

Understanding the Role of Family in the Long-Term Care Team:

A Framework for Family Involvement in Long-Term Care

By

Fadumo Khalif-Robinson, BScN

A Project Submitted in Partial Fulfillment of the

Requirements for the Degree of

MASTER OF NURSING

In the School of Nursing

University of Victoria

Faculty of Human and Social Development

## Table of Contents

Title page	1
Contents	2
List of Figures	3
List of Tables	4
Abstract	5
Introduction	6
Literature Review Process	8
Theoretical Framework	9
The Data Evaluation Steps	11
Who Works in Long-Term Care?	24
Understanding the Family Perspective	28
Recommendations for Improving Staff-Family Relationships	30
Ethical Implications for Nursing	37
Conclusion	38
References	39

List of Figures

Figure 1. Critical Map for Research Analysis

12

List of Tables

Table 1. Literature Reviewed

14

Supervisory Committee

Dr. Joan MacNeil, Supervisor

Dr. Debra Sheets, Committee Member

### Abstract

Long-term care in Canada has evolved through legislative change to allow and encourage both family and resident involvement in care. Care has become more resident-centered. Nonetheless, families often feel that they have little involvement or voice in the care provided to their loved ones. In this paper, I review the literature on the topic of family/staff relationships in the long-term care setting. The focus is on peer-reviewed studies, with both research studies and practice driven articles published in nursing journals considered. The review is limited to the years 2000 to 2012. research studies and practice-driven articles identified on CINAHL, Google Scholar, and Medline. My aim is to identify the main difficulties in the staff-family relationship in long-term care that have been addressed in the research. The literature review is supplemented with reflections grounded in my experience as a nursing administrator in long-term care. I conclude with recommendations for the changes needed to engage families more productively in long-term care by strengthening the staff-family relationship, which can enhance residents' care and quality of life.

**Key Words:** Long-Term care, continuing care, nursing homes, and family/staff relationship.

## Introduction

Changes are occurring in the culture of the long-term care area and the care relationship between residents and their families with nursing staff. The days are gone when older adults and their families had no choices concerning the options available for long-term care and the nature of care in those various settings. Today, older adults can age in place with support from home care and private home support, or they may choose from a continuum of supportive housing options that include lodges and retirement communities. According to a report published in 2012 by the Canadian Institute of Health Information (CIHI), there has been a decline in the number of Canadian seniors seeking institutionalized care. Between 1981 to 2006 the percentage of those age 75 and older who were living in a care facility declined from 17 percent to 12 percent (CIHI, 2012). Seniors are living longer, and those who end up in long-term care have more complex disease profiles. Long-term care residents are increasingly frail and have chronic health care needs that require around-the-clock professional nursing care.

The continuing growth of the aging segment of the Canadian population is well-documented. Older Canadians are the fastest growing subgroup of the population. The number of Canadians over the age of 65 is projected to increase from four million to almost ten million by 2036 (Statistics Canada, 2011). And the number of oldest old, those age 85 and older, is growing even faster. Currently there are 196,000 Canadians age 85 and older, and this age group will increase to nearly 800,000 by 2036 (Statistics Canada, 2011).

According to a 2005 Statistics Canada Report, there were 250,387 residents living in care facility throughout Canada in the year 2008-2009. Population aging and consumer advocacy have contributed to a growing emphasis for person-centered or person-directed care in institutional settings. The focus of person-centered care is on individualized care that maximizes

autonomy and choices, including control over resident's care environment. A core principle of person-centered care is family involvement (Boise & White, 2004; Crandall, White, Schuldheis, & Talerico, 2007; & Koren, 2010). Including family members in the care process and decision-making, particularly in long-term care, is essential to providing individualized care for many older adults. The family is a critical source of information. The family is also an integral part of the resident's social network and can advocate for the needs and preferences of the resident (Boise, & White, 2004).

Traditionally, family members have been viewed as bystanders rather than as partners-in-care. Until the early 1990s, the medical model was the dominant philosophy in long-term term care. The medical model is staff-centered and task-focused. In the medical model, the goal of care is determined by the nursing staff, consulting physicians, and the facility administrators, with little input from the resident or the resident's family. The primary goals are to treat the individual's disease or disability and to meet the basic needs of his or her activities of daily living (Calkins & Bush, 2009). The person-centred care movement to broaden care and to include the input of the family and resident has brought some tension for staff accustomed to following the medical model. While the person-centered care philosophy has been accepted in long-term care in Canada for over a decade, its application has been uneven or erratic, impeded by various systemic limitations. Its application has been fraught with anxiety and confusion for staff and families. Hertzberg & Ekman (2000) identified 3 main areas of staff/family misunderstanding: family members having an influence over and participating in the resident's care; role uncertainty; and communication difficulty. Later studies (Berman et al., 2009, Austin et al., 2009;& Bramble et al., 2009) confirm that these three main areas remain constant sources of irritation.

In providing person-centered care, it is important to understand the relationship between the care providers and the resident's family. The circumstances of the resident and his or her family when the resident is admitted to long-term care are influenced by many factors. Many older Canadians stay in their homes for as long as possible with home care services. This means that when they are assessed as requiring long-term care and it is no longer possible to remain in their homes, the older adults' needs are often complex. The senior is often dependent with advanced disease processes, such as dementia.

Research on the topic of the staff/family relationship in long-term care is limited (Hertzberg 2000, 2003; Bauer 2006; Tisher et al., 2009, Austin et al., 2009; & Bramble et al., 2009). Insufficient attention has been paid to this topic by nursing researchers; the earliest research on the topic emerged in the late 1980s and there have been fewer than 25 articles since 1986 (Hertzberg, 2000). A research-informed nursing dialogue regarding how to establish a collaborative and interdependent staff/family relationship in long-term care is overdue.

### **Literature Review Process**

This literature review examines primarily qualitative nursing research studies that examine the relationship between nursing staff and the families of long-term care residents, although two quantitative studies were also included in this review. The first aim of this project is to understand the nature of the existing staff-family relationship in long-term care. The second aim is to inform efforts to improve that relationship and enhance quality of life and care of the residents. It is essential, therefore, that the identified research focuses on the human experience and on understanding the emotional dimensions of long-term care. Although both quantitative and qualitative studies were examined; the qualitative method proved most useful and relevant to



this review which focuses on the emotional and the various perceptions of the staff-family relationship in long-term care (Vishnevsky & Beanlands, 2004; Higginbottom, 2009).

In this literature review, the search for the core concept of the staff-family relationship in long-term care was limited to peer-reviewed articles published between 2000-2012 that are available in CINAHL, Google Scholar, and Medline. Cooper (1998) emphasizes the importance of remaining open-minded and using a reasonably broad conceptual definition at this stage. In order to identify as many studies as possible, I used multiple search terms within the carefully delimited area of long-term care: nurse-family relationship, staff-family relationship, family involvement in care, staff family conflict, nurse-family conflict, and family experience of placing a loved one in long-term care. My inclusion criteria were nursing research articles that explore the relationship between residents' family and staff in an institutional setting (i.e. long-term care). I excluded any articles that addressed pediatric clients or developmentally delayed adults living in an institutional setting.

Thirteen qualitative studies, two quantitative articles, and one mixed-method research analysis were identified in the search. Although my initial focus was on qualitative studies in the area, I decided to examine the two quantitative studies as well. Due to the limited research study on the topic, it is important to examine all of the available studies including quantitative studies. I also used a number of practice-focused articles that outline how to include families in care or how to create family-centered care.

### **Theoretical Framework**

Articles were analyzed using a concept map and grouped into two categories of nursing theories: Caring and Feminist. None of the articles explicitly states its theoretical framework, but the analysis suggests that grounded theory was being applied to develop mid-range theory. Originally formulated by Glaser and Anselm in 1967, grounded theory is defined by Munhall

(2011) as a research approach that demands theoretical analysis of the factual aspects of the domain of study. Grounded theory is inductive, moving from the facts toward a theoretical deduction that has some analytical complexity, identifying the relationships between key theoretical concepts (Munhall, 2011, p. 226). The Caring and Feminist perspectives were particularly prominent. For example, Ward-Griffin and McKeever (2000) use a social-feminist approach to examine the relationship between the formal (staff) and informal (family) caregivers, who are predominantly female. Ward-Griffin & McKeever found that the relationship between these two groups of caregivers involves substantive power struggles and is highly exploitive. This study focuses on families caring at home for either a dying loved one or a loved-one who required around-the-clock care. The findings of the study were supported by later studies conducted in institutional settings (Hertzberg 2000, 2003; Bauer 2006; Berman et al., 2009; Austin et al., 2009; & Bramble et al., 2009). Ward-Griffin and McKeever conclude that the staff-family relationships are more strained in the community than in a facility setting. In the community, staff did not recognize family knowledge and efforts; did not advocate for the family, and, as in the institutional setting, took over the care of the client without involving the family in care. This approach often jeopardized staff-family trust and resulted in a strained relationship (Ward-Griffin, 2000). When it comes to elder care, clearly there is a care deficiency in recognizing the role of the family, regardless of setting.

Most of the nursing articles used a Theory of Caring to underpin their research (Hertzberg 2000, 2003; Bauer, 2006; Bluestein & Latham, 2007; & Gaugher, 2005; Boise & White, 2004; Crandall, White, Schuldheis, 2007; & Koren, 2010). Although the concept of caring has been a foundation of nursing, it was not significantly explored until postmodern nursing dialogue. Liu (2004) details the introduction of the caring concept by Carper in the

1970s. Liu explains Carper's normalization of "caring" as an important concept in nursing. As Liu explains, Carper first defined the eight main components of caring: knowledge, alternating rhythms, patience, honesty, trust, humility, hope, and courage (Liu, 2004, p. 143). Carper's work on caring was followed by Jean Watson's Theory of Caring. The fundamental building block of Watson's Theory of Caring is the principle that nurses must develop the ability to detect or sense the condition of the patient; then, they can respond to it appropriately. While Watson's original work was specific to the nurse-patient relationship, the caring relationship has since been expanded to include the patient-support/caregiver roles, such as those we encounter in the families of residents in long-term care (Capik, 1997).

### **The Data Evaluation Steps**

This project reviews the nursing literature staff-family relationship in long-term care to develop a framework for collaborative partnership between the resident's family and staff in long-term care. Ryan et al. provide a comprehensive process for the analysis of nursing research articles. A framework for critiquing nursing research was adapted from Ryan, Coughlan & Cronin (2007) and used to evaluate each study in an in-depth manner (see Figure 1).

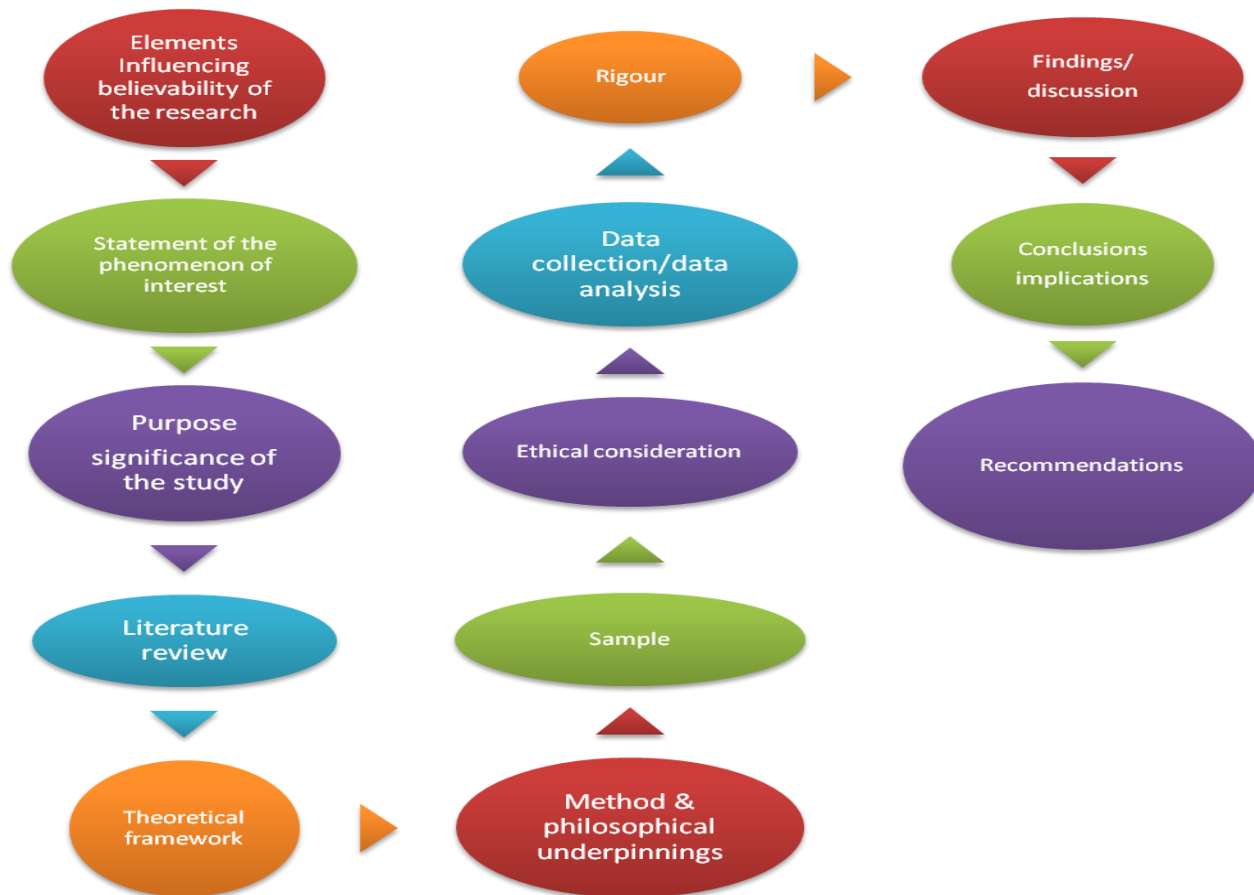


Figure 1. Critical Map for Research Analysis

Each article was evaluated for the element of believability as coined by Ryan et al (2007). According to these authors, several elements influence the believability of the research. These include writing style, structure, and minimization of jargon. Style is also closely linked to argument structure, logic, and consistency. While the articles are written for nurses and hence use the accepted terminology of health care practice, they are jargon-free and easy to understand. Though none of the articles explicitly declares its theoretical underpinning, 90% of the articles have clearly outlined the aim, design, method, result, and conclusion of the study. Another category of believability of research is the researcher's qualifications. The academic and professional qualifications of the researcher(s) are of utmost importance, as are the skills demonstrated in presenting the study (p. 738). In each of the articles, the researchers were

masters or doctoral students and published academics. Further, the articles used in the study were also examined for what Ryan et al. (2007) call *elements influencing robustness of the research*. These elements determine the integrity of the research study and thus its reliability. These include a clearly stated research question, literature search, theoretical framework, method, data collection, rigor, and ethical considerations. Once the relevant articles were selected and approved for soundness and robustness as outlined by Ryan et al. (2007), they were analyzed for their thematic content and for their particular recommendations for practice shifts on the topic of the staff-family relationship in long-term care.

Table 1. Literature Reviewed

Author & Year	Purpose	Sampling	Method	Findings	Limitations	
1.	Austin et al, (2009).	To examine the relationships between families of residents of traditional continuing care facilities and the health care team.	Participatory action research. 3-focus groups of 3-12 participants (groups: family, staff & administrators). Staff with at least 6-months of employment & family with relative in LTC for at least 3months.	Three focus groups were audio-taped for a period of 6-months. Tapes were then transcribed	LTC residents are getting more complex & frail. LTC funding is poor= poor staffing levels. Families have high expectations that do not match resources in LTC. LTC culture needs change to engage families in partnership.	Small sample Too much focus on funding Did not compare private LTC to public.
2.	Bauer (2006)..	How nursing home staff experience their work with residents' families in LTC.	Naturalistic paradigm: Data were collected from 30 nursing home staff members drawn from a range of metropolitan and rural facilities in Victoria, Australia	Non-randomized - 39 RNs & Nursing assistants were selected for an in-depth interview of 60-90 minutes long over 12 months. Interviews were autotyped & transcribed.	Attitudes about families as adversarial continue. Staff recognized the family struggle with the transition to LTC. Evidence for family friendly practices.	Focus on staff & their view of the family.
3.	Bramble et al.(2009).	The purpose of the study was to outline the experiences of family caregivers in Brisbane, Australia who have placed a relative with dementia into long-term care.	Descriptive qualitative approach.10 participants who were representative of 57 family members	Semi-structured interviews of one-hour were conducted and transcribed.	By the time a loved-one was admitted into LTC,-the family caregivers were exhausted. Family felt guilt & apprehension about the placement. Families wanted to develop close relationship with staff.	Small sample. Australian LTC system— applicability question.
4.	Daly et al.(2001)..	To understand how workers in long-term care facilities experienced	Mixed-methods  Quantitative closed-ended survey responses	Survey was sent to different nursing homes  917 surveys	Higher levels of violence against staff were found in Canadian LTC.	Limited literature review.

		working conditions	with structured qualitative open-ended focus group responses. Researchers conducted the survey, followed the focus groups, and then completed an integrated analysis.  2,322 workers were randomly targeted from 18 LTC in Ontario.	were returned from the 2,322 surveyed and analyzed.	Staff –resident ratios were found to be higher in Canadian LTC compared to similar European studies.	
5.	Gaughler (2005).	Examined whether visiting and the provision of care have effects on the emotional stress and psychological well-being of family members who have a relative in LTC.	Data were derived from the Caregiver Stress and Coping Study (CSCS; Aneshensel et al., 1995). Sample of 550 individuals were interviewed.	Analysis of 4-year study With yearly interviews published in 1995.	Finding suggests that family involvement following institutionalization may operate differently than when in the community: Family involvement was not related to care needs of the resident. No significant relationship was determined between the level of guilt & level of family involvement.	Examination of older study with a different goal/aim. Findings are too general
6.	Hertzberg et al. (2000).	This study describes family-staff relationships in LTC & how these relationships may impact the care of residents with dementia in LTC.	The researcher's role as a silent non-participant observer as relationship & caregiver Three groups of 5 members each-made of frontline staff (both professional & para-professional), & family. Individuals who are currently working in LTC & those who have family; those who	Focus group discussions: Each group met 6 times total of 18 meetings each 90 minutes long.	Families were more open in talking about their experience, but staff more restrained. Key complaint by family: their opinions about the care were not taken seriously. Key complaint by staff: Families were too interfering.	Dated study. Though the findings are still relevant, all of the participants were professional staff; whereas in the current LTC, the majority of staff non- or para-professional.

			knew each other or had worked together were excluded.			
7.	Hertzberg et al.(2001).	How does family involvement in care giving change post LTC admission of a loved one?	Qualitative content analysis. 28 individuals who have a family member living in a nursing home. Samples from three nursing homes. Willing participants in the selected 3-nursing homes.	60-90 minute Interviews that were taped & transcribed	Families felt that their presence and insistence were the key to ensure “good” care for their loved one. Staff approach to family was often the source of conflict. Key finding was communication barrier between staff-family.	Dated study. Small sample group No control group. Interview questions could have been persuasive.
8.	Hertzberg et al.(2003).	To explore and describe RNs’ views and experiences of relatives of residents who live in nursing homes.	Qualitative, explorative, descriptive design. 19 RNs at three nursing homes Three not-for-profit nursing homes were selected and RNs were invited to participate.	Open interviews were conducted and transcribed.	The RNs acknowledged & understood the importance of family involvement in care. They wished they had more time for the family. They felt that families were often too demanding and had unrealistic expectations. The need to help each other understand has been identified.	Majority of the staff in LTC are not RNs, but the study focused on RNs.
9.	Majerovitz et al. (2009).	Understanding barriers to good communication associated with both nursing homes and family caregivers	Qualitative analysis of interview and survey responses Participants were recruited from 26 nursing homes in the New York City metropolitan area: 103 caregivers were selected.	Questionnaires followed by one-hour long structured interview.	Major communications barriers exist between families-staff: including staff turnover, inadequate training, policies based on a medical model, rigid routines, poor staff communication, and work schedules that do not coincide with family visits.	A number of interpretations can be drawn from the data. It is not clear whether the nursing homes were all similar socio-economically.



10.	Paulus, et al.(2005).	To investigate the relationships between informal and formal care givers.	The quasi-experimental design. Two LTC sites with total beds of 262 were selected.	Staff and family were asked to document shared care for a period of six months. Forms were developed for each group	Informal caregivers did play an important role in residential settings.	Approach was specific to the setting. Findings may have been influenced by the method used.
11.	Perry et al. (2010).	The aim of this study was to explore the presence of compassion fatigue in family members who assist staff with care of older relatives in long-term settings.	Interpretative research approach. Narrative data were collected from five families from units of a large facility in urban Canadian setting. Only families of the above center were included.	observation and conversational design to gather narrative data	Two major themes emerged: role engulfment and enveloping sadness about the loved one's loss of function & capacity.  Implication for practice-nurses to educate families re: potential for compassion fatigue.	Limited sample which limits generalization of the study. The principal investigator was the primary instrument of data collection and analysis, making bias likely.
12.	Schultz et al. (2004).	To assess the impact of placing a loved one in LTC.	1222 caregiver-patient dyads were randomly selected from 6 US states.	Standardized survey instruments and several open-ended questions were administered during the admission of 185 residents-for a period of 18 months.	Caregivers who placed a loved one in care had showed no change in the anxiety/depression scale. Functional decline of residents post admission to LTC may contribute to how family members feel about the placement.	Not clear if caregiver's mental health is due to the care giving. No follow up was done to indicate continuation or decline of the mental health concerns identified among the caregivers.
13.	Specht et al. (2000).	To provide an overview of family involvement in care intervention of African American and Caucasian family members of persons with dementia in nursing home settings.	20 Nursing homes in three states were examined for their use of Family Involvement in Care Protocol Total of 42 families & 80 staffers were selected.(FIC). Inc/Exc. Criteria: Three subject groups were enrolled in the study at each site:	A repeated measures, quasi-experimental Design. Questionnaires, interviews, and record reviews. Quantitative and qualitative approaches were used.	Staff & family education about the disease process, each other's roles, and how working together is the key to success in care-partnership in LTC. Facilities must establish a formal system to address staff-family partnership in care.	Research only looked at those with advanced dementia.

			residents with advanced dementia, family members of the residents, & nursing home staff providing direct care to residents.			
14.	Ward-Griffin (2000).	Examining care required for individuals that are LTC level care, but are at home due to limited funding in LTC & how that family experience impacts staff-family relationship post LTC admission.	A critical ethnographic approach. Was used. Inc/Exc. Criteria: Families living in urban area who are caring for LTC level care family-member & their relationship with the Home Care nurses.	23 family-nurse dyads. In-depth focused interviewing Approach. 38 interviews audio-taped, each interview was 75 minutes in length.	Nurse-Family relationships are complex & it went through four-different stages: <ul style="list-style-type: none"> <li>• Nurse-helper</li> <li>• worker-worker</li> <li>• manager-worker</li> <li>• nurse-patient</li> </ul> Study found that they were too unstable & potentially exploitive; thus not conducive to partnership. Findings challenge nature of therapeutic nurse-patient relationship.	Study did not acknowledge or explore what impact the home setting had on the relationship. And while the findings are useful in understanding some of the experiences families are coming with as their loved one is admitted into LTC, it is not 100% applicable to institutional setting  All of the nurses in the study were RN & most Canadian born.
15.	Weman et al. (2004).	Examined the RNs' view of family-staff relationship in LTC.	Qualitative-Content analysis 210 RNs on work with elderly in the community or in LTC. Inc/Exc. Criteria: Geographical designed area (South Sweden).	Questionnaire made of six questions measured by the Likert scale.	Nurses were overall dissatisfied with the family-nurse relationship. Need for education and research was identified.	Limited to a part of Sweden. Population is homogenous & duplication is questionable.

16.	Wilson et al. (2009).	The goal was to explore how relationships in care homes influence the experience of older People, their families and staff.	Data were collected over two years between 2003–2005 across three care homes in England- using participant observation, interviews with residents, families and staff and focus groups	Constructivist approach to explore relationships in care homes from the perspective of residents, families, and staff.	Staff & family developed a collaborative approach to working together.	The solutions are specific to the setting and applicability to other settings is questionable.
-----	-----------------------	---	--	--	--	--

Though there are numerous descriptive publications on how to improve the residents' family and staff relationship in long-term care, there are limited scientific studies published on the topic; thus my decision to evaluate articles published as early as 2000. Hertzberg and Ekman (2000) from Sweden conducted one of the earliest and most referenced qualitative studies on the family/staff relationship in long-term care. The aim of their study was to identify key interactions, communications, and experiences that could promote or obstruct staff/family relationships in long-term care. Hertzberg and Ekman found that the core of the conflict was located in four key elements. The first element was the families' wishes for increased influence over and participation in the care of the residents. The second element was the families' uncertainty about the staff's ability to provide the care needed, which produced distrust and questions about competency. The third element was difficulty in communication, involving a range of issues such as the failure to have scheduled meetings. The fourth element was the families' impressions that staff members were distant and did not relate to families on a human level. Hertzberg and Ekman concluded that the source of the problem from the families'

perspectives was insufficient or superficial communication. Families were not asked to provide feedback. Families were not invited or encouraged to participate in care. The staff did not create opportunities to connect with families on a human level (small talk). Staff openly admitted to a lack of knowledge about the residents' preferences and history. From the staff perspective, poor communication on behalf of families was the crux of the conflicts. Families were suspicious of staff but never asked questions to confirm or deny their suspicions. Families interfered with care without knowledge of its goals and methods. Families failed to appreciate the knowledge and professionalism of the staff.

In 2000, Specht, Kelley, Maas, Reed, & Rantz (2000) in the U.S. published one of the few quantitative studies on the subject of the staff-family relationship in long-term care. This quasi-experimental study on family involvement in long-term care examined 20 nursing homes in three states. Even though the study was quantitative and thus quite different in method, its conclusion was nearly identical to that of Hertzberg and Ekman (2000). Specht et al. (2000) concluded that in most cases, the level/type of family involvement was determined by the policies of the facility. The level/type of family involvement in care was not determined by the family's interest, skill, or ability. For example, some of the family members in the study wanted to get involved by volunteering in the facility at large, but they were prevented from it and asked to focus solely on doing limited duties for their loved ones (Specht et al. 2000). Legislative stipulations such as privacy law and union contractual relationships can impose strict limitations on what families can do at a care facility.

In my own professional practice, I have witnessed these limitations. For example, in Alberta, Canada, the continuing care (long-term care) standard for showers is once a week; therefore, most operators offer baths/showers only once per week (Government of Alberta,

2008). Many families object to this and see it as inadequate care; as a result, family members offer to provide the shower to their loved one. Administrators, fearing liability and union backlash, often do not allow families to provide this care. In fact, families can be safely trained to use equipment and can be required to sign a waiver for liability. In some cases, staff supervision can be easily provided, as staff would normally be present to provide the service. Instead, facility operators refuse to entertain this type of collaborative care. As a result, families are forced to hire “added support” in order to give their loved one the type of care they feel is appropriate. If they cannot hire “added support”, families are forced to accept the status quo (one shower per week). Specht et al. found similar conflicts over what families felt should have been provided by the caregivers. In the 20 American nursing homes studied, Specht et al. concluded that administrators needed to create a culture that allowed/promoted family involvement early. This would involve allocating agency resources to educate staff and to allow staff time to work with families. It would also allow some necessary legal protections for the institutions and some rewards for staff collaboration with families in providing improved care (Specht et al., 2000, p.73).

Taking into account the staff perspective is also helpful in understanding and remedying this important relationship. Weman, Kihlgren, & Fagerberg (2004) conducted a qualitative study which surveyed 210 Registered Nurses working in communities and nursing homes. They concluded that an overwhelming number of the nurses understood the importance of family involvement. The results showed that almost half of the nurses felt dissatisfied with their relationship with the families, but these same nurses felt that it was unlikely that their professional care relationships with patients’ families would improve. As reasons for this inertia, they cited the systemic or institutional barriers of limited available resources or the care culture,

plus the cultural reality of unrealistic family expectations. All of the nurses in the study affirmed the importance of co-operation between themselves and the family members. They also advised the development of communication and care models that could improve staff/family co-operation. Again, this quantitative study, like the one conducted four-years earlier by Specht et al. (2000), concluded that open communication and collaborative relationships between families and staff positively impacts residents' care as well as staff satisfaction.

Bauer (2006) examines the early phase of care, in the short period immediately after a loved-one has been placed in a long-term care facility. Bauer discovered that this transitional phase is one of heightened uncertainty and stress for family members. In turn, this uncertainty and stress often characterize the later stages of the relationships between families and staff. Bauer notes that understanding the transition phase is a key to preventing the conflict and laying the foundation for care partnerships between the family and the staff in long-term care. The careful and deliberate building of a positive staff/family relationship is also the focus of a study conducted by Wilson & Davies (2009). Their goal was to examine how family-staff relationships develop in long-term care. They discovered that families based their opinions of the staff on how the staff approached care. As Bauer (2006) and Wilson and Davies (2009) found, opinions are formed early in the relationship during the transitional phase, shortly after placement of the resident in long-term care. These studies concurred that "the first impression" is very important for families who are often anxious about whether their loved ones will be cared for adequately in their new homes. In their qualitative research on the Australian family experience after long-term care placement, Bramble, Moyle & McAllister (2009) emphasized the importance of the post-admission phase with regard to the staff/family relationship. These authors examined the experiences of families after a loved one had been admitted to long-term care. They discovered

that, before admission, families often care for their elderly loved ones in a number of ways. Adult children provide instrumental aids to daily living (IADL) such as shopping and laundry. A spouse assists his or her partner with daily living activities such as toileting, grooming, dressing, and eating. Often, by the time an elderly relative is admitted into long-term care, the family has been providing care for some time. Family members are anxious and concerned about whether their loved one will get the care he or she requires and deserves. Bramble et al. point out that none of the respondents felt ready for the transition to institutional care. As a result, they experienced stress, grief, and trauma during the transition” (Bramble et al. 2009, p.3121).

Research by Paulus, Raak & Keijzer, (2005) showed that though informal and undocumented, families still provide a considerable amount of care for loved ones who are institutionalized. Therefore, it is not surprising that they may be inclined to monitor closely the staff’s approach to the care of their loved ones—searching for individualization and knowledge of the individual’s preferences and history. Understanding what families may be going through and implementing strategies to support them during this anxious transition phase can be crucial to developing positive staff/family relationships in long-term care.

Austin, Goble, Strang, Mitchell, Thompson, Lantz, Balt, Lemermeyer, & Vass (2009) examine the topic of the staff/family relationship from a Canadian perspective. In their participatory action research, they examine the source of staff-family conflict from the triple perspective of staff, family, and system resources. They confirm that the conflict is rooted in the early transitional phase, when boundaries of trust, care expertise, and mutual respect are being established between staff and families (Hertzberg & Ekman, 2000; Specht et al., 2000; Wilson & Davies (2009; & Bauer, 2006). Austin et al. perceive the problem through the lens of the Alberta provincial experience in the age of budget cutbacks and skill-mix changes in long-term care.

Austin et al. recommend a three-level approach. They advise changes at the facility level, the organizational level, and the sector level in order to foster more collaborative and supportive partnerships with families of long-term care residents. For example, at the facility level, they recommend that families get a facility orientation; that families be invited to staff meetings; and that staff provide families with in-services and educational workshops on topics such as dementia (Austin et al., p. 378, 2009).

### **Who Works in Long-Term Care?**

In reviewing the literature, it is clear that there is a gap between family expectations and the available resources in long-term care (Austin et al., 2009). This finding is evident in my own professional experience. The long-term care sector is becoming more diversified and streamlined into different care levels/needs. The many layers of care include assisted living, which focuses on seniors who are more medically stable and require lighter care. At the same time, the long-term care facilities are accepting more complicated residents who require extensive personal care and who are also medically complex. Yet, staffing patterns do not necessarily reflect this shift to a higher level of acuity in the care needs of the current long-term care population; For example, in their mixed method study, Daly, Albert, Armstrong, Armstrong, and Szebehely (2011) found that 80% of Canadian long-term care facilities have high-staff-resident ratios. This is true for all types of staff, but it is particularly concerning in relation to nursing staff of all levels. Registered Nurses [RNs], Licensed Practical Nurses [LPNs], and Health Care Aids [HCAs] often leave important parts of the care undone. For example, in Ontario, long-term care residents receive an average of 2.86 hours of nursing and personal care per day (RNAO, p. 6, 2007). It is similar in Alberta, where the staffing levels depend on the shift, while long-term care facilities have limited staffing at all levels. Day shifts have a better RN-resident ratio. The RN-resident ratio in my own



organization, which is typical, is one RN per 30 residents for day shift and one RN per 120 or more residents for evening and night shifts. Similar ratios exist for LPNs and HCAs.

Specifically, the typical ratio for long-term care facilities in Alberta is one-LPN for 25-65 residents; and one-HCA for 6-10 residents on day shift. Due to inadequate funding, all staffing levels are generally poor in long-term care (Austin et al, 2009). The low staffing levels are often a key source of conflict between staff and residents' families. A Canadian survey found that being short-staffed leads to staff leaving undone basic tasks such as oral care, which precipitates families' vigilance and doubt about the care their loved ones are receiving (Daly et al., 2011).

Bauer's (2006) findings were similar to those of Hertzberg (2000, 2003). For staff, the most common complaint was families demanding unrealistic one-on-one care. Also, staff felt that some families did not appreciate them and did not recognize the efforts they made to provide quality care for their loved ones. The family members' concerns were related to unsympathetic staff attitudes; as a result, the relationship became adversarial very quickly. Families found a routine approach to the care of their loved one to be disappointing and inadequate. Families also reported frustration about not getting adequate information from staff about the routine care and treatment interventions. Instead, they hoped for and expected an individualized or personalized approach. In the unfamiliar environment of the nursing home, some families struggle to fit in and to relinquish the control that they once had in caring for their loved-one. Bauer advises that the solution includes recognition of the frustrations on both sides of the staff-family relationship; as well, administrators must establish a care plan that includes rather than excludes family (p.48).

In order to understand staff/family relationships in long-term care, it is important to understand the common staffing pattern in this sector. Berta, Laporte, Zarnett, Valdmanis, & Anderson, (2006) examined the staffing type and levels for institutional long-term care in

Canada. They acknowledge variations between regions and between for-profit versus not-for-profit long-term care centers. They report that, notwithstanding variations, most Canadian long-term care centers depend exclusively on health care aides (HCAs) to provide almost all direct care to residents. This work is done primarily by immigrant women; it is physically demanding, stressful, and low paying. Although a Registered Nurse (RN) may be available, residents receive a minimum of the RN's time. Even as older adults in long-term care have become increasingly frail and with complex medical needs, the number of RNs available is severely limited.

Very little has changed in Canadian long-term care since this study in 2006. Most provinces and territories have now completed or initiated a basic training requirement for HCAs. For example, to work in a long-term care facility in Alberta, HCAs must have a 6-month certificate and be included in a provincial database. The number of professional staff such as RNs in long-term care centers remains extremely low. Since HCAs are overwhelmingly immigrant women, they experience deep cultural and social gaps in their dealings with the families of residents. These gaps are often the sources of family concerns. Many of these immigrant women are learning the English language, customer service, and workplace culture and behavior. In addition to these personal challenges, they are expected to provide appropriate care for seniors in a culture very different from their own. At the same time, they are burdened with the additional responsibility of responding in some way to family concerns and engaging families in the care of their loved ones (Reinhard-Priester & Reinardy, 2003). The success or failure of person-centered care in their facilities is placed largely on their overburdened shoulders. Browne & Braun (2008) recognized the changing demographics of the long-term care worker in the U.S. These authors acknowledge that fewer and fewer American-born workers are choosing to work in long-term care, which is known for heavy workload and low pay. Therefore,

new immigrants (1-5 years) are filling the gap. As a hiring manager, I see the same pattern in Alberta. We recently opened a new program in one of the largest continuing care facilities in western Canada (a 500-bed facility), and we had only 3-Canadian born staff apply for 65 LPN and HCA positions.

Browne & Braun emphasize two important areas that require special attention in training the health-care aid staff: language training and cultural competencies. Without cultural competency training, there will remain major gaps in how these health care aid workers engage with and relate to families. The majority of residents in long-term care are Caucasians of European descent. Because of their cultural and linguistic differences from the residents and families they serve, the frontline workers may feel intimidated and be reluctant to engage Caucasian families in dialogue. Lack of proficiency in the English language leads them to avoid family interactions. The same reluctance may well be felt, because of the same linguistic and cultural barriers, on the part of the Caucasian families. The health care aid workers are unable to report to families on the condition or the changed care needs of their loved ones. These workers are intimidated by family members and are not able to engage families by addressing their concerns or questions across large linguistic and cultural barriers.

Hurtado, Sabbath, Ertel, Buxton, & Berknab (2010) examined the long-term care sector as an occupational setting. This study confirmed earlier findings by Browne et al. (2008) that long-term care facilities pay low salaries and that they often attract workers from socio-economically disadvantaged populations, who are often immigrants. This study concludes that minority and immigrant workers in nursing/long-term care are paid low wages for extremely heavy workloads. Because of these circumstances, health-care aids are also more likely to get

injured on the job. Often, they do not know how to advocate for themselves or to address concerns with supervisors.

For the personal support worker to engage families and be able to build a collaborative relationship, there needs to be a level of cultural comfort, workplace comfort, proficiency with the primary language, and overall confidence. In order to explain clearly the care needs of the resident and to respond accurately and helpfully to the concerns or questions of residents' families, the health care aid needs to be supported and empowered. But the literature attests that, in this sector of care, immigrant personal support workers report more marginality and job strain than their Caucasian counterparts. This is not the case for the better-educated professional staff in the same field such as Registered Nurses and Licensed Practical Nurses (Hurtado et al., 2010, p. 241).

### **Understanding the Family Perspective**

There is widespread evidence in research about the importance of family involvement for the residents in long-term care (Bauer, 2006; Bluestein, 2007; & Perry, 2010). Families provide emotional support for their loved ones and are also a crucial source of information in assisting the staff to understand the resident's present condition in the context of his/her history. This is particularly vital for residents who have dementia. Boise et al. (2004) outline how a family's involvement is the foundation of person-centered care. The family is a source of information, an advocate for the resident, a much-needed social network, and a link to the resident's community. This is confirmed by studies in various countries. The articles used in this project were published in Sweden, Finland, England, Australia, the United States of America, and Canada. All of the studies, both the qualitative and the quantitative, though published on three different continents,

arrive at similar conclusions about the nature of the staff-family relationship in long-term care and the problems besetting it.

An important first step in building mutual respect and engagement is beginning with the understanding that families are going through a difficult life stage when they place a loved one in care. For many families, their loved one's admission is seen as the end of family care-giving and the beginning of institutionalization, which is associated with a diminishment of their loved one's independence, agency, and identity. In reality, it is not the end of family care-giving or a loss of agency but rather the beginning of a different role for the family and a different lifestyle for the new resident. Naturally, this discrepancy between assumption and reality can elicit strong mixed feelings on both sides. Schulz et al. (2004) studied the impact of placing a relative in long term care. These researchers studied 1, 222 caregiver-patient dyads recruited from six U.S. sites. Their findings were surprising even to the researchers themselves. They found that a large number of the relatives who placed their loved ones in care experienced guilt, anxiety, and depression. Astonishingly, a large number of family participants reported residual feelings of the same kind. Guilt was expressed through over-involvement in the care of their loved one and being overly critical of the facility staff and how they provided care. Schultz and colleagues recommended that acknowledging these feelings could assist long-term care operators to better support families, especially in the transitional phase shortly after a loved one has been admitted into long-term care.

Gaugler (2005) also found that by the time elderly family members are placed in care, family caregivers have often experienced some if not all of the emotional, psychological, physical, and financial impacts of being care providers. The family is assisted in adjusting to the institutionalization of their elderly loved one by remaining involved after admission. Gaugler

stresses the importance of the staff and administrators understanding the stresses families go through in caring for their elderly loved ones. Gaugler advises that encouraging continual family involvement in care may eliminate potential guilt and can foster a closer relationship between family and staff (p.74). Bringing these best practices into reality, however, requires a systemic change in long-term care.

### **Recommendations for Improving the Staff-Family Relationship**

In long-term care, not unlike other health care environments, both a high quality of care and a positive clinical outcome are paramount. To achieve both of these outcomes, strong and competent nursing leadership is imperative. While the hands-on care in long-term care is provided by health care aids and licensed practical nurses, registered nurses are the team leads and managers. Yet RNs receive little training in leading a team of health care aids. Few nursing programs prepare graduates to delegate or supervise paraprofessional staff (Harvath, Swafford, Smith, Miller, Volpin, Sexson, White, & Young, 2008, p. 188). Harvath et al. found that nursing leaders in long-term care are often placed in complex multi-layer leadership roles that require an advanced level of training and education. While nurse leaders are important in the operational and business aspect of the health care system, they are most important in providing clinical leadership. Advanced Practice Leaders (APLs) are experts in their respective domains. They are engaged in activities that extend beyond the narrow use of technical procedures. APL nursing practice involves the sophisticated in-the-moment use of knowledge and skills (Daly & Carnwell, 2003, p.163).

APL nurses in long-term care could enact changes in the staff-family relationship in long-term care. APLs are capable of bringing about a shift in philosophy, in workplace culture, and in the policies of the organization. APL nurses can shift the culture by providing the education

needed for staff and families. Staff members need to learn about family engagement and customer service. Families can be supported to become familiar with policies and legislation that govern care in long-term care. For example, at the facility in which I work, families will often develop a close relationship with their loved one's roommate or neighbor on the unit. Families would often ask health-related questions about the roommate's health or cause of death. When staff state that they can not give health information due to Freedom of Information and Protection of Privacy (FOIP), some families have difficulty understanding this type of institutional policy. With the proper orientation, APLs can familiarize families with such laws and practices. Studies have shown that APL nurses influence both staff and organizational culture in the areas of practice and patient/residence satisfaction (Daly & Carnwell, 2003; Capezuti, Taylor, Brown, Strothers, & Ouslander, 2007). Specht et al. (2000) conclude that in order for families to be true partners in care, action is needed from administrators and nurse leaders. These leaders need to remove environmental and institutional barriers that hinder family involvement in care. Such barriers might be lack of privacy for family members to visit, limited access to supplies for provision of care, no consistent nurse for family members to contact, and policies that hinder family involvement (Specht et al., 2000, p. 74).

Concrete actions are needed to shift the philosophy and the culture of long-term care away from a focus on safety, standardized care, and medical issues. These actions are needed to accomplish not only an institutional shift but also a legislative and political shift. Institutions have to find a way to establish partnerships with families in order to provide a higher quality of care for the resident. For example, it could become a priority to have honest and open dialogue with residents and families about their wishes, tolerance for risk, and views of balancing safety

and quality. The result could be a more balanced and meaningful care for elders in nursing homes, rather than the status quo in medical practice of always placing safety above all.

To create a sustainable institutional culture that welcomes, seeks, and encourages family input and involvement requires policy change and a formal commitment. Formal commitment requires resource allocation (Austin et al. 2009). Meanwhile, long-term care organizations can change their own local cultures to focus on quality of life as determined by the resident and his/her advocates (the family). Specht et al. (2000) emphasize the importance of allocating resources for family involvement. For example, a site could offer support groups for families of residents with dementia, Multiple Sclerosis, or Huntington's disease. Resources could be used to provide regular and ongoing family education. Resources can be used to hold regular family-staff meetings that are separate from the housekeeping/operational meetings that units hold for their staff. Resources can be allocated to educate staff in how to engage and welcome families into the care of their loved ones. An institution might employ a family liaison worker who assists families to navigate the system. To bring families into care partnership will take cultural, political, and resource commitment. This kind of change cannot be expected to self-generate out of good will alone.

This commitment is demonstrated through how families are greeted, engaged, informed, and through how often staff members seek family involvement in the care. The resources may be used to train families to use equipment or to educate families about care in an institutional setting. This kind of investment would allow families to be informed partners in care rather than distanced or puzzled bystanders. I have seen staff informing family members that they are not allowed to transfer their loved one from the bed, as families have not been taught how to use the mechanical lift. While not all families are willing to be involved at this level of the care, inviting



family members to participate in the care is a goodwill gesture. The invitation could be followed by training and participation. This kind of cultural and philosophical shift from “we will do it” to “you can help too” requires not only a philosophical commitment but also resource allocation. The shift in philosophy and the associated resource allocation constitute an acceptance of a partnership in care. They acknowledge implicitly that the physical and the emotional needs of the elderly client can be met best by the staff-family partnership (Logue, 2003).

Having policies that allow and encourage family involvement at all levels of care lets both family and staff know that collaboration in the care of the resident is expected (Voutilainen, Backman, Isola, 2006). For residents who are their own decision-makers, their desired level of family involvement should be respected. Not all families are helpful or even healthy for the resident. These differences in attitude and capacity should be handled accordingly. Most family involvement is, nonetheless, important for the well-being of the resident. Creating a policy is a sign of the organization’s commitment to inclusive care for its residents. Having a policy also creates accountability on behalf of management and staff to make the effort to build relationships and to embrace family involvement in care.

The orientation of families into the new facility is very important. Orientation takes place at a high-stress time for families. They are looking for reassurance that the facility is a good fit for their loved one. A well-planned, well-organized, and thoughtful orientation could lay the foundation for a supportive, respectful, and collaborative staff/family relationship. Ideally, orientation should take place prior to the resident moving into the facility. This is possible if the resident is being admitted from the community. It is not always feasible if the resident is being admitted from a hospital. In the latter case, the orientation should take place as soon as possible after the resident moves in. The orientation should be used for addressing family concerns,

questions, and worries about the care. This is the time to introduce the team, provide a tour of the unit and the facility, and provide information about communication channels – to whom and where to take concerns and comments (Voutilainen et al., 2006 & Tisher et al., 2009).

Austin et al. (2009) outline a foundation for staff/family partnership through orientation and co-education. Austin et al. stress that the care process and the care team are important. In addition, ongoing education that allows co-learning could bring more collaboration. For example, workshops on Alzheimer's disease, diabetic management, or the importance of activity in preventing contractures could create opportunities for dialogue. This type of education also allows families to better understand the disease process (Austin et al., 2009, p. 378). Following orientation, a team meeting, including the resident and family, should allow the team to collaborate in creating a care plan that is realistic and relevant.

This approach is beneficial on a number of levels. First, it allows the family members to be advocates, historians, and supports for their loved one. Second, it allows them to grasp the new role they will have in the care of their loved one. Third, this is also a good opportunity to evaluate communication lines and reaffirm commitment to open communication, especially since care planning usually takes place some period after admission. There is evidence in the literature that when families are included in the care planning, the results are an increase in the family's collaboration with staff and in its trust of the facility (Gaugler, 2005).

There is reliable evidence that frontline staff do understand the importance of the family to the residents' care (Weman et al., 2004; Bauer, 2006; Austin et al., 2009). The issue is that they often do not have the skills to partner professionally. Building professional and therapeutic relationships is not a topic that is emphasized in the brief health care aid (HCA) training. Because there are far fewer registered nurses in long-term care, the licensed practical nurses

(who are often the team leads in long-term care) and the HCAs need initial and ongoing education on how to interact with, engage with, and involve families in care. They also need education on how to handle difficult families. The training does not have to be long and expensive. To some extent, it is a matter of using basic customer service skills focused on greeting family members, listening, and providing updates on the loved one. Staff must be aware of and facilitate family involvement in care. For example, if a family member wants to assist his/her loved one with feeding, grooming, or other activities, the staff can encourage the involvement, set up the needed supplies, and provide direction where needed. This type of collaboration helps the families to feel included and fosters partnership between staff and family. The success of this type of training will depend on the organizational culture and mission regarding family involvement. The staff will value family involvement as much or as little as the managers do, since they take their cues from their leaders.

As evidenced by Schulz et al. (2004), it is important to understand the family's motivation to be involved. This understanding cannot be gained by reading over the application for their loved one or by verbal communication of anecdotal information from the sending acute care center. It can only come from having frank conversations with the family right from the start. It is not easy for families to adjust to the new role they are now in after admitting their loved one into a facility. They may understand their new role to be that of monitoring care, since they no longer can provide the care themselves. It is important for caregivers to redefine the staff/family relationship as one of ongoing, vital, and friendly collaboration. Those of us who work in long-term care know that all families are involved. So, understanding the family's experience and providing support to ease their anxiety starts the staff/family relationship off with an expression of consideration and respect. Mutual respect is the core of relational ethics. As

Bergum (2012) argues, mutual respect is not only a key element of relational ethics; it is also fundamental to collaboration (p.134).

Bauer (2006) undertook a study to examine long-term care staff experiences in working with the family members of residents. Bauer collected data from a large selection of staff from 30 different nursing homes in Australia. Bauer discovered that although staff members had a generally good understanding of the importance of family involvement for the resident, they believed that the care in the long-term care setting was their domain. Participants understood the importance of family involvement in care, but they believed that such involvement should be relegated to feeding, grooming, emotional care, and social events. Deciding what care to give and actually providing it were considered medical matters that were beyond the expertise of family members. Caregivers wanted to keep the border between family involvement and medical care absolute rather than relative (Bauer, 2006, p. 49). Understanding the family's experience can, however, be a powerful tool for engaging them and forming a partnership. Establishing mutually respectful and collaborative staff/family relationships in long term care is very important. It is important for the resident admitted to the site; it is important for the family; and though not as obvious, it is important for the staff. Most of the staff/family conflict in long-term care seems to be in three particular areas: communication, role clarity, and involvement in care (Majerovitz, Mollott, , & Rudder, 2009). Though staff members are trained to receive residents and to provide care immediately, it takes time to get to know a resident, his/her needs, and those of the family. The long-term facility is the last home of the resident. Establishing a supportive and collaborative staff-family relationship requires planning, supportive procedures, and a real commitment from the organization, management, and staff at all levels. To create a solid family-oriented culture, there must be five core entities in place: policy, staff training, family

orientation, resident care planning, staff-family rapport and communication, and collaboration (Levine, Halper, Peist, & Gould, 2010).

### **Ethical Implications for Nursing**

Nursing is a privileged profession. Nurses are privy to some of the most intimate, vulnerable, emotionally wrenching, and spiritually uplifting moments that people live through. We witness and intervene in some of the most joyous, painful, and momentous times of our patients' lives. In these moments, more than at other times, humans need to be understood, included, and respected. In long-term care, due to disease process or disability/injury level, intervention may be withdrawn in certain circumstances, but the nurse never withdraws care and compassion. Compassionate care requires that the resident's view of his or her needs must be taken into account in the care. Caring for the patient/resident includes understanding and fostering the role of the family (Meiers, & Brauer, 2008). In order for this to happen, there has to be an understanding and collaboration between the nursing staff and the residents' families, who are often the voice of the resident.

The nurse's relationship with the patient's family is arguably a necessary extension of the nurse-patient relationship. This is particularly true in the long-term care setting where most of the patients can no longer make decisions about their care. The family in this case is the voice, ears, judgement, and entire sensibility of the patient; thus, the nurse is obligated to establish a therapeutic relationship with the patient's family. Doane & Varcoe's (2012) review of the literature supports the conclusion that nurses who form "good" relationships with clients are considered to be not only more responsive, respectful, and trustworthy, but also more ethical and effective in the care they provide (Doane & Varcoe's, 2012, p. 145). These authors emphasize the nurse's obligation to understand the role of the therapeutic relationship in establishing trust

and respect between the nurse and the patient (family). It is a moral imperative for nurses to cultivate.

### **Conclusion**

In short, the role of the family in the long-term-care team is significant due to a combination of an increasingly aged population and a shift from the medical model to person-centered care. There is now substantial research to support the importance of family involvement in the care of the elderly in long-term care. Recognition of the importance of the family in the care team must begin at the point of admitting the loved-one into long-term care. It must begin with an acknowledgement of the family's journey as caregivers. It must continue with an appreciation and utilization of the family's expertise and knowledge concerning their loved one's history of care. It must be motivated by a constant recognition of the family's right and desire to influence and participate in the care of their family member. Organizations must recognize the role of the family and must engage families early in the care relationship. Engaging families in care requires a fundamental shift in the philosophy of the long-term care sector. This shift should be demonstrated through changes in long-term care culture, policy, nursing practice, and resource allocation.

## References

- Alberta Government. (2000). *Alberta Health Professions Act*. Retrieved October 20<sup>th</sup>, 2012 from <http://www.health.alberta.ca/professionals/regulated-professions.html>
- Austin, W., Goble, E., Strang, V., Mitchell, A., Thompson, E., Lantz, H., Balt, L., Lerner, G. & Vass, K. (2009). Supporting Relationships Between Family and Staff in Continuing Care Settings. *Journal of Family Nursing*, 15: 309-323.
- Bauer, M. (2006). Collaboration and control: Nurses' constructions of the role of family in nursing home care. *Journal of Advanced Nursing*, 54(1), 45-52.
- Berta, W., Laporte, A., Zarnett, D., Valdmanis., V, Anderson, G. (2006). A pan-Canadian perspective on institutional long-term care. *Health Policy*, 79, 175–194.
- Bergum, V. (2012). Relational Ethics for Health Care. In Storch, J., Rodney, P., & Starzomski, R. (Eds.). (2012). *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed.). Don Mills, ON: Pearson Education Canada.
- Bluestein, D., & Latham Bach, P. (2007). Working with families in long-term care. *Journal of the American Medical Directors Association*, 8(4), 265-270.
- Browne, C., Braun, K. L. (2008). Immigration and the Direct Long-Term Care Workforce: Implications for Education and Policy. *Gerontology & Geriatrics Education*, 29(2), 172-188.
- Boise, L., & White, D. (2004). Aging matters. the family's role in person-centered care: Practice considerations. *Journal of Psychosocial Nursing & Mental Health Services*, 42(5), 12-20.
- Bramble, M., Moyle, W., & McAllister, M. (2009). Seeking connection: family care experiences following long-term dementia care placement. *Journal of Clinical Nursing*, 18, 3118–3125.
- Calkins, M. P. & Bush, J. (2009). Improving Quality of Life in Long-Term Care. *Perspective On*

*Gerontology*, 14(2), p. 37-41.

Canadian Institute of Health Information (2012). *Health care in Canada, 2011: A Focus on Seniors and Aging*. Retrieved September 29<sup>th</sup>, 2012 from

[https://secure.cihi.ca/free\\_products/HCIC\\_2011\\_seniors\\_report\\_en.pdf](https://secure.cihi.ca/free_products/HCIC_2011_seniors_report_en.pdf)

Capezuti, E., Taylor, J., Brown, H., Strothers, H., & Ouslander, J. (2007). Challenges to implementing an APN-facilitated falls management program in long-term care. *Applied Nursing Research*, 20(1), 2-9.

Capik, L. K. (1997). The Watson Theory of Human Care Applied to ASPO/Lamaze Perinatal Education. *Journal of Perinatal Education*, 6(1), p. 43-7.

Crandall, L. G., White, D. L., Schuldheis, S., & Talerico, K. A. (2007). Initiating person-centered care practices in long-term care facilities. *Journal of Gerontological Nursing*, 33(11), 47-56.

Cooper, H. (1998). *Synthesizing Research: A guide for literature reviews* (3<sup>rd</sup> ed.). Thousand Oaks: Sage Publication.

Daly, W., Carnwell, R. (2003). Nursing Roles and levels of practice: A framework for Differentiating between elementary, specialists, and advancing nursing practice. *Journal of Clinical Nursing*, 12, 158-167. Cited by Canadian Nursing Association: Advance Practice Leadership: National Framework. Retrieved November 20, 2010. From [http://www.cna-aiic.ca/CNA/documents/pdf/publications/ANP\\_National\\_Framework\\_e.pdf](http://www.cna-aiic.ca/CNA/documents/pdf/publications/ANP_National_Framework_e.pdf)

Daly, T., Albert, B., Armstrong, P., Armstrong, H., Szebehely, M. (2011). Lifting the 'Violence Veil': Examining Working Conditions in Long-term Care Facilities Using Iterative Mixed Methods. *Canadian Journal on Aging*, 30(2), 271-84



- Doane, G. H., Varcoe, C. (2012). Relationship Practice and Nursing Obligation. In Storch, J., Rodney, P., & Starzomski, R. (Eds.). (2012). *Toward a moral horizon: Nursing ethics for leadership and practice* (2nd ed.). Don Mills, ON: Pearson Education Canada.
- Gaugler, J. (2005). Family Involvement in Residential Long-Term Care: A Synthesis and Critical Review. *Aging Ment Health*, 9(2), 105–118.
- Government of Alberta. (2008) Alberta Continuing Care Service Standards. Retrieved October 10, 2012 from <http://www.health.alberta.ca/documents/Continuing-Care-Standards-2008.pdf>
- Harvath, T. A., Swafford, K., Smith, K., Miller, L. L., Volpin, M., Sexson, K., White, D., & Hertzberg, A., & Ekman, S. (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.
- Hertzberg, A., Ekman, S., & Axelsson, K. (2001). Staff activities and behaviour are the source of many feelings: Relatives' interactions and relationships with staff in nursing homes. *Journal of Clinical Nursing*, 10(3), 380-388.
- Hertzberg, A., Ekman, S., & Axelsson, K. (2003). 'Relatives are a resource, but...': Registered nurses' views and experiences of relatives of residents in nursing homes. *Journal of Clinical Nursing*, 12(3), 431-441.
- Higginbottom, G. (2009). Qualitative research. *Nurse Researcher*, 16(4), 4-6.
- Human Resources and Skill Development Canada (HRSGC). (2012). Canadians in Context – Aging Population. Retrieved January, 6th, 2012 from <http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-eng.jsp?iid=33>

- Hurtado, D.A., Sabbath, E.L., Ertel, K.A., Buxton, O.M. & Berman, F. (2012). Racial disparities in job strain among American and immigrant long-term care workers. *International Nursing Review* **59**, 237–244
- Koren, M. J. (2010). Person-centered care for nursing home residents: The culture-change movement. *Health Affairs*, *29*(2), 312-317.
- Levine, C., Halper, D., Peist, A., & Gould, D. A. (2010). Bridging troubled waters: Family caregivers, transitions, and long-term care. *Health Affairs*, *29*(1), 116-124.
- Liu, S. (2004). What caring means to geriatric nurses. *Journal of Nursing Research (Taiwan Nurses Association)*, *12*(2), 143-152.
- LoBiondo-Wood, G., & Haber, J. (2013). Nursing research in Canada: Methods, critical appraisal and utilization with study guide (3rd ed.). Toronto: Mosby Elsevier.
- Logue, R. M. (2003). Maintaining family connectedness in long-term care: An advanced practice approach to family-centered nursing homes. *Journal of Gerontological Nursing*, *29*(6), 24.
- Long-term facilities-based care. Definition adapted from: Ottawa (ON): Health Canada; 2005 [cited 2007 Dec 28]. Available from: [http://www.hc-sc.gc.ca/hcs-sss/home-domicile/longdur/index\\_e.html](http://www.hc-sc.gc.ca/hcs-sss/home-domicile/longdur/index_e.html)
- Majerovitz, S. D., Mollott, R. J., & Rudder, C. (2009). We're on the same side: Improving communication between nursing home and family. *Health Communication*, *24*(1), 12-20.
- Munhall, P. (2011). Nursing Research: A qualitative Research Perspective. (5<sup>th</sup> ed.). Miami, Florida: Jones & Barlett Publishing.
- Nursing Ethics. (2012). In Mosby's Medical Dictionary (2009), 8th ed., Elsevier. Retrieved March 25th, 2012 from <http://medical-dictionary.thefreedictionary.com/nursing+ethics>

- Paulus, A., van Raak, A., & Keijzer, F. (2005). Informal and formal caregivers' involvement in nursing home care activities: Impact of integrated care. *Journal of Advanced Nursing*, 49(4), 354-366.
- Perry, B., Dalton, J. E., & Edwards, M. (2010). Family caregivers' compassion fatigue in long-term facilities. *Nursing Older People*, 22(4), 26-31.
- Reinhard-Priester, J.D., Reinardy, J.R. (2012). Recruiting Immigrants for Long-Term Care Nursing Positions. *Journal of Aging & Social Policy*, 15:4, 1-19.
- RNAO. (2007). Staffing and care Standards for Long-Term Care Homes Retrieved October 23, 2012 from [http://rnao.ca/sites/rnaoca/files/storage/related/3163\\_RNAO\\_submission\\_to\\_MOHLTC\\_-\\_Staffing\\_and\\_care\\_Standards\\_in\\_LTC\\_-\\_Dec\\_21\\_2007.pdf](http://rnao.ca/sites/rnaoca/files/storage/related/3163_RNAO_submission_to_MOHLTC_-_Staffing_and_care_Standards_in_LTC_-_Dec_21_2007.pdf)
- Rowley, J., Slack, F. (2004). "Conducting a literature review". *Management Research News*, 27(6). 31-39.
- Ryan, F., Coughlan, M , Cronin, P. (2007). Step-by-step guide to critiquing research. Part 2: qualitative research. *British Journal of Nursing*, 16(12), 738-44.
- Schulz, R., Belle, S., Czaja, S., McGinnis, S., Stevens, A., Zhang, S. (2004). Long-term Care Placement of Dementia Patients and Caregiver Health and Well-being. *JAMA*, 292(8),:961-967.
- Specht, J. P., Kelley, L. S., Manion, P., Maas, M. L., Reed, D., & Rantz M. J. (2000). Who's the Boss? Family/Staff Partnership in Care of Persons with Dementia. *Nursing Administration Quarterly*, 24(3): 64-77.
- Statistics Canada. (2006). *A Portrait of Seniors in Canada*. Retrieved September 10<sup>th</sup>, 2012 from <http://www.statcan.gc.ca/pub/89-519-x/89-519-x2006001-eng.pdf>
- Statistics Canada (2011). *Residential Care Facilities 2008/2009*. Retrieved September 10<sup>th</sup>,

2012

The Role of Immigrant Care Workers in an Aging Society: The Canadian Context and

Experience. Retrieved September 11<sup>th</sup>, 2012 from

[http://www.compas.ox.ac.uk/fileadmin/files/Publications/Research\\_projects/Labour\\_markets/Migrant\\_care\\_workers/Canada%20ICW%20Report%20-%20Executive%20Summary%20Final.pdf](http://www.compas.ox.ac.uk/fileadmin/files/Publications/Research_projects/Labour_markets/Migrant_care_workers/Canada%20ICW%20Report%20-%20Executive%20Summary%20Final.pdf)

Tisher, T. B., S. Dean., Tisher, M. (2009). Aged Care Residential Facility and Family Interface:

A Training Program for Staff. *Clinical Gerontologist*, 32(3), 309-323

Vishnevsky, T., Beanlands, H. (2004). Qualitative Research. *Nephrology Nursing*, 31(2), p. 234-32.

Voutilainen, P., Backman, K., Isola, A., Laukkala, H. (2006). Family Members' Perceptions of the Quality of Long-Term Care. *Clinical Nurse Research*, 15(2), 135-149.

Ward-Griffin, C., McKeever, P. (2000). Relationships between Nurses and Family Caregivers: Partners in Care? *Advance Nursing Science*, 22(3), 89–103.

Weman, K., Kihlgren, M., Fagerberg, I. (2004). Older people living in nursing homes or other community care facilities: Registered Nurses' views of their working situation and cooperation with family members. *Journal of Clinical Nursing*, 13, 617–626.

White-Chu, E., Graves, W. J., Godfrey, S. M., Bonner, A., & Sloane, P. (2009). Beyond the medical model: The culture change revolution in long-term care. *Journal of the American Medical Directors Association*, 10(6), 370-378.

Wilson, C. B., Davies, S. (2009). Developing relationships in long term care environments: the contribution of staff. *Journal of Clinical Nursing*, 18, 1746–1755.