.ca), or the University of Manitoba Human Ethics Secretariat Margaret Bowman (margaret_bowman@umanitoba.ca).

I will call you in approximately one week to discuss the project and request consent for your facility's participation. Thank you for considering my request.

Sincerely,

Lucy Trotta, B.A., M.S.W. Student
lucytrotta@shaw.ca

Appendix D – Research Instrument
Family Involvement and Importance of Family Involvement Scale

Directions: Read each statement and think about the extent to which it is present in the facility that your family member lives in. Place your responses to these statements in column A on the *left* hand side by using the scale provided. Then consider how important each of these ways of including you in the care of your family member is to you regardless of whether or not the facility provides it. Place your responses to these statements in column B on the *right* hand side by using the scale provided.

A. Present in Facility ***B. Important to Me***

SCALE 1 Strongly disagree 2 Somewhat disagree 3 Somewhat agree 4 Strongly agree		*SCALE* 1 Unimportant 2 Somewhat important 3 Quite important 4 Extremely important
a. _____	Staff have created opportunities for me to meaningfully participate in my family member's day.	_____
b. _____	I have been asked about my family member's personal history.	_____
c. _____	I have been asked about my family member's preferences and values.	_____
d. _____	Staff have helped me to understand how dementia affects my family member.	_____
e. _____	I am able to dine with my family member if I want to.	_____
f. _____	I have been asked to bring in pictures, letters, and other personal items to teach staff about my family member.	_____
g. _____	I feel like I am involved in decision-making about my family member's care when he or she cannot make decisions for themselves.	_____
h. _____	Staff have taught me how to communicate with my family member as the disease has progressed.	_____
i. _____	The facility has a support group.	_____
j. _____	I was introduced to the different staff members at the facility when my family member was admitted.	_____
k. _____	Staff explained to me the rules and procedures at the facility upon admission.	_____
l. _____	Administrators have asked my opinions about the quality of care provided at this facility.	_____

A. Present in Facility ***B. Important to Me***

SCALE 1 Strongly disagree 2 Somewhat disagree 3 Somewhat agree 4 Strongly agree		*SCALE* 1 Unimportant 2 Somewhat important 3 Quite important 4 Extremely important
m. _____	The facility holds family information meetings.	_____
n. _____	I feel like my family member has been well cared for.	_____
o. _____	I trust the staff members at this facility.	_____
p. _____	I am informed about changes in my family member's care plan.	_____
q. _____	Staff have helped me understand the difficult behaviours that my family member sometimes has.	_____
r. _____	Staff have helped me to plan for the death of my family member.	_____
s. _____	Staff have helped me to plan for the handling of my family member's estate upon his or her death.	_____
t. _____	I feel comfortable phoning staff members and talking to them about how my family member is doing.	_____

Please respond to the following questions:

1. Are you: ____male ____female

2. How long has your relative been living in a personal care home?

____

3. How often do you visit? _________________________

4. Before your relative was admitted into a personal care home, were you their primary caregiver?
____yes ____no

5. If you responded "yes" to question #4, for how long? _________________________

6. If you responded "no" to question #4, was another family member their primary caregiver?
____yes ____no

Appendix E – Poster

(reduced from original size of 11" x 17")

FAMILY INVOLVEMENT IN PERSONAL CARE HOMES

1. Are you a family member or close friend of someone living at (name of PCH here)?
2. Are you 18 years of age or older and visit at least two times per month?
3. Have you had any type of contact with various staff at (name of PCH here)?

If you answered '*yes*' to the above questions, you may be interested in participating in a study looking at the promotion of family involvement in Winnipeg personal care homes.

If you are willing to spend approximately 10 minutes completing a short questionnaire related to the types of involvement opportunities in Winnipeg Personal Care Homes, you can pick one up at the front desk.

All information will be kept strictly **confidential** and once you have been given the questionnaire package, (name of PCH here) will no longer be involved in any way.

All participation is completely voluntary and you are free to decline at any time with no negative consequences.

This research project has been approved by the University of Manitoba Psychology/Sociology Research Ethics Board as a thesis requirement for the Masters of Social Work program.

521 Tier Building
Winnipeg, Manitoba
Canada R3T 2N2
Telephone (204) 474-7050
Fax (204) 474-7594
Social_Work@UManitoba.CA

Appendix F - Letter to PCH Designate

UNIVERSITY OF MANITOBA | Faculty of Social Work

The Degree of Family Orientation in Winnipeg Personal Care Homes

Dear Designate,

My name is Lucy Trotta and I am a Master's student in the Faculty of Social Work at the University of Manitoba. I am presently working toward completion of my degree and as part of my program I am conducting a study of personal care homes (PCH) in Winnipeg. (insert name of Administrator or Executive Director) has agreed to participate and has designated you to help me with the distribution of packages to participants. I sincerely thank you for taking time out of your very busy schedule to help me with this project.

To briefly summarize, a resident's *personhood*—the qualities, preferences, history, etc. that make one an individual—often cannot be fully understood without the help of family members. Literature suggests that *individualization* is essential to providing high quality care and that family involvement is a key component to being able to provide care that is individualized. However, the extent to which families feel comfortable being involved in their relative resident's care in Winnipeg PCHs is not fully understood and this is what I hope to learn by having participants complete a short questionnaire. Specifically, the objectives of my study are:

1. To uncover the families' views regarding the present state of family orientation in PCHs throughout the city of Winnipeg.

2. To examine how important family involvement is to families in Winnipeg.

3. To ascertain the relationship between actual opportunities for family involvement and the importance placed on that involvement in Winnipeg PCHs.

Enclosed is an 11" x 14" poster. I ask that you display it in a location where visitors are certain to see it which will give them the opportunity to approach you if they are interested in completing a questionnaire. I am also asking that you let family visitors know about the study and give a package to those individuals who show interest. To simplify this, I have included a script which you can use as a guideline when informing potential participants about the study.

There are minimal criteria for participation however please follow them as closely as possible: (1) participants will be at least 18 years of age; (2) they visit their relative resident at least twice per month, and; (3) have had any type of contact with facility staff members on various levels.

**(Please note that the term 'family member' will be used in this study to describe any individual with extensive knowledge of the resident's history, personality, preferences and habits, etc. Therefore,* anyone *who knows a resident intimately enough to understand all of these facets will qualify as a 'family member' and participant for this study).*

The total number of participant packages given to you is based on 25% of your facility's resident population and each package contains the following: an information letter, two consent forms (one for the participant to keep and one to return to me), the questionnaire, as well as an envelope for returning the completed questionnaire and consent form directly to me. Based on this percentage a total of (# packages) have been provided however under no circumstances are you obligated to ensure that all packages are distributed. If they are not all distributed by the deadline date (to be determined), I simply ask that you call me and I will pick up the remaining packages.

Upon completion of the project, I will send a summary of the overall findings (they will *not* be facility-specific) to (name of PCH) with extra copies for interested individuals to have. Participants will also be given the opportunity to provide their address to me so that I can mail a summary of findings to them directly.

This research project is being supervised by three faculty members at the University of Manitoba – Dr. Sharon Taylor-Henley and Kathryn McKnight (Faculty of Social Work) and Dr. Lorna Guse (Faculty of Nursing). The project has been approved by the University of Manitoba Psychology/Sociology Research Ethics Board. If you have any questions about this research project, please feel free to contact me, my advisor Dr. Sharon Taylor-Henley; (thenley@ms.umanitoba.ca), or the University of Manitoba Human Ethics Secretariat Margaret Bowman (margaret_bowman@umanitoba.ca).

Your assistance is very important for me to obtain an accurate picture of the level of family involvement in personal care homes throughout the city of Winnipeg. Thank you again for taking the time and making the effort to help me complete this project.

Sincerely,

Lucy Trotta, B.A., M.S.W. Student
lucytrotta@shaw.ca

Appendix G – Family Information Letter

UNIVERSITY OF MANITOBA | Faculty of Social Work

521 Tier Building
Winnipeg, Manitoba
Canada R3T 2N2
Telephone (204) 474-7050
Fax (204) 474-7594
Social_Work@UManitoba.CA

The Degree of Family Orientation in Winnipeg Personal Care Homes

Dear Family Member,

My name is Lucy Trotta and I am a Master's student at the University of Manitoba. As a program requirement I am preparing to write a thesis which entails carrying out a study to learn about family involvement in Winnipeg personal care homes. I am asking family members and close friends of residents living in Winnipeg personal care homes to complete a short questionnaire related to the types of involvement opportunities that exist for families in the homes. Completing this questionnaire will take approximately 10 minutes of your time and will help me gain a better understanding of how involved families are and how involved they would like to be in the care of their relative. (Name of PCH) is one of 6 PCHs participating in this study.

It is generally understood that family involvement is very important to not only the quality of life, but also to the quality of care that residents in personal care homes receive. This is based on the fact that only families and very close friends truly know their relative. In other words, with your involvement and input, employees in personal care homes can gain a greater understanding of your relative's history, needs, preferences, and wishes. This is especially true if your relative cannot communicate these things on their own. However, the extent to which families feel comfortable being involved is not fully understood and this is what I hope to learn.

The objectives of my study are:

1. To uncover the families' views regarding the present state of family orientation in Personal Care Homes throughout the city of Winnipeg.

2. To examine how important family involvement is to families in Winnipeg.

3. To ascertain the relationship between actual opportunities for family involvement and the importance placed on that involvement in Winnipeg Personal Care Homes.

There are minimal criteria for participation: (1) participants will be at least *18 years of age*; (2) visit their relative resident *at least twice per month*, and; (3) have had *any type of contact* with facility staff members on various levels.

There are a number of good reasons to participate in this study. For example, it will give families a chance to confidentially voice if and how involved they are in various aspects of their relative's life in a personal care home and how important involvement is to them. The findings of this project will also valuable to personal care home administrators and employees who are striving to achieve higher standards of quality care. The findings may also prove to be beneficial to family members who want to have greater involvement in the care of their resident relative, but do not fully understand or know the ways in which to do so.

All participation is entirely voluntary and if you agree to participate in this study, you will be given a package containing two consent forms, the questionnaire and a return envelope. You are asked to: (1) review and sign one of the consent forms (the second copy is for your records); (2) complete the brief questionnaire, and; (3) mail them both to me in the postage-paid envelope provided.

To ensure confidentiality, when I receive your consent form and questionnaire, the two documents will be immediately separated and *before* I review the questionnaires the consent form will be placed in a separate envelope. For the duration of the research, all materials will be stored in a locked filing cabinet in my home of which I am the sole key-holder. The only individuals with access to the information you provide will be me and my Advisor Sharon Taylor-Henley and immediately upon completion of the project and acceptance of my thesis, all documents will be shredded (no later than February of 2009).

You will note some letters and numbers on the back of your questionnaire. For the purposes of this study, all personal care homes in Winnipeg have been separated into categories of small, medium and large. Therefore, in order for me to identify the size of facility from which your questionnaire came, all questionnaires will have a "size code" (i.e., *sm, mdm, lrg)*. Also, all questionnaires will be numbered so that the researcher can determine what proportion of questionnaires was completed per category but no codes will be used to identify specific facilities.

After you have received this package, the personal care home in which your relative resides will no longer be involved. However, upon completion of the project, I will send a summary of the overall findings (they will *not* be facility-specific) to each personal care home that participated with extra copies for interested individuals to take. If you agree to participate, you will also be given the opportunity to provide your address to me so that I can mail a summary of findings to you directly if you so wish. The summary will be available by February 2009.

If the findings of this research are published, your anonymity and the anonymity of your relative in care will be protected and at no time will there be disclosure of any information that could lead to the identification of either of you. There are no risks involved in participating for either you or your relative in care, however please be aware that I am legally obligated to notify the appropriate authorities should the abuse of a personal care home resident be disclosed to me.

If you are reading this letter, you have taken the initial steps to participate in this study. However, if at any time you decide not to proceed, there will be no negative consequences whatsoever.

This research is being supervised by three faculty members at the University of Manitoba: Dr. Sharon Taylor-Henley and Kathryn McKnight (Faculty of Social Work) and Dr. Lorna Guse (Faculty of Nursing) and has been approved by the University of Manitoba Psychology/Sociology Research Ethics Board. If you have any questions or concerns about this research project at any time, please feel free to contact me, my advisor Dr. Sharon Taylor-Henley; (thenley@ms.umanitoba.ca), and/or the University of Manitoba Human Ethics Secretariat Margaret Bowman (margaret_bowman@umanitoba.ca).

Sincerely,

Lucy Trotta, B.A., M.S.W. Student
lucytrotta@shaw.ca

Appendix H - Family Consent

521 Tier Building
Winnipeg, Manitoba
Canada R3T 2N2
Telephone (204) 474-7050
Fax (204) 474-7594
Social_Work@UManitoba.CA

UNIVERSITY OF MANITOBA | Faculty of Social Work

Research Project Title: The Degree of Family Orientation in Winnipeg Personal Care Homes

Researcher: Lucy Trotta, University of Manitoba; lucytrotta@shaw.ca

Advisor: Dr. Sharon Taylor-Henley, University of Manitoba; thenley@ms.umanitoba.ca

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.

I know and understand that:

1. My participation is entirely voluntary. If at any time I decide not to proceed, there will be no negative consequences whatsoever. *In other words, even if I have accepted a package,* ***I am not obligated to participate.***

2. I have been asked to participate because I meet the following criteria:
   (a) I am at least *18 years of age*;
   (b) I visit my relative resident (or very close friend) *at least twice per month*, and;
   (c) I have had *(any type of) contact* with facility staff members on various levels.

3. The objectives of this study are:
   (a) To uncover the families' views regarding the present state of family orientation in Personal Care Homes throughout the city of Winnipeg.
   (b) To examine how important family involvement is to families in Winnipeg.
   (c) To ascertain the relationship between actual opportunities for family involvement and the importance placed on that involvement in Winnipeg Personal Care Homes.

4. My participation involves completing the questionnaire enclosed (which will take approximately 10 minutes) and returning it along with one signed consent form (this document) in the envelope provided. I am to retain one consent form for my records.

5. At no time will there be disclosure of any information that could lead to my identification or the identification of my relative in care. However, I understand that the exception to this is that Lucy is legally obligated to notify the appropriate authorities should she be informed of the abuse of a personal care home resident.

6. All materials will be stored in a locked filing cabinet in Lucy's home and destroyed following completion of this project (no later than February 2009).

7. After providing a participant package to me, the personal care home in which my relative resides will no longer be involved in the research process and all information that I share will be kept strictly confidential – only Lucy Trotta and her supervisor Sharon Taylor-Henley will have access to the information I provide.

8. Neither the names of individuals nor those of facilities involved will be used in this study therefore if the findings of this research are published, my anonymity and the anonymity of my relative in care will be protected.

9. A summary of overall findings (not facility-specific) will be available following the completion of the project at the personal care home from which I obtained this package by February 2009. I can provide my address below if I would like a summary mailed or emailed to me directly.

10. I can contact Lucy should I need to discuss any issues that arise from this project for myself or my relative in care. Questions or concerns can also be directed to Dr. Sharon Taylor-Henley or the Human Ethics Secretariat Margaret Bowman (margaret_bowman@umanitoba.ca).

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate. In no way does this waive your legal rights nor release the researchers or involved institutions from their legal and professional responsibilities. You are free to withdraw from this study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so please feel free to ask for clarification or new information throughout your participation.

____

Participant's Signature Date

If you would like a summary of the findings mailed or emailed to you, please indicate this by providing the appropriate address below:

____

____

____

Appendix I - Correlated and Non-correlated Questionnaire Items

Scale Item	**Kendall's Tau**
A. Staff have created opportunities for me to meaningfully participate in my family member's day.	.608
B. I have been asked about my family member's personal history.	.242
C. I have been asked about my family member's preferences and values.	.352
D. Staff have helped me to understand how dementia affects my family member.	
E. I am able to dine with my family member if I want to.	.421
F. I have been asked to bring in pictures, letters, and other personal items to teach staff about my family member.	.545
G. I feel like I am involved in decision-making about my family member's care when he or she cannot make decisions for themselves.	.322
H. Staff have taught me how to communicate with my family member as the disease has progressed.	
I. The facility has a support group.	
J. I was introduced to the different staff members at the facility when my family member was admitted.	.434
K. Staff explained to me the rules and procedures at the facility upon admission.	.560
L. Administrators have asked my opinions about the quality of care provided at this facility.	.290
M. The facility holds family information meetings.	.358
N. I feel like my family member has been well cared for.	
O. I trust the staff members at this facility.	
P. I am informed about changes in my family member's care plan.	
Q. Staff have helped me understand the difficult behaviours that my family member sometimes has.	
R. Staff have helped me to plan for the death of my family member.	.322
S. Staff have helped me to plan for the handling of my family member's estate upon his or her death.	.434
T. I feel comfortable phoning staff members and talking to them about how my family member is doing.	.539