EASING THE TRANSITION FROM COMMUNITY CARE TO LONG-TERM CARE

FINAL REPORT

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EXECUTIVE SUMMARY

Study Purpose
The purpose of this study was to examine the transition process from community care to long-term care from the perspective of family caregivers of older adults, and to identify specific ways in which facilities might help ease the transition for both the families and their relatives. These objectives were met by conducting in-depth, semi-structured interviews with twenty-one family caregivers who had recently, within 6 to 8 weeks, admitted their relative into one of three long-term care (LTC) facilities in southern Ontario. Family members represented various caregiving roles including: adult daughters (12), spouses (5), adult granddaughters (2), adult siblings (1), and adult sons (1).

Key Findings
Several major themes emerged which reflect the experience of the transition process for family members:

Significant Aspects of the Transition Process
The overall transition process was described as extremely complex and typically triggered by either a change in the family caregiver’s health or in the health of their relative. The transition was also described as a time-consuming process involving touring various LTC facilities to find the preferred facility for their relative. The waiting period for a bed to become available encompassed intense feelings of anxiety, urgency, uncertainty, and ambiguity. Receiving the call with a bed offer, and the subsequent 24 to 48 hours to accept the offer created a tremendous amount of stress and pressure for family caregivers. The 24 to 48 hour time period to make the decision was perceived as insufficient to make this important decision and
prepare for the move. According to one family member, “the 24 hour thing…that is a lot of pressure to make a decision like that”.

**Challenging Aspects of the Transition and Actual Move**

In describing the challenges of the overall transition for family caregivers, families described *guilt* associated with the feeling that *they* had “put” their relative in the LTC facility. Family caregivers also expressed their *difficulty in accepting the deterioration of their relatives’ disease process*. This was especially evident in those caring for a relative with dementia. Family members felt that the *enormous responsibility* placed on them throughout the transition was very challenging, as was the *stress* associated with the uncertainty of waiting for a bed to become available, having 24 to 48 hours to decide whether to accept or deny the spot, and then only a few more days to actually move their relative to the facility. Further, family members felt a *lack of choice* in facility as they felt pressured to accept the bed offered. In describing the challenges associated with the actual move, some families anticipated that their relative would receive *poor care* at the LTC facility and believed this reflected insufficient and overworked staff. Family caregivers also expressed *difficulty in accepting their relative’s new living space*, which was perceived as a small and impersonal room where only a few personal items were allowed. Several family members felt there was a *lack of welcome* when they arrived at the nursing home. In their own words, “when I walked in, there was nobody there…we didn’t expect a red carpet but…” and, “they could have met me when I walked in the door…I had no clue where [the unit] was”.

When caregivers described their perception of *challenges facing their relatives* during the overall transition, a majority described their relatives’ *loss*. This loss was associated with moving out of their own homes, becoming less independent,
and having fewer contacts with friends and family. Also perceived as a challenge for their relatives on the day of the move was the feeling of sadness associated with so many changes such as being in a protected living environment and being distant from family. Family members also perceived the current transition as difficult for those who had previously made multiple moves: from one facility to another or back and forth from the community to facilities.

**Positive Aspects of the Transition**

For family members, moving their relatives to a LTC facility was frequently associated with a sense of relief; relief because they felt their relative was being taken good care of in a safe place by competent staff. A number of factors appeared to be related to a positive experience during the transition. For example, those who had the opportunity to prepare the room before their relative moved in were at ease that their relative was in a place that was familiar to them. This preparation appeared to help the new resident feel more comforted upon arrival, which in turn, made the transition easier for families. Also, the support that family members received from friends, other family members, staff at local Alzheimer Society chapters, CCAC case managers, and other service providers was paramount to a positive transition experience. On the actual day of the move, welcoming staff, their relatives’ excitement about moving, and familiarity with the facility made the move a more positive experience for them.

Family members also identified a number of factors that they perceived eased the transition for the older relative. It appeared that the most important factors for their relatives were a strong connection with and presence of family throughout the transition as well as regular visits after the move. Good care, friendly staff and good activities at the facility were also deemed important for a positive transition
to the facility. Another positive aspect of the actual move identified by family was their relatives’ lack of awareness. This particular theme was only identified by those family members whose relative had a diagnosis of dementia. Family members suggested their relatives’ lack of awareness was positive because, in the words of one family member, “it [the move] is easier if your mind is completely gone…it’s a blessing”. For some, the facility was very welcoming during the actual day of the move making it a positive experience for their relative.

**Recommendations and Strategies to Help Ease the Transition**

Caregivers identified a number of strategies for LTC facilities to ease the transition to LTC.

**Prepare Families**

Family members need more preparation for the move to LTC. This might include explaining more fully the entire process, providing checklists of key questions to ask, people to contact, and all items needed on the day of the move. Preparation should also involve teaching families how to make visits more meaningful after placement.

**Provide More Time to Move**

Caregivers need more time to make a final decision about placement. They expressed the need to make this decision without the pressure of time. Family caregivers also expressed the need for more time to transport and move their relative into the facility.
**Provide a Welcoming Environment**
Caregivers and their relatives described the need to feel welcomed when they arrive at the facility. This involves meeting families at the entrance to the facility, and helping them to move their belongings into their new room.

**Individualize Care**
Family caregivers expressed a desire for LTC facilities to respect and act upon the individualized needs of residents and their families. This includes allowing admissions at the family’s convenience, allowing residents to eat meals with whomever they wish, and allowing more personal items in each room.

**Build Stronger Connections with Community Services**
A number of caregivers felt the transition would have been made easier if LTC facilities had stronger ties with community services. They believed that maintaining connections with day programs and local support groups would assist the relative in adjusting to the move. This would keep familiarity and routine in the daily lives of their relatives, thus making the transition easier.

**Enhance Communication Between Families and Staff**
Many family members felt that the transition would have been made easier if there was better communication between families and staff. This includes staff wearing nametags to clearly identify themselves and having a direct link to the LTC facility instead of having to go through the CCAC.

Other recommendations derived from the findings include:
**Educate Staff**
Educating the staff about the complexity of the transition process for some family members and raising awareness of the stress of caregiving would sensitize staff to the difficulties experienced by families.

**Provide Family Support**
All family members expressed how emotionally difficult the transition to LTC was for them. Providing support for families to help them deal with guilt, the deterioration of their relatives, and the sense of loss some experience would help ease difficulties experienced by the families.

**Minimize the Impact of the Transition on the Older Adult**
While the transition to LTC was a difficult experience for the family caregivers, families also recognized that the move was also difficult for their relative. To ease the transition for the relative, LTC facilities could provide support services for residents to deal with their feelings associated with the move. Also, reducing the number of moves older adults make from one facility to another, and ensuring placement on appropriate floors would help minimize the negative impact of the move to LTC.
INTRODUCTION

Older adults represent the fastest growing segment of the population in Canada, and worldwide. It is estimated that by the year 2011 over 15% of the Canadian population will be 65 years or older (Elliot, Hunt, & Hutchison, 1996). Given that the risk of dementia increases with age, it is likely that the prevalence of dementia will follow a similar trend. In fact, while in 1994 a total of 364,000 or 1 in 13 Canadians over the age of 65 years had Alzheimer Disease or a related dementia, it is projected that by the year 2021 this number will increase to 592,000 (Canadian Study of Health and Aging, 1994; Elliot, Hunt, & Hutchison, 1996). Therefore, not only will the health care system have to adapt to this aging population and increase in dementia, so will families who may be called upon to provide elder care.

The role of the family caregiver is extremely complex. While little consensus on the definition has been reached, there are clearly several essential dimensions to the caregiving role. The provision of emotional and/or instrumental support is key to the caregiving role; however, the degree of involvement differs for each family and each individual family member (Malonebeach & Zarit, 1991). A large body of research is dedicated to exploring the significant impact family caregiving can have on the lives of caregivers. A much smaller portion of this literature
documents the positive aspects of caregiving for an elderly relative. This limited body of research has shown that most caregivers can identify positive aspects of their caregiving role. Some specific examples of positive aspects of caregiving include: companionship, fulfillment and reward, enjoyment, meaning and increased quality of life for both the caregiver and the care recipient, and love for the care recipient (Cohen, Colantonio, & Vernich, 2002). A majority of the literature, however, recognizes that caregiving has many negative impacts on the caregiver, including heavy stress and burden. Often this stress and burden, coupled with several other risk factors, lead family caregivers to place their relative into a long-term care (LTC) facility (Neilsen, Henderson, Cox, Williams, & Green, 1996).

The transition process from community care to long-term care can be extremely challenging and stressful for family members, many who are already experiencing severe burden from their caregiving roles. Nonetheless, very little research has examined the experience of the transition process for family caregivers. The purpose of this research study was to explore the experiences for family caregivers as they move their family member to a long-term care facility. More specifically, this study examined the transition process from community care to long-term care for family members of older adults in order to identify specific ways in which facilities might help to ease the transition for both family members and new residents.

This report begins with a review of relevant literature related to the move to a long-term care facility. Explored in detail are the following topics: why moving to a LTC facility takes place; factors contributing to the decision to move a relative to a LTC facility; the procedures involved in the actual transition process; impacts and
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consequences on families when their relatives move to a LTC facility; and how facilities might help to ease the transition from community care to a nursing home for families. A brief description of the study procedures and a summary of key findings are then provided. The report ends with specific recommendations and strategies targeted at long-term care facilities to help ease the transition from community care to a LTC facility.

REVIEW OF RELEVANT LITERATURE

Why Move to a LTC Facility: Risk Factors for Placement

There are many factors affecting the final decision to move a relative to a LTC facility. With the growth of the older adult population and the increased incidence of dementia, there is a greater demand for long-term care services. By determining the predictors and risk factors associated with moving older adults and persons with dementia to a LTC facility, it is possible to predict the future demand for long-term care and potentially develop interventions that delay or prevent the move to a LTC facility (Tomiak, Berthelot, Guimond, & Mustard, 2000). Further, identifying these risk factors for placement in long-term care facilities can give family members an idea of how long an older adult, particularly an older adult with dementia, may need in-home care and when LTC placement will be necessary (Fisher & Lieberman, 1999).

The following section explores risk factors associated with the move to a LTC facility. These risk factors can be grouped into three major categories: characteristics of the older adult, characteristics of the caregiver, and characteristics associated with the functioning of the family system.
**Risk Factors for Placement: Characteristics of the Older Adult**

Inconsistencies exist in the literature as to what factors associated with characteristics of the older adult actually increase the risk for LTC placement. These inconsistencies can be attributed to weaknesses in measurement and/or a lack of research confirming such risk factors and suggest that much more research is needed before a clear set of risk factors for LTC placement can emerge. Several key risk factors, however, are consistently identified in the literature and will be discussed in the following section; these include level of cognitive impairment, age, living arrangements, and medical complexity.

**Level of Cognitive Impairment**

It has been widely documented that cognitive impairment is one of the primary risk factors for LTC placement. Furthermore, severe impairment or the presence of a dementia is even more highly associated with LTC placement. As many as 90% of individuals diagnosed with dementia become institutionalized before death (Yaffe, Fox, Newcomer, Sands, Lindquist, Dane, et al., 2002). Several other studies have documented the finding that as cognitive impairment increases so does the risk of LTC placement (Aneshensel, Pearlin, & Schuler, 1993; Chiu, Woei-Cherng, Yu-Hwa, Shiou-Ping & Chang, 2001; Wimo, Gustafsson, & Mattson, 1992;). This finding makes intuitive sense since the decline of an individual’s cognitive abilities is highly associated with an increase in their needs, thus, care becomes more demanding for the informal caregiver.
Age

Increasing age has consistently been associated with an increased risk of placement in a LTC facility. A number of studies have found older age (greater than 65 years of age) to be the strongest predictor of LTC placement (Miller & Wissert, 2000; Smith, Kokmen, & O’Bien, 2000; Wilmoth, 2000). This effect of age also appears consistent when controlling for gender. That is, advanced age appears to be a significant predictor of LTC placement for both males and females (Tomiak et al., 2000). This risk factor is likely linked to the level of assistance with every day activities that increases with age. While nine percent of those between ages 65 and 69 years need personal assistance, up to 50 percent of adults over 85 years of age need assistance with everyday activities (American Psychological Association, 2003).

Living Arrangements

Living arrangements prior to placement vary considerably for older adults. While many live in the community alone, a large number also live with a spouse and/or children. The nature of living arrangements appears to predict LTC placement. For example, a summary report on predictors of institutionalization found living alone strongly and consistently increased an older adult’s risk of institutionalization (Miller & Wissert, 2000). Another study on predictors of institutionalization of elderly found that individuals with informal carers who lived apart from these carers were more likely to be moved to a nursing home than those who lived with their carers (Spruytte, Van Audenhove, & Lammertyn, 2001). Further, in a study on risk factors for placement among persons with dementia by Smith et al. (2000), results showed that being single and living in a retirement or supervised apartment at dementia onset were independent risk factors for LTC
placement. Similarly, an earlier study determined that the level of needed supervision was a risk factor, with an increased level of supervision predicting LTC placement (Wimo et al., 1992).

Medical Complexity
Studies have found that with increasing medical complexity, there is an increased risk of LTC placement. For the purpose of this review, medical complexity includes difficulties with physical functioning, behavioural problems, and other health issues. Smith et al. (2000) found a higher number of health issues to be associated with increased risk of LTC placement. Similarly, Tomiak et al. (2000) noted that the presence of medical conditions such as musculoskeletal disorders, stroke, and mental health disorders significantly predicted LTC placement. Again, this risk factor is likely associated with the decreased ability to perform activities of daily living. A decline in the ability to perform activities of daily living (e.g. eating, toileting) has been associated with institutionalization among older adults receiving community-based care (Miller & Wissert, 2000; Scott, Edwards, Davis, Cornman, & Macera, 1997).

Behavioural problems also add to the risk for LTC placement. A study by Whitlatch, Feinberg and Stevens (1999) concluded that an individual’s level of problem behaviours, such as wandering, agitation, and combative behaviour, directly predicted placement. Miller and Wissert (2002) similarly found that disorientation and behavior problems increased the risk of LTC placement. These findings also suggest that as more complex care is required, the likelihood of remaining in the community declines.
Additional Risk Factors Associated with the Older Adult

Other demographic factors and service use history have also been found to predict LTC placement; however, these factors have received much less attention in the literature. Gender differences in risk of LTC placement have varied. While many studies have found no significant differences between sexes in terms of LTC placement, Colerick and George (1986) reported women as overall more likely to be placed in a LTC facility than men. The authors suggested that this relationship exists due to their finding that caregivers of female relatives tend to be employed daughters who are also juggling motherhood. Another potential explanation contends that females tend to outlive their spouses, who are a significant support system (Freedman, Berkman, Rapp, & Ostfeld, 1994). Other factors influence gender differences in risk of LTC placement. For example, the presence of a spouse for men is one of the most important factors for reducing institutionalization (Tomiak et al., 2000). A higher level of past service utilization also predicts LTC placement. That is, hospitalization in the year prior to moving to a LTC facility, and a previous LTC placement increase the risk of LTC placement. Finally, service-level factors such as the availability of LTC beds and number of physicians also affect the risk of placement among the elderly, whereby more LTC beds and fewer physicians in a community increase the risk of LTC placement (Tomiak et al., 2000).

Risk Factors for Placement: Characteristics of the Carer

There is also literature that identifies risk factors associated with caregiver characteristics associated with placement to a LTC facility for their relative. Once again, there is some debate among researchers regarding how consistent certain
caregiver characteristics are in predicting LTC placement. Those risk factors mentioned most consistently include: the relationship of the caregiver to the care recipient, and caregiver stress/distress.

Relationship of Caregiver to Care Recipient
The research has demonstrated repeatedly that the caregiver’s relationship to the care recipient influences the risk of LTC placement. Specifically, spousal caregivers appear to be most determined to keep their relative in the community. Tomiak et al. (2000), for example, concluded that having a spousal caregiver decreased the risk of LTC placement, and if supported by another caregiver, the risk of LTC placement decreased even more. In contrast, these authors found that having a non-spousal caregiver was a risk factor for LTC placement (Tomiak et al., 2000). Lieberman and Kramer (1991) also found that having a spouse as a sole care provider was the lowest significant risk factor for LTC placement, while having a son/daughter caregiver with help from family friends was the highest significant risk factor for LTC placement. Scott and colleagues (1997) documented analogous results. In their study, which reported relative risks for institutionalization, older adults with child caregivers were 4.8 times more likely to be institutionalized than older adults with a spousal caregiver, while older adults with non-relative caregivers were 9.3 times more likely to be institutionalized than older adults with spousal caregivers (Scott et al., 1997).

One study, specifically investigating the risk of nursing home placement for older adults with dementia, found that those with child caregivers were at greater risk of being placed in a nursing home than those with spousal caregivers (Colerick & George, 1986). This finding suggests that the risk of LTC placement due to the
relationship between caregiver and care recipient is consistent across all older adult groups.

*Caregiver Stress/Distress*

The most common reason caregivers place their family member into a LTC facility is the burden of providing 24-hour care (Chenoweth & Spencer, 1986, cited in Aneshensel et al., 1993; McCarty, 1996). Research strongly supports the notion that caregivers feel so overwhelmed with caring for their relative that their own physical and mental health suffers and eventually they can no longer cope (Chenier, 1997; Yaffe et al., 2002). One of the biggest predictors of LTC placement, therefore, is the level of support a caregiver can access that helps relieve the stress they are experiencing. In fact, some research suggests that relieving caregiver stress actually delays or reduces institutionalization (Aneshensel et al., 1993; Mittelmantel et al., 1995, cited in O’Rourke & Tuokko, 2000). Nonetheless, an increased use of supportive services, such as community support services also has been associated with an increased risk of LTC placement (Whitlach et al., 1999)

Role captivity, a term defined as the unwanted role assumed by the caregiver who feels caregiving is obligatory, describes the experience of many caregivers who feel imprisoned in their caregiving role (Aneshensel et al., 1993). In fact, the role as caregiver is not normally chosen, nor is it “…something people typically are socialized to desire, seek, or expect…they often become caregivers by default” (Aneshensel et al., 1993, p. 67). Upon moving the relative to a LTC facility, this feeling is usually alleviated; however, it is the “overload that prompts institutionalization” (Aneshensel et al., 1993, p. 67).
Other risk factors for LTC placement of the care recipient are associated with caregiver burden and stress. These include: depression and increased use of psychotropic drugs (Colerick & George, 1986); a decline in caregiver health status (Whitlatch et al., 1999); an increased level of exhaustion of the spousal caregiver, prior to placement (Frazer, 1999; Wimo et al., 1992). In contrast to this last result, Pot & colleagues (2001), however, found that caregiver psychological distress before placement was not a risk factor for LTC placement.

Additional Risk Factors Associated with Caregiver

Some additional demographic factors have been found to predict LTC placement; however, these factors are not as widely discussed in the literature. For example, having a caregiver who is employed in addition to providing care to an older relative was found to increase the risk of LTC placement (Colerick & George, 1986). The gender of the caregiver also appears to influence the risk of placement. Having a son caregiver increases the risk of LTC placement of the care recipient by 28% as compared to having a daughter or another female family caregiver (Bauer, 1996).

Risk Factors for Placement: The Functioning of the Family System

The third category of factors posing a risk for LTC placement for older persons discussed in the literature is the functioning of the family system. While the majority of research in this area has focused on family conflict (e.g. Smith, Smith & Toseland, 1991; Strawbridge & Wallhagen, 1991), a few studies on the emotional support within the family system have been reported (e.g. Horowitz, 1985).
Fisher and Lieberman (1999) found that family characteristics were most significant risk factors of placement for families with a relative in early stages of dementia. These same authors reported three main characteristics of the family system that predicted LTC placement. First, the authors found that emotionally close families are more likely to place their elderly relative in a LTC facility than families that are emotionally distant. This finding may suggest that emotional closeness may facilitate decision-making by avoiding the kind of emotional distance that often leads to apathy. Similarly, Fisher and Lieberman (1999) argue that emotionally close families may be more sensitive to the emotional disruptions that caregiving may create and, therefore, place their relative before a negative situation occurs. Second, the study found that family caregivers who are less efficient in terms of planning and organizing are more likely to place their relative in a LTC facility. This may occur due to an inability to coordinate family responsibilities and deal with behavioural issues that require prediction and preparation. Third, families that experience negative affect are more likely to place their relative in a LTC facility. Negative affect, which includes emotions such as guilt, anger, sadness, and loneliness, may pose a threat to the physical and emotional health of family caregivers, thus requiring placement (Fisher & Lieberman, 1999). An earlier study by Lieberman & Kramer (1991) supports these findings, concluding that family problems associated with caregiving pose a significant risk for placing a relative in LTC. Specifically, financial and psychological problems were significantly more common among families that decided to institutionalize their relatives.

Gaugler, Pearlin, Leitsch & Davey (2001) found that the process of searching for a suitable LTC facility was most difficult for families experiencing conflict within the family system. This was particularly true for family caregivers who perceived
that they received little help from professionals and from other family members. This study emphasizes the challenges experienced by families and importance of social support networks to the caring and placement processes.

While a paucity of literature exists documenting family-level characteristics as risk factors for LTC placement, there appears to be little controversy in the literature about what those factors are. This suggests that the functioning of the family system plays an important role in the placement of a relative into a LTC facility.

Making a Decision: The Decision to Move a Relative to a LTC Facility

Little research has focused on the decision to move a relative to a long-term care facility and what that process looks like. The research that does exist suggests that several key factors contribute to the decision to move an older relative to a LTC facility. Described below are the role of attitudes of family and the key stages in the decision making process. Much more research, however, is needed in this area.

The Role of Attitudes and Perceptions of the Family

The attitudes and perceptions that families hold towards community-based long-term care and LTC placement have a major impact on their decision to finally move their relatives to a LTC facility. Collins, King and Kokinakis (1994), for example, found that family caregivers’ perceptions of community services had a major effect on their decision to choose LTC placement over continued care in the community. Consistent with past research, this study found that the majority of participants did not perceive that additional services would have delayed
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institutional placement. At the same time, the most frequently reported perception of service factors influencing the decision were the inability to find services in the community and lack of affordability of services (Collins et al., 1994).

Chiu et al. (2001) explored key factors affecting the attitudes of family caregivers of people with dementia towards LTC placement. After conducting telephone interviews with 144 family caregivers, they found several key factors affecting attitudes towards placement. A negative perception of long-term care held by a number family members regularly and frequently involved in caring for their relative in the home, negative health changes of the caregiver as a result of the caregiving experience, and psychological distress contributed to the negative attitudes of caregivers towards LTC placement. This study also concluded that the mental status of the person with dementia directly affected the attitude of caregivers towards LTC placement. More specifically, those taking care of individuals with moderate to severe cognitive impairments were more likely to have positive attitudes towards LTC placement and, therefore, tended to access long-term care more frequently than caregivers taking care of individuals with milder cognitive impairments (Chiu et al., 2001).

Phases in the Decision-Making Process

Making a decision to move a loved one to a LTC facility is a very significant point in the caregiving career. Caregivers describe the decision to move a relative to a LTC facility as one of the most challenging decisions they have to make in their caregiving roles (Wackerbarth, 1999). Some studies have explored the experiences of caregivers as they move through the decision process. Penrod and Dellasega (2001) interviewed informal caregivers at several key stages of the admission
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process and identified six distinct phases or stages through which informal caregivers move.

In the initial stage, a crisis usually emerges and provokes the consideration of placement. Examples of the crisis may include increased frailty, a fall, acute illness, dementia upset, or more demands placed on the caregiver beyond what they are capable of handling (Aditya, Sharma, Allen & Vassallo, 2003; Tomiak et al., 2000). The crisis event creates a need for families to begin evaluating their resources and leads to the second phase.

The second phase in the decision process is the need for families to evaluate their ability to continue to care by consulting with doctors and getting input from other professionals. A family’s evaluation may lead them to experience feelings of ambivalence and inner conflict. For instance, caregivers in the Penrod and Dellasega (2001) study wanted to continue to take care of their family members but had to look realistically at their own boundaries and the suggestions from professionals. One family caregiver expressed the struggle: “everybody discouraged me. Everybody! Even the nurses…But I just thought boy I’m gonna do it. I’ll do it. Everybody, like I said, from the doctor to nurses to just people on the streets, so to speak, discouraged me and said ‘you can’t do it’ and finally I figured, well, probably I can’t” (Penrod & Dellasega, 2001, p. 33).

The third phase, the inner struggle for caregivers, finally leads to the decision to place their family members in a LTC facility, even though families do not generally see it as a ‘favorable’ option. Caregivers felt some relief after making the decision, but this was often short-lived as family members finally came to understand that difficult times remained ahead.
The final three phases in the process of institutionalization relate to finding a LTC facility, which involves navigating a very complex health system, redefining their own role as caregivers, and then feeling isolated and alone when their family member is finally placed (Penrod & Dellasega, 2001).

It is important to note that in the context of finally deciding to move a relative to a LTC facility, few families involve the person with dementia in the decision to move (Mastrian & Dellasega, 1996; McAuley, Travis & Safewright, 1997). Thus, this is an area of study in need of much further investigation.

**Procedures Involved in the Actual Transition Process**

Moving to a long-term care facility is a complex process. In the province of Ontario, Canada, it involves contacting the Community Care Access Center (CCAC), completing the application process, determining eligibility criteria and finally, being placed on a waiting list before a move to a LTC facility. This section summarizes the placement procedures in Ontario and also examines the search and selection process for families and the process of waiting for a LTC bed.

**The Role of the Community Care Access Centre in LTC Placement of the Older Adult**

In Ontario, Community Care Access Centres (CCACs) arrange all admissions to long-term care facilities in Ontario. The main role of the 43 centers across the province is to manage and coordinate the transition for a client moving to a long-term care facility. CCACs provide a list of facilities for clients to consider,
information on the facilities and referral services, and assistance with eligibility for admission to these LTC facilities. CCACs also maintain waiting lists and approve all admissions to LTC facilities. After placement, CCACs often follow up with a client satisfaction survey. CCAC policies and processes around placement can be revised or changed at any time. For the purpose of this literature review, existing policies and processes will be presented.

Living arrangements prior to LTC placement vary considerably for older adults. While many older adults who move to a LTC facility in Ontario come from a community setting, a considerable number are also relocated to a long-term care facility directly from an acute care setting such as a hospital (Castle, 2001). Regardless of the location that precedes LTC placement, the process follows similar steps. In general, a client’s needs are assessed by a CCAC case manager, the client is placed on a waitlist according to the identified needs, and, when a bed becomes available, families are given a fixed period of time in which they are required to decide whether to accept or decline the placement (Rider, CCAC manager of client services, personal communication, 2003).

**Steps in The Placement Process**

The following describes, according to the CCAC, the steps of the placement process in more detail:

*Step 1: Assessment*

After a family member inquires with the CCAC, expressing an interest in moving their family member to a LTC facility, a CCAC case manager is assigned. This person then conducts an in-depth assessment of the person’s need for LTC
placement and gains a sense of the degree to which community/home support services have been used. From the perspective of the CCAC, it is important to use the community and home support services to their fullest capacity before looking to place the older adult in a LTC facility. Usually information is provided to families about the availability of community and home support services in the case where their family member can be managed at home longer. Also, at this point a health report must be completed, usually by the family physician.

**Step 2: Determine Eligibility**

To determine if the person is eligible for LTC placement, eligibility criteria are used by the CCAC. These criteria include: 1) the caregiver must be over 18 years of age insured under the Health Insurance Act; 2) there must have been an effort to use all formal and informal services to their maximum capacity; and 3) the care receiver must meet at least one of the following conditions before being considered for long-term care placement: requires 24-hour care; requires daily assistance with activities of daily living; requires on-site supervision or monitoring at frequent intervals during the day to ensure safety and well-being; be at risk of being emotionally, financially or physically harmed if person lives at his/her own residence; be at risk of suffering harm due to environmental conditions which cannot be reduced if person lives at his/her own residence; and/or the person may harm another if they remain at his/her residence. According to the Ontario Ministry of Health and Long-Term Care LTC Standards (1993) these criteria identify that those in emergency situations should be given priority for admission.
Step 3: Discuss Appropriateness of Facilities

Once assessed, if the individual is deemed eligible for LTC placement, the assigned CCAC case manager discusses the most appropriate facilities as well as financial considerations with the family and the individual being placed. Information about ideal facilities is then provided to the family, who then may visit each facility to determine their most preferred options. The family must identify a maximum of three preferred facilities.

Step 4: The Search and Selection Process

Families often describe the search for a LTC facility as hectic, stressful, and extremely complex. A study by McAuley et al. (1997) identified selection criteria often employed by family members seeking LTC placement for a relative: 1) the facility is close to home; 2) friends and other family members have lived there before; 3) the facility is clean; and 4) staff seem friendly. Another study found that the more desperate a caregivers feels, the more pressure they feel to take the first bed that becomes available (Dove, 1986). Common emotions experienced during this process include guilt, sadness, and stress regarding the entire institutionalization process (Dove, 1986).

During the search for and selection of a LTC facility, the role of the facility is to offer tours to interested families. The tour provides an opportunity for families and the potential resident to get a feel for the facility, ask questions, make a decision, and finally, place themselves on a waiting list through the CCAC.
**Step 5: Placement on a Waiting List**

If the person meets the eligibility criteria, the care recipient is then placed on a waiting list. In Ontario, the waiting time for LTC placement varies depending on the person’s level of need, type of accommodation requested, and the number of available LTC beds in that geographic location. Research suggests that long waiting periods for placement can have significant negative impacts on caregivers. For example, in an examination of the effects of long wait lists on caregivers, Meiland, Danse, Wendte, Klazinga, and Gunning-Schepers (2001) found that it was more strenuous and energy-consuming to continue to care for a family member over the waiting period after a decision was made to place the relative into a LTC facility than if the family member had been immediately placed into a LTC facility.

**Step 6: Bed Offer**

After waiting for a period of time and a bed becomes available, an offer is made for placement. Families have until the following day to make a decision about the bed offer and, once the decision is made, have up to five days, depending on the facility, to actually move into the facility. If the bed is refused, LTC application is closed. The applicant cannot reapply for a period of six months, unless the situation changes or the applicant is already in a LTC facility or in a hospital.

**Step 7: The Move**

Once a decision is made to accept a long-term care bed in a specific facility, family caregivers are responsible for organizing and carrying out the actual move to the LTC facility. This might include arranging for personal possessions to be moved, and the set up of the new room. The new facility must assume all responsibility
and care of the person being admitted as well as all responsibility for addressing family members concerns.

Impacts and Consequences of the Transition Experience

The majority of the literature documenting the transition experience for older adults moving to a LTC facility and their caregivers mainly explores the experience after the relative has moved to a long-term care setting. Very few studies have explored the actual experience while decisions are being made about the placement or during the actual placement process. This section of the literature review will, therefore, mainly focus on the impacts and consequences on caregivers after the placement of a relative into a LTC facility. However, it will begin with a brief exploration of the impacts and consequences associated with the actual transition experience.

The Caregiver’s Experience of the Transition Process

Emotions in the Transition Experience

A few studies have examined the experience and perceptions of caregivers as their family members were moved to a long-term care facility. In a study by Penrod and Dellasega (1998), in-depth interviews were conducted with family caregivers who experienced the move of their relative from a hospital setting to a LTC facility. Dellasega & Nolan (1999) used the Placement Response Scale (PRS) to collect data on the stressfulness and applicability of a series of scenarios related to the placement of a relative in a LTC setting. Similarly, Gorchynski (2001) used the PRS to explore family experiences of admitting an elderly relative into a LTC
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setting. Several key findings, many of which are consistent across studies, are discussed in this section.

One of the most consistent aspects of the decision to place a family member into LTC is the feeling of ambiguity and ambivalence. In particular, Penrod and Dellasega (1998) reported uncertainty surrounding the choice of the facility, the availability of a LTC bed, and the medical condition of their family member. Dellasega and Nolan (1999) documented ambiguity surrounding the emotions of caregivers. That is, while caregivers experienced a sense of relief, many also experienced feelings of guilt and reported feeling they had disappointed their relative. Gorchynski (2001) revealed that caregivers feared that the personal and emotional needs of their relatives would not be met in the LTC facility.

Family members also described a lack of control in the process, and disappointment with the health care system. More specifically, caregivers felt as if they had to surrender to the health care system and were defeated by that system. They further felt that the system had failed them in many ways. The studies also found that family caregivers experienced a strong sense of urgency when making decisions about the placement, which made the transition process even more difficult. For example, in a majority of cases, families felt rushed into accepting the first placement location available (Dellasega & Nolan, 1999; Penrod & Dellasega, 1998).

Family caregivers expressed insecurity with the decision to place their relative in a LTC facility and needed to feel validated about this decision. It was important for them to determine the right time, and to be sure that placement was at an appropriate facility and on an appropriate unit within that facility. To this effect,
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caregivers described constantly seeking information that would validate their choices (Gorchynski, 2001; Penrod & Dellasega, 1998).

Gorchynski’s study also found that one of the most difficult aspects of placing a relative into a LTC facility involved the feeling of empathy family members felt for the relative being placed in the LTC facility. Caregivers found it difficult to consider the loss of independence and control, and the loss of privacy experienced by their relatives because of placement (Gorchynski, 2001).

Moving to a LTC Facility From Hospital/Acute Care

In 1986, approximately 10% of older adults in the United States moved from hospital care to a LTC facility (Sahyoun, Pratt, Lentzner, Dey & Robinson, 2001) while approximately ten years later, in 1997, 58% of nursing home residents were admitted directly from a hospital and 33% came from private homes. Moving from a hospital to a LTC facility can be a very different experience for older adults as compared to moving from their own home to a LTC facility. It is also a very different experience for their caregivers. Rosenthal, Sulman, and Marshall (1993) interviewed ninety-one patients who had been staying in a hospital awaiting nursing home placement. As well, they interviewed the caregivers about factors affecting their own health. The study concluded that family caregivers displayed higher negative health symptoms of depression than what would be expected of caregivers of community dwelling elderly. Such symptoms were related to feeling too many demands, feeling torn between their own and their family members’ needs, not getting sufficient sleep, and spending large amounts time visiting their family member while they were in the hospital.
A study conducted in the United Kingdom by Cotter, Meyer and Roberts (1998) explored the transition experience from hospital to a nursing home for older adults and their carers, and included older adults with dementia. In-depth interviews took place with older adults and their carers at three different times: while still in hospital, just after discharge, and six months post discharge to a nursing home. Observations and focus group discussions with staff from both the hospital and the nursing home were also part of the data collection. The study discovered several key themes. First, both older adults and their family caregivers expressed the feeling that they were not heard during the process (Cotter et al., 1998). This was particularly true for persons with dementia, as only the carer was involved in any decision making about the move to the LTC facility. Second, the older adults placed in the LTC settings and carers felt that the assessment process, which took place in the hospital and the LTC settings, was fragmented and confusing. Most often older adults and their carers lacked an understanding of its purpose and function.

The Experiences of Caregivers After Placement

Stress and Burden
Pre-placement and post-placement stresses have a long-lasting effect on how caregivers experience the placement of their relatives to a long-term care facility. Caregivers talk about feeling a great deal of guilt and loss after placement to a LTC facility. King, Collins, Given and Vredgewood (1991) interviewed 35 family members of elderly persons recently institutionalized to examine the impacts of institutionalization on family members’ health. The authors found that the stress level actually increased rather than decreased after institutionalization primarily because family members’ health was compromised and because family members
often experienced financial stress with institutionalization. Other reasons for increased stress and burden include difficulties experienced in visits with the relative, providing assistance to their relative with activities of daily living, interacting with staff at the nursing home, handling other care arrangements, and experiencing a strong sense of ambiguity with the sudden role change (Zarit & Whitlach, 1993). This and other research suggests that placement does not necessarily alleviate stress, and in some cases may exacerbate stress levels for family caregivers. Stress, as a result of the placement experience, is often higher for women than for men (Zarit & Whitlach, 1993). Post-placement stress is further exacerbated because many caregivers must also carry on their daily employment lives outside the home (Zarit & Whitlach, 1993). These authors emphasized, “…the careers of caregivers do not stop at the institution’s door, but continue in an altered and still stressful way. Caregivers do not give up their role; they shift their responsibilities” (Zarit & Whitlach, 1993, p.35).

Once the elderly family member has moved to an institution, caregiving is a very different experience for sons and daughters. After interviewing 75 sons and 256 daughters about their overall levels of depression, Brody, Dempsey & Pruchno (1990) found daughters were more depressed, reported higher negative emotions related to their parents living in a nursing home, and reported more health problems than sons. Daughters also felt more time pressure as compared to son caregivers. The authors suggest that differences may be due to differences in the socialization process. That is, daughters are often socialized to become caregivers and nurturers, and often see themselves as responsible for care.

For some caregivers, after their family member moves to a nursing home, stress and burden can actually decrease and caregivers who felt emotionally trapped in
the relationship, say they feel freedom after their family member moves (Gaugler, Leitsch, Zarit & Pearlin, 2000). Gaugler et al. (2000) collected data from 185 caregivers before and after the placement of their care recipient in order to understand how stress prior to institutionalization affects caregivers’ involvement after placement occurs. These authors hypothesized that if caregivers experience stress prior to placement, then there was a strong likelihood of them having a negative experience during the placement, particularly with visiting, staff relationships, and with the nursing home environment. The results supported this hypothesis. For example, residents who displayed severe behavior problems before they moved to a nursing home were visited less by their families. The researchers suggested that in these situations, family caregivers may want to avoid these problems after placement. Also, family members of individuals who needed more instrumental care while being taken care of at home formed a negative perception of staff at the nursing home. Those caregivers who had strong social support while their relative was at home, however, were less likely to have problems with staff. Stress prior to nursing home placement, however, did not predict satisfaction with the nursing home environment compared to other caregivers. Factors related to satisfaction with the nursing home environment were related to caregiver characteristics. That is, older caregivers were more likely to indicate satisfaction, while spousal caregivers were less satisfied with the nursing home environment. Further, caregivers who reported problems with staff also indicated less satisfaction with the nursing home environment (Gaugler et al., 2000).

Appendix

Attachment
Attachment is defined as “an independent behavioral system based on the relationship between a mother and young child or caregivers and child” (Bowlby,
1988, cited in Loring-Crispi, Schiaffino, & Berman, 1997, p.53). This relationship is a complex one that provides strength and comfort during times of difficulty and grief. The attachment relationship was explored by Loring-Crispi et al. (1997) to examine how a sense of security might affect caregiving by adult child caregivers after a parent moves to a long-term care facility. After analyzing 108 surveys completed by adult children of persons with dementia residing in nursing homes, the authors found that a secure ‘attached’ relationship between parent and child had a significant effect on the degree of stress in the caregiving relationship after placement. Specifically, those who were securely attached had lower levels of caregiving difficulty as compared to those who said they had insecure attachments. Therefore, caregivers who have secure attachments to their relatives may be better able to handle the transition to a long-term care facility as compared to those caregivers insecurely attached to their parents. Nonetheless, more research is needed in this area.

Visiting
Visiting a relative in a LTC facility is a way to stay connected, keep the relationship going and express love and devotion. Ross, Rosenthal and Dawson (1997) interviewed wives of men who had recently been admitted into a LTC setting. The wives talked about being motivated to visit their husbands, which they did on an average of 2 to 4 hours per week, mainly by love and devotion to their spouse. They also talked about visiting as a response to a feeling of duty, obligation, being available to assist their spouse and the staff, and being able to monitor their spouses’ well-being. The literature challenges the myth that once admitted to a nursing home, family members abandon their relative (Gaugler et al., 2000; Kelley, Swanson, Maas & Tripp-Reimer, 1999; King et al., 1991).
Many factors influence the frequency of visits made by family and friends after a relative is placed in a LTC facility. Some of these factors include: the distance needed to travel to the facility, the level of education friends and family have attained, how family members and friends view their role, and the length of time the relative has been in the LTC facility. Gaugler et al. (2000), for example, found that caregivers who were more educated were actually less likely to visit their relatives and that relatives who resided in the nursing home for longer time periods had more frequent visits from family. In general, caregivers visit relatives in the nursing home an average of eight hours per week (Gaugler et al., 2000).

A study by Kelley and colleagues (1999) explored the meaning of visiting a family member with dementia on a special care unit. Of the thirty interviews that took place with family members, they talked about visiting being a duty and an act of being a faithful family member. They also talked about visiting as providing an opportunity to monitor the family members health and spending one-on-one time with their loved ones. Family members, who were most often spouses and daughters, found visiting difficult as they had to constantly face the truth of their changing relationship. Visiting, however, helped to “maintain some sense of family” (Kelley et al., 1999, p.19).

Difficulties Experienced During Visits
While visits to a relative in a LTC facility have many benefits, including providing support for the relative and being able to oversee care provision, many family caregivers experience difficulties during these visits (Kelley et al., 1999). Family caregivers often feel uncertain about how to interact with staff, and how much responsibilities they should take on. This has been found to lead to ambiguity and frustration over the roles families and staff are expected to assume (Wilken,
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Farran, Hellen, & Boggess, 1992). A study by Duncan and Morgan (1994) identified sources of distress for family caregivers during their visits to a LTC facility. Families in this study wanted recognition that they had expertise regarding their relative and that this knowledge could make an important contribution to the care. Another significant source of distress involved supervision and monitoring of staff. Families expected staff to provide both technically exceptional and emotionally involved care. Therefore, satisfaction with how things were done was equally important as satisfaction with what was done (Duncan & Morgan, 1994).

The emotionally demanding nature of visiting a relative in a LTC setting also makes visiting difficult. Many family caregivers continue to have difficulties accepting the deterioration of their loved one, continue to feel guilty about their decision to place their relative in long-term care, and begin to deal with changing roles and relationships. Caregivers of persons with dementia also experience difficulties communicating with their relatives as the dementia progresses, which can make visits even more frustrating and difficult for family members.

The Changing Relationship

“Placement…transforms the caregiving role…” (Gaugler et al., 2000, p.338). Once the person with dementia moves to the nursing home after being cared for at home by a family member, the relationship between them can change significantly. According to King et al. (1991) “caregiving does not cease at institutionalization” but the role of the family does change. In a study by Mackenzie and MacLean (1992), six elderly spouses were interviewed in order to understand how elderly individuals whose partners had been placed in a LTC facility experienced the transition. These authors found that spouses experienced feelings of loneliness,
loss and isolation. They also experienced the new relationship as one of “marking time”; that is, they felt as if they were truly unable to get on with their lives and they were marking the days. The third major theme that emerged from the interviews was that “the placement was a shock and the shock hits you every time you go to visit” (Mackenzie & MacLean, 1992, p.116). This theme captures the conflict spouses often feel between their past role and the loyalty they feel towards their spouse, and their new and changing role.

Rosenthal and Dawson (1991) discovered that this changing relationship has a significant effect on spouses. In a pilot study by the same authors aimed to develop a conceptual model of the experience of moving a spouse to a LTC facility, the authors interviewed fourteen wives whose husbands had immediately entered a LTC facility. The authors developed the concept of “quasi-widow” to describe the challenging and changing role experienced by spouses caring for a partner in a LTC facility. These spouses are still married and at the same time must live alone without their partners. One month following admission, these women mainly felt loneliness and poor mental and physical health. Also, they experienced ambivalence due to a back and forth shifting of positive and negative feelings; that is, at one moment they felt relieved and at another they felt guilt and sadness. Uncertainty was also a strong feeling experienced by the women just after the admission of their husbands to a nursing home. They were uncertain about the course of their husbands’ illness and about the institution and it’s staff (Rosenthal & Dawson, 1991).

In the follow-up study, which aimed to further develop and understand the conceptual model of quasi-widowhood, 69 wives were interviewed over an 18-month period, five different times, beginning one month after the admission of
their husbands. This study confirmed the previous findings from the pilot study. That is, the wives described the time after admission as being characterized mainly by interpersonal concerns such as depression and poor health, uncertainty about their husbands’ condition, and ambivalence, which was a result of changing feelings of satisfaction and relief (Rosenthal & Dawson, 1991).

**Positive Impacts of the Transition Experience**

From the above research, it can be concluded that when an elderly relative or friend moves to a nursing home, there are significant negative implications for the family. Nonetheless, some researchers have also identified some of the positive implications for caregivers associated with moving a relative to a LTC facility. An early study by Smith and Bengston (1979) explored the positive impacts of the institutionalization process, and found that LTC placement could result in a renewed closeness between children and their parents, which helped to strengthen the family. Also, a positive result of moving to a nursing home was the creation of a new love and affection by children for an elderly parent. Adult children found that this new closeness continued throughout the institutionalization process.

More recently, Gorchynski’s (2001) research examined the experience of caregivers before, during and after moving a relative to a LTC facility. Results from interviews with thirteen caregivers and five elders with dementia suggest that there were a number of benefits to moving an older relative with dementia to a LTC facility: their family member received appropriate care, their relative was safer than if they lived at home with the caregiver, living in a LTC facility offered many social opportunities for their relative, the caregiver was finally able to feel some relief from day-to-day caregiving responsibilities, and for their relative, there
was some relief from caring for themselves. Nonetheless, few studies conducted have focused on the positive impacts of placement for families and the resident. Much more work is needed in this area.

**Recommendations for Easing the Transition**

A few studies, which focused on examining the impact of the placement experience on families, also provide some insight on how the transition can be made easier for family members and the person being placed in a LTC facility. The following is a description of factors that might ease the transition suggested in the literature.

**Have Contact with Families Prior to Admission**

Nolan and Dellasega (1999) explored the overall transition experience for family caregivers before, during and after placement of a relative moving to a LTC facility. They suggested that the LTC facility contact the family prior to placement, which would help involve the family in the care planning process prior to admission.

**Celebrate the Transition**

To ease the transition experience, it would helpful for the facility to create a very welcoming environment for families so they feel as if they want to be involved in the care of their family members at the facility. Schneewind (1990) recommends having a major ceremony during and/or around the time of admission to
acknowledge the significance of the change. For example, the facility could hold a big dinner party and treat it like a housewarming party.

*Provide Education Sessions for Staff and Family*

Penrod and Dellasega (1998) believe that professional education would help staff to better understand the decision making process for families. For example, if staff were more aware of the consequences of the placement for families they would find better ways to support families. Drysdale, Nelson & Wineman (1993) provided education sessions for new family members about the aging process, for example, how to visit, and how to adjust to a nursing home. Families found these sessions to be very positive, which helped ease the transition. Another source of education for families would be to provide information about typical reactions to LTC placement (Gorchynski, 2001).

*Ease the Movement Through the System*

Families express frustration and confusion with the LTC system from the beginning of their contact with the system (Dove, 1986). Therefore, it would also help to have one contact person to assist family members through the placement process because family members find the whole placement experience stressful and overwhelming (Dove, 1986). Rosenthal & Dawson (1991) suggest that during and immediately following admission and for some time later, spouses should be viewed as clients as well as the family member who is actually admitted. This means providing support to both residents and their families throughout the transition process. Gorchynski (2001) also makes a number of suggestions on how to ease the transition. Families need to have more time to make the placement
decision, have the opportunity to honestly weigh the pros and cons of placement, and have the ability to see and select appropriate environments.

**Strengthen the Relationship Between Families and Staff**

After interviewing 282 patients and their primary caregivers, Penrod, Kane and Kane (2000) found that family members’ involvement in providing hands-on care while their family member was in the nursing home actually increased the odds of them being discharged back home. The authors stated that it was not the visiting but the actual care being provided by family members that affected the ability for the resident to improve. More attention, therefore, needs to be given to find ways to “create a truly synergistic relationship between paid caregivers and caregiving families in the nursing home” (Penrod, Kane & Kane, 2000, p.79). According to Nolan and Dellasega (1999), roles between families and staff need to be clarified and staff need to value and access family caregivers’ knowledge and expertise because families know the stories of the residents (Rowles & High, 1996). Further, if family caregivers have a positive perception of the admission process, they will be more likely to want to be partners with staff to continue to support their family member in the nursing home. Gaugler et al. (2001) suggested providing an opportunity for families to interview staff members so they can get more acquainted with them. Further, having positive interactions with staff at the facility, ensuring good communication between families and facilities, and clearly identifying responsibilities may also serve to strengthen relationships between family and staff (Gorchynski, 2001).

**Support Groups for Families**
A number of studies (Drysdale et al., 1993; Gaugler et al., 2001; Mastrian & Dellasega, 1996) suggest the need for and benefits of providing a support group for family members once their family has been admitted into a nursing home. This helps family members link with others who have already been through the transition experience. Gorchynski (2001) identified that having the opportunity to talk with someone who has already been through the transition process may provide support to families.

From the literature in this area, it can be concluded that the transition is a more positive process if family members are involved in the overall plan for care (Mastrian & Dellasega, 1996; Rowles & High, 1996). Zarit and Whitlach (1993) emphasize that finding effective ways to integrate families into the LTC setting will be beneficial not only for family members but for the resident and the facility staff as well.

**Acknowledging and Respecting Knowledge Bases of Family Members**

Gorchynski (2001) identified that staff at the LTC facilities need to show their respect for families in order to help ease the transition. This could be accomplished by providing affirmation and validation to families regarding the decision, acknowledging the knowledge families have regarding the new resident, and ensuring communication between staff and families continues after admission (Gorchynski, 2001).
Further Areas of Study

The study of the experience of moving an older relative to a LTC facility when having cared for them at home is still in its exploratory stages. As the older adult population grows, and the population of individuals with dementia continues to increase, more and more individuals may require care within a LTC facility. We will, therefore, need to continue to study this phenomenon in order to find ways to ensure it is an experience of ease and comfort for families and the person moving.

More specifically, Zarit & Whitlach (1993) suggest we need to be able to identify the consequences of the actual placement experience. That is, those outcomes that are most likely to be affected by the event versus those consequences which are not affected by the actual event of moving. Also, we need to know, from the family’s perspective, how to ease the overall transition experience. This remains lacking in the literature.
STUDY QUESTIONS AND METHODS USED

The purpose of this study was to examine the transition process from community care to long-term care for family caregivers of older adults and to identify specific ways in which facilities can help to ease the transition both for families and for residents. A number of research questions served to guide this investigation:

1) How do families describe the experience of placement for themselves?
2) How do family members describe the transition experience for their relative?
3) What were the most challenging aspects of the transition process and why?
4) What did family members find to be most supportive or helpful throughout the transition experience and why?
5) What could the facility have done to ease the placement experience?

These questions were addressed by conducting in-depth, semi-structured interviews with twenty-one family caregivers who had recently, within 6-8 weeks, admitted their relative into one of three long-term care facilities in southern Ontario. All three facilities that participated in the study are research sites for the Murray Alzheimer Research and Education Program (MAREP), which is located within the Faculty of Applied Health Sciences at the University of Waterloo. Family members represented various caregiving roles, including: adult daughters (12), spouses (5), an adult sibling (1), an adult son (1), and adult granddaughters (2). All family members who were interviewed identified themselves as the primary caregiver for their relative. Of the twenty-one family members interviewed, thirteen of the family members were caring for a relative who had been diagnosed with dementia at the time of admission to the LTC facility. The
relatives of the remaining eight family members were diagnosed with other conditions such as stroke, Parkinson’s disease, depression, and a heart condition.

An interview guide was prepared for the interviews and is presented in Appendix A. Specifically, the interviews were designed to examine the experience of the transition process for the family caregiver, caregivers’ perceptions of the experience for their relative, difficult aspects of the transition process for families and new residents, aspects of the transition process that were perceived to be supportive or helpful, and specific recommendations families had for improving or easing the transition process. The majority of the interviews took place in the home of the participants, while the other interviews took place in a private location at the nursing home where their relative resided. All interviews were tape recorded with the full consent of family members and then were transcribed verbatim. Analysis involved reading and re-reading the transcripts to identify patterns and major themes. A constant comparison method was used until a state of saturation was reached (Glaser & Strauss, 1967; Strauss & Corbin, 1990).

Prior to the interview with family members, an information interview was held with the key staff person in charge of the admission process at each of the three facilities. The purpose was to understand the admission processes and procedures specific to that facility and/or region where that facility was located. These interviews suggested that the procedures used at all three facilities were similar.

Before a MAREP researcher contacted potential participants, the contact staff person at each of the facilities telephoned family members approximately two weeks following admission of their relatives. In this phone call they briefly described the study; determined their interest in receiving a phone call from a
MAREP researcher to hear more about the study; and, if the family member was willing to be contacted by a MAREP researcher, their phone number was given to a MAREP researcher. The MAREP researcher then telephoned the family member, described the study in more detail, determined their interest in participating in an interview, and if they agreed, arranged for an interview time and location. Generally, interviews lasted between 1 to 1.5 hours. Data gathering took place between June and November 2002.

**FINDINGS**

**Significant Aspects of the Transition Process**  
**Prior to Moving their Relative to a Long-term Care Facility**

Family caregivers described a number of themes that reflect aspects of the transition process prior to moving the relative to the LTC facility. These themes include: the complexity of the transition experience; the trigger to move to long term care; the role of the Community Care Access Center; touring long-term care facilities; the waiting process; and, the call...then 24 hours to decide.

*Complexity of the Transition Experience*

Family members described the overall transition process of their relative moving to a long-term care facility as complex. Most often, it consisted of their relative moving from one location to another over a period of time depending on their relative’s state of health and/or the availability of beds in retirement homes and LTC facilities. A majority of the older relatives had been previously placed in at least two locations. They had frequently been placed in a hospital, a retirement
facility, or another LTC facility, prior to finally moving to the facility at which they currently resided. Figures 1, 2, 3, and 4 depict several examples of the ‘transition process’ at the time of the interview for relatives of family members interviewed.
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Figure 1. Transition of a Grandmother

- Own apartment
- Retirement facility
- Second Retirement facility
- LTC Facility
- Second LTC Facility

Figure 2. Transition of a Father

- Own home
- Hospital
- Daughters home
- Hospital
- LTC Facility

Figure 3. Transition of a Father

- Own home
- Hospital
- Retirement home
- Supportive care in a LTC Facility
- Hospital
- Supportive care in a LTC Facility

Figure 4. Transition of a Mother

- Own apartment
- Hospital
- Hospital/Rehab focus
- Retirement Facility
- LTC Facility
The Trigger to Move to Long-Term Care

The trigger for family members to move their relative into a long-term care facility was primarily due to either a significant change in the health status of their relative or their own recognition that they “are on the edge of a breakdown” and are no longer able to cope and that “something had to be done.” In some cases both a change in the relative’s health status and a change in the caregiver’s ability to cope triggered the LTC placement. For some family members, the ‘trigger’ was a crisis such as aggressive behavior in the care receiver, as one family member described: “he hit me and he wanted to kill me and I wanted to kill him.” For others, the trigger was a sudden crisis or change in the primary caregiver’s situation or with the facility in which the relative lived. For example, in one case a retirement home was unable to cope with a particular health change of the resident and recommended the move to a LTC facility. Whatever the trigger, action was then taken to begin the process of moving the relative into a LTC facility.

Role of the Community Care Access Center (CCAC)

Family members of a relative living in the community at the time of the move to a LTC facility indicated that the CCAC was the organization they contacted to begin the process; however, if their relative was in hospital, the hospital’s social worker took over the process of coordinating the move. Family members described the process to include an assessment of their relative by a case manager, completion of much paper work, and recommendations made by the CCAC case manager. Most family members commented that the CCAC process was confusing. The confusion related to the amount of paperwork and administration involved as well as the uncertainty about the entire process of applying and waiting for a bed. Two
participants had very negative experiences with the CCAC. The file of one family member’s relative “…got sent to Toronto and was lost,” while the other family member’s relative was inappropriately placed because, “they didn’t do the background on Grandma,” and she was placed on a unit for people with dementia but she did not have dementia.

**Touring Long-Term Care Facilities**

After contacting the CCAC, most families toured many facilities in order to determine which three facilities were their ‘preferred’ choices. One spouse went on several tours, interviewed key people at the facility and evaluated each using a classification system with four categories and a rating scale that he designed himself. With the exception of a few family members, the transition experience always involved a tour of several other facilities, which were conducted either on their own or with their relative present.

**The Waiting Process**

The phenomenon of waiting appeared to be very common in the experience of moving a relative to a long-term care facility. In this context, families are ‘waiting’ for a bed in a long-term care facility to become available so their relative can move into that facility. They have placed their relative on the ‘waiting list’ and have been told by the CCAC or by the person coordinating the move at the hospital that they now have to wait for a bed to become available before their relative can be placed.
There seemed to be a strong sense of urgency to this ‘waiting period’. One family member phoned CCAC often, “I kept calling and calling” while another family member called every two weeks for a year to determine where her relative was on the ‘waiting list’. After her relative finally moved to a long-term care facility, she now recommends that other family members “hurry” to get their relative on the waiting list.

Along with the urgency associated with waiting was a strong sense of uncertainty and ambiguity, which made it very frustrating and hard to plan, made decision-making difficult, and made it hard for family members to know how to proceed. One family member commented: “…that was the most frustrating part, not knowing if it was two months or two years.” While waiting, however, some families adapted their home to make it easier for their relative to cope, and others hired paid help.

The vast majority of family members interviewed talked about getting “the call,” telling them a bed was available, and having to make a decision in the next 24 to 48 hours. Families described this as extremely stressful. For example, one family caregiver said: “I get a call saying a bed’s available…at which point I put my head down on my desk and cried.” Another family caregiver described how much needed to be done in a short period of time: “we had to come and see the room, make a decision… get his stuff ready…move him in here…and actually say goodbye.”

Another family member described how stressful the process was for her:
I came back from [Europe], it was a Monday morning, my first day back and I get a call at 11:30 that there is a bed available…but I have to take it that day; move him that day. I was completely booked so I had to cancel all of my clients…get a moving truck to move his stuff…arrange for him to be transported and say hi dad I haven’t seen you for a couple of weeks but guess what, we are moving you today, he was traumatized by that.

The pressure resulting from the call about the availability of the bed, making a very quick decision to accept or deny the bed, and having to arrange the move created tremendous stress for family members.

Challenging Aspects of the Transition

Family members talked about many aspects of the entire transition experience that were most challenging and difficult for them and for their relative. More specifically, they talked about challenges experienced in the overall transition as well as challenges encountered during the actual day they moved there relative to the long-term care facility.

The Family’s Experience of the Overall Transition

Guilt

For family members who moved their relative to a long-term care facility, “the feeling of guilt is HUGE.” Of those family members interviewed, most of them talked about the guilt they felt in “putting” their family member into a LTC facility. They felt as though they “should” be able to look after them at home and yet felt emotionally burdened by not being able to do so. In the words of an adult daughter about her father, “he is in an institution and he should be home with us.”
In describing the overall experience, one sister talked about her guilt in moving her brother to a long-term care facility: “I put him in there…I did this…I really felt as if it were my fault…” For many, this guilt was self-imposed; however others felt guilt due to the blame imposed on them by their relatives. For example, one family member stated: “he blames me for putting him in there.” Others were reminded by their relatives “YOU put me in here.” Also, some family members were affected by the public perception of abandoning their relative. After the move, some family members questioned whether they should have ever moved their relative to a nursing home due to their own overwhelming feeling of guilt.

Not only did families feel guilty for moving their relative to a nursing home, but they also felt guilty when they did not visit their relative as often as they believed they “should.” For example, one daughter caregiver explained the most difficult part of placing her mother into LTC: “It is trying to organize your life…to fit them in. Because if you don’t you feel guilty. You know, because they have been so good to us.” Guilt, therefore, seems to be a very large part of the transition experience of moving a relative to a long-term care facility.

Acceptance of the Disease Progression
Another significant challenge to family members in this study was the difficulty they experienced in observing and accepting the deterioration of their relative’s disease process. This theme was most prevalent for those family members caring for a resident with dementia; however, family members of residents with a diagnosis of stroke or Parkinson’s disease also found it challenging to accept the decline of their relative due to the disease process. Family caregivers talked about how “awful” it was to watch their loved one decline and how hard it was to accept that the disease would eventually worsen, especially for those with dementia. One
adult daughter, who lived a far distance from her mother who had dementia, stated: “…I know the disease process and I know what to expect, but when it happens to you, it is really just hard to accept.” A wife described how difficult it was for her to watch the deterioration of her husband, particularly watching him eat pureed food, be restrained, lose his independence, and lose his bladder and bowel control. She explained that to “see him drool and his speech slurred… is hell… it’s a horrendous experience.” One adult daughter called dementia an “evil disease.” Some family members talked about the frustration they felt, as they could not do anything to help or even stop the disease process from worsening. Their challenge in accepting the state of health of their relative also made visiting a very difficult experience. For instance, one caregiver explained that, “it’s been tough…she was an awesome mom and she is not the same person.”

Poor Care and Communication at the Facility

A number of family members said they were challenged by the poor care they felt their relatives were receiving at the long-term care facility. This may be because “people are just not suited for this job…” or because there was a lack of staff to provide good care. One adult daughter referred to the lack of staff as “disgraceful” and “distressing” while another family member connected the lack of staff to an increased loss of her fathers’ independence and an increase in his level of incontinence. According to several families, staff who were present were “overworked,” which families said was an issue everywhere they went. Staff try their best, some families agreed, but there were just not enough of them to provide good care.

Several family members talked about being challenged by the poor communication that they felt existed between the staff members and family at the facility. When
asking why her mother was placed on a dementia unit when she did not have dementia, the adult daughter was told, “…ya, go ask that person, no go to that person and that person will help you down there…,” which made her feel as if she were going around in a “vicious circle.”

**Overwhelming Responsibility**

Families who are in the process of moving their relatives to a LTC facility experienced an enormous amount of responsibility. In the words of one adult daughter, “I get all the brunt of it…because it was all kind of put on me…. the onus was on me.” One adult granddaughter reflected on the responsibility the facility places on the family: “its totally up to the family to arrange for the doctors orders to be transferred, to arrange for medication orders to be conveyed from facility to facility…” Another adult daughter described the responsibility placed on her during the move: “I have to worry about getting mom into the proper place, and I also have to sell the house and the finances and do it all at once…” Finally, in the words of a spouse who had been separated for the first time from her husband of 54 years, “…and now I’ve got to do EVERYTHING regardless of if I’m well or not well. I have to do it all…and I’m alone with everything.” The responsibility placed on the shoulders of the key family member taking the initiative in the transition experience was overwhelming.

**Stress**

When asked what was most difficult about the entire transition experience, many family members described examples and situations that conveyed a transition experience that was extremely stressful. Overall, the stress was expressed as being related to the uncertainty of waiting for a bed to become available and receiving the phone call that told them a bed was now available and they had 24 hours to
decide if they were going to accept it or not. Furthermore, several family members talked about the degree of paperwork and “bureaucracy” involved in the entire process which they did not feel prepared for, paperwork “that would make a government official blush if they saw it,” stated one adult granddaughter.

When describing the overall transition experience for herself, one adult daughter said, “it’s been difficult, stressful and it drives me nuts…,” while another adult daughter emphasized, “its been stressful, [and] I’d rather do anything else but…life is just not fair” and another adult granddaughter described the overall experience as, “rushed, stressful and very time consuming.” For two adult daughters moving their father with dementia to a long-term care facility, the overall transition experience was “horrible. We had a lot of anxiety and tears and stress…we were thrown into it so quickly, we didn’t really have time to prepare ourselves emotionally for it.”

Lack of Choices
Family members interviewed for this study identified a lack of choice and not feeling in control as a major challenge in the experience of moving an older relative from community care to long-term care. One area in which families felt very little control was in the choice of a bed and facility. One family caregiver explained: “…we had no choice. The government makes you go there like that was the first bed…” Families said they felt as though they had no option or they would have to suffer the consequences, “I had to take whatever one [bed] came up or he’d have been taken off the list.” One wife’s husband needed to be at a facility that could provide care for his g-tube and trachea; therefore, she had no choice in facilities that could accommodate her husband’s needs.
One family member also felt frustrated that she lacked choice in deciding who her mother’s doctor would be at the facility. Finally, if a relative moved from a hospital to a LTC facility, family caregivers felt they had no choice in the decision-making process. They perceived that all decisions were made by the person at the hospital, usually the social worker, coordinating the move.

*Loss*

Though not a major theme, several spouses talked about their own loss associated with moving their spouse to a long-term care facility. Their loss, as they described it, related to their separation from their spouse and missing them. For one spouse, this move was the first time in fifty-four years that she had been separated making it very lonely for both the woman and her husband. The wife explained: “You sit here at night, you know…he was always sitting in that chair…you are lonely.” She also described the separation from her husband’s perspective: “he says, we’ve never been separated, he said, this is too long.”
The Family’s Experience During the Actual Day of the Move

Difficulty Accepting the Move

“The day it happened, was awful,” states an adult daughter talking about the day she moved her mother to a LTC facility. During the actual move itself, family members talked about the difficulty associated with accepting the size of the room their relative was going to live in, which one family member calls a place where you just “…stand and pivot and everything is there for you…” Family members also had a hard time accepting that they could only bring very few personal items to the facilities for their relatives “you hate to see your mom going with a suitcase and just a limited amount of clothes to take and that’s it…it’s sad.”

For other family members, the room did not feel like home, “…I just couldn’t accept…when I came to see the room, it didn’t feel like home…like…it’s an institution…it’s a nice place but it’s not home….” The most difficult thing to accept for one daughter and her mother on the actual day of the move was having to finally leave her father behind. The adult daughter explained: “and leaving him here was very difficult. I remember driving home, my mom was crying and I was crying and it was very difficult to leave him here and to realize that this was going to be his place from now on.”

The Move Felt Rushed

Several family members found that the actual move happened too quickly making the experience of moving their relative to a LTC facility very difficult for them, “it happened so suddenly…I heard it [that we had to move] on Friday and he had to come as soon as possible, it was kind of a shock…I wish it wasn’t so sudden, it is too sudden.” One adult daughter called the move “chaotic” because she was told,
“we have three hours to move your Mom.” Moving a relative with dementia or a relative who is aging offers many challenges, but forcing the move to happen too fast creates additional difficulties for family members.

Facility Unwelcoming and Inflexible
At least three family members talked about the difficulty of not being welcomed the day they arrived. For example, one caregiver stated: “when I walked in, there was nobody there…we didn’t expect a red carpet but…” Similarly, another family member emphasized: “they could have met me when I walked in the door…I had no clue where [the unit] was.” The staff at one facility were not flexible about the time of the admission, “they wanted her there by ten. I said little old ladies don’t get up, have breakfast, get dressed and get anywhere by ten on top of an hour and a half of driving…and they were pretty firm about it, that’s the time we do admissions.”

The Family’s Perception of their Relatives’ Experience of the Overall Transition

During the interviews, family members were also asked to reflect on the transition process for their relative and to describe their perception of the experience for the relative being placed. Three themes emerged which describe aspects of the experience for the new resident: loss and lack of acceptance, difficulties associated with moving around, and difficulties associated with inappropriate or unsuitable placements.
Loss and Lack of Acceptance

One of the most difficult aspects of the overall transition process for residents perceived by their family caregivers was the sadness and sense of loss associated with the entire experience. This feeling was associated with the loss of their previous life, particularly the loss of their home, and their routine. For example, one daughter caregiver explained that the most difficult aspect of the move to a LTC facility for her father was “just the familiar things that he’d lost, he had a routine like a baby.” Also, feelings of loss were related to the realization that going home would not be an option: “what was really difficult for her…realizing that she wasn’t coming home, because she does want to come home.”

Other families described their relatives’ loss to be associated with sadness about losing their independence and losing their ability to make choices for themselves because “everything [in a nursing home] is decided for them.” For many, this loss is associated with changes in their state of health and the loss associated with the deterioration of the disease process. As one adult daughter described it, the loss associated with having dementia made it feel as if “everything came crashing down” for her mother.

For some relatives, loss was more related to losing connection with friends in their community and also friends they had made if they were in a hospital or another institution prior to moving to a LTC facility. Many residents who moved to a LTC facility had been in other LTC or retirement facilities or in hospital for a period of time prior to moving to the facility and often made friends and connections with other residents and staff in these settings. In most cases, their relative often had to
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leave very quickly and, therefore, was unable to bring any closure to those relationships. For example, one family caregiver explained that it was difficult for her relative to: “[leave] those people behind that she had been living with for two years.” Loss was also related to not seeing family as frequently, especially for those relatives who had been living with children prior to the move. One daughter caregiver reflected, “maybe at first she missed seeing me as often.”

Moving Around
Several family members recounted that it was very difficult and “very exhausting” for their relative to move around from one place to another prior to finally moving to the present LTC facility. Caregivers felt that this “moving around” made the entire transition a very difficult experience. For instance, one family member recounted “I think it was exhausting for her. Especially two moves in literally under ten days.” Another family caregiver felt that the moving around was physically difficult for her relative. Moreover, she explained: “that had a part in his deterioration too because he was just up and down, up and down, like between the hospital and home, it was just too much.”

Inappropriate Placement/Placement Not Well Suited
Although not a major theme from the interviews, some family members described how difficult the process was for their loved ones when inappropriate placement decisions were made, or the relative was not ready for the move. One adult granddaughter, for example, perceived that her relative had been placed in an inappropriate unit, which “they [CCAC and the facility] said was a mistake.” She felt that this made it more difficult for her relative to adapt to the new facility.
Two adult daughters felt that their relative was not ready to move to the unit where they were eventually placed. They felt that this made the entire transition experience for their relative very difficult. One of these adult daughters felt that, because the other residents on the unit where her mother was placed appeared much worse off compared to her mother, the whole experience actually “traumatized” her mother. She was concerned that her mother was stigmatized for being on a dementia unit because she asked to wear a badge stating she was from “upstairs.” The daughter further explained that this process of labeling was “sort of embarrassing and it again isolates her…”

The Family’s Perception of their Relatives’ Experience

During the Actual Day of the Move

Resident Confusion
On the actual day of moving their relatives to the long-term care facility, many family members were challenged because their relatives were “unaware of the actual move” or were confused by what was happening. Only family members whose relatives were diagnosed with some type of dementia expressed confusion as a challenge. For example, one adult daughter described the actual day of the move for her mother who had dementia as follows: “…she really didn’t understand what was happening and was very angry with me.” Words or phrases used to describe the state of mind of their relative on the actual day of the move by family members were: “bewildered,” “irrational and frightened,” “disoriented,” “he didn’t realize what was happening to him,” and, “he wasn’t aware of what was going on.”
Easing the Transition

Difficult and Sadness Associated With Change
Family members described the actual day of the move to be difficult for their relatives because of the overall sense that relatives perceived the change as sad and very hard to accept. One adult daughter recalled attempting to get her mother ready to leave for the nursing home: “…I said we better get ready to move…and then the coffee cup flew in my direction, full of coffee.” One sibling caregiver also found that “the most difficult part [for my brother] was to finally admit that he had to go into a nursing home.”

There is often sadness associated with change and the sadness for one relative was “… just the sadness of [going] somewhere where she is protected.” For another relative, the sadness was associated with the change of being so far away from family.

Positive/Supportive Aspects of the Transition
Family members talked about many aspects of the entire transition experience that helped make the process easier for them and for their relative. More specifically, they talked about positive and supportive experiences in the overall transition as well as aspects encountered during the actual day they moved there relative to the long-term care facility that eased the transition.

Positive Aspects for the Family of the Overall Transition

Relief
A number of family members who were interviewed for this study felt that a positive aspect of the overall experience of moving their relatives to a LTC facility was the sense of relief they felt. Several weeks after admitting her husband to a
nursing home, one wife said, “I felt myself relax… [because] there is a level of competence here…” Family members felt secure that their relative was being taken care of by trained staff. They felt relieved that their family member was in the best possible facility, considering the circumstances. In the words of an adult daughter and her husband: “this is the first time we have been able to relax because she is in appropriate care…”

Family members also felt much relief knowing that their relative was safe. For some family members, their relative had been living with them or in a situation perceived to be unsafe, and moving them to a LTC facility where it was safe brought them a feeling of relief. Family members commented: “…we didn’t have to be afraid of her getting into trouble anymore,” and “the main part to me is that he is looked after…[which means] I don’t have to worry,” and “I realized that I could not take care of him [father]…and this eased the guilt.” Associated with this feeling of relief due to a sense of safety was knowing that there was always someone to look after their relative. “I think what was comforting to me…was that he would have 24-hour care. That there would always be someone there to answer him.” They felt that this would make their relative feel safe as well. Also, caregivers thought that constant social interaction would make their relative less lonely and happier. For instance one daughter felt that having people around constantly helped to “[keep] them going. This way they are not just couch potatoes, they don’t just sit there and have negative thoughts all the time.”

**Familiarity**

Another positive aspect of the entire transition experience for family members was the knowledge that their relatives felt comfortable and familiar with the facility. Many family members found it to be very comforting to be able to prepare the
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room in the nursing home prior to their relative moving. One daughter explains: “Everything was set…all her pictures were done ahead of time so I think it made a difference.” It was important for families to be able to make their relative’s new home “familiar” and decorate it with things their relative was accustomed to and that they recognized. Therefore, families said it was helpful that they had access to the room where their relative was to stay prior to the actual move. Families believed this brought their relative greater comfort, which resulted in comfort for themselves.

Good Staff

Another aspect of a positive transition experience, as described by some family members, was a sense of security of knowing their relative was being taken care of by good staff. Many families commented on the good care and sensitivity expressed by the staff at the facility towards them and their relative. They felt that the staff were competent and prepared to deal with their situation. For instance, one family member explained: “this is the first time that we have been able to relax because she is in appropriate care.” Another felt that the move from one LTC facility to a new one was a good decision because “you get a sense that things are done better…selection was done much better…the people are also better trained for their job.”

Family members also said that the staff at the facility were supportive; they helped the family to understand how the health care “system” worked and explained the overall process and procedures of moving a relative into the LTC facility, which they found helpful. One daughter described her experience with the LTC facility staff: “I never felt uncomfortable with the people that worked there. They were supportive and that was very helpful.” She went on to explain that “the staff
encouraged you to get to know them, and I was on a first name basis with them.”
Another family caregiver described how friendly and welcoming staff were:
“…she [the staff member] was really wonderful. She was very friendly and explained everything in detail and I found her to be quite comforting too.” This feeling of comfort with the staff contributed to a sense of relief and a confidence in the decision to move the relative to a LTC facility.

The familiarity of the facility, overall, also made the entire transition experience more positive for both the family caregiver and the new resident. For example, some family members were familiar with the facility their relative moved into because their relative had attended a day program at that facility or they had stayed there for respite purposes. Speaking of what made the transition easier for her husband, one woman explained: “the only thing was [that] the day program got him used to [the facility]…this is just one great big long day program.” Family members expressed that this overall sense of familiarity was a beneficial element to them in the overall transition of moving their relatives to a LTC facility.

**Support**

According to family members, the support they received throughout the entire experience of moving their relatives to LTC facilities was paramount. Some family members talked about the significance of the informal support they received from their friends and family. Others, however, referred to the value of the support they received from formal services. For example, reference was made to the Alzheimer support group provided by their local Alzheimer Society chapter, which offered connection to others in similar situations and educational sessions: “I joined the Alzheimer Support group while [my father] was still at home and I found that to be really helpful.” Some family members also described the support they received at
the day programs where their relative went for respite and social activities. Another woman praised the support she received from an Alzheimer outreach program: “They have been a blessing to us. We couldn’t have survived this without them.”

Other family members referred not necessarily to the value of the actual program and service but to the people, or one person in particular, associated with those programs and/or services. For example, the CCAC case manager was “wonderful” for one adult daughter who moved her father with dementia to a nursing home:

…I could phone her up and ask her questions and she always had time for me. She was always very friendly and very helpful with suggestions…she actually hugged us all goodbye…and that was comforting…she gave me the support that I needed.

For other family members the particular person who provided support and comfort to them was their family doctor, and for others it was the friendly visitor who cared for their relative in their home prior to them moving to the facility. The clergy person at the LTC facility was an important support for other family caregivers.

Positive/Supportive Aspects for the Family During the Actual Day of the Move

Welcoming Staff
For the actual move of their relative to the nursing home to be a positive one, family members expressed the importance of staff being caring and welcoming. What family members seemed to find most important was the friendliness of staff and their pleasant attitudes. One comment was even made about the “nice” paramedics who drove a caregiver’s husband to the facility from the hospital on the day of the move. A few family members commented on how nice it was to be met
at the front door the day they arrived at the facility and how some staff did little things to make them feel welcome. For example, on the day of the move, an adult daughter shared a meal with her mother at the new facility, “…we went out to the patio and he [the staff] brought a table cloth to make us feel comfortable…”

*Relative Looking Forward to the Move*

When asked what made the actual day of moving their relatives to the facility a positive one for them, several family members said that it was pleasant because their relatives were “looking forward to the move.” This was the case when relatives were being moved to the LTC facility from an acute hospital, or another LTC facility in which they were unhappy.

*Familiarity*

Several comments were made by family members about the value of feeling a sense of familiarity on the actual day of the move. For example, at one facility, the staff person who conducted tours for family members was also the key admission person. This consistency helped an adult daughter feel more comfortable and at ease on that day. For a few other family members, the facility itself was familiar to them on the actual day of the move because their relative had been there before to attend a day program or for respite. Family members said this provided them with a sense of comfort.
Connection with Family and Visits
Connection with their family and regular visits from them made the entire experience of moving to a LTC facility comforting for their relative. Several family members actually worked at the facility where their relative was placed making visits easier. Caregivers said that regular visits from the family helped their relative adapt more easily to their new home. In one instance, having a telephone in his room allowed one husband to be able to phone his wife as often as he wished. For another relative, regular family visits allowed him to maintain some degree of his regular routine. Being surrounded by family on a regular basis was said to help make the entire transition of moving to a LTC facility more comforting for their relative.

Familiarity
A few family members mentioned the significance of familiarity for their relative. Their relatives’ familiarity with the facility, either because they had attended a day program or had received respite care at the facility prior to placement, helped to make the entire transition process more comforting for their relative. One wife commented on how well her husband adapted to the new facility: ‘…I think he was at ease with the whole transition because of the day program…the day program got him used to [the facility]…’ In a number of cases the person moving to the facility had a family member working there; and this helped to make the entire transition experience a more comforting one as well.
Unaware

For some family members, that their relatives were “unaware” of the actual day of the move to the nursing home was perceived as having very positive implications for their relative. Those family members whose relative had a diagnosis of dementia were the only individuals to identify this perspective as being significant. According to these family members, “it [the move] is easier if your mind is completely gone…it’s a blessing.” Other family members stated: “it’s easier that she didn’t know what was going on,” and “because of his dementia, and he is unaware, he is content, he is at peace.” Family members identified this state of being “unaware” as having a very positive effect on their relative on the day of the move.

Welcoming

Finally, family members said that staff being particularly friendly and welcoming on the actual day their relative moved to the facility made the move more comforting for their relative. Family members talked about the value of staff “who showed an interest” in their relative, and staff who provided reassuring words to their relative, as well as staff who hugged their relative, as actions and qualities that made the day of the move a more positive experience.
STRATEGIES AND RECOMMENDATIONS TO HELP EASE THE TRANSITION

During the interviews, family members were asked to make recommendations to long-term care facilities about what could be done to make the transition easier for themselves as well as their relatives. Many highlighted the challenges to transition that were discussed in the previous sections and wished LTC facilities would help them to overcome those challenges. Education and support were very important aspects that family members suggested would help ease the transition. The following describes the families’ recommendations in more detail.

Recommendations Made by Family

*Prepare Families for the Transition*

Family members want to feel prepared as much as possible to deal with the entire transition process. Families want to have the entire process explained to them including the entire admission and waiting process. Also, they want “to be told a little bit beforehand of the day and what is going to go on and how it’s going to be.” In the words of another family member, “some transitions have to be explained to families…and interpreted… for families and their relative.” This role can either be taken on by the CCAC or the facility, one family member recommended. Facilities or the CCAC might offer information sessions to families before they admit their relative, “to prepare you,” while you are on the waiting list.

After they know their relative is being admitted, family members suggested the following be made available to them: a list of items to bring to the facility, a list of
contact numbers at the facility, a list of days when the doctor is available, a list of suggested items if their relative is moving to retirement or to supportive care, and maybe even a list of expectations of responsibilities for the family. Basically, families say they want more guidance throughout the transition process.

After their relative has moved to the facility, some family members suggested that it would be of great assistance for the facility to teach them practical strategies to deal with their relatives challenging behaviors and to make visits a more meaningful experience.

Several families felt a strong sense of urgency about ‘getting on the waiting list’ and said they wished they had felt more prepared. Therefore, they recommended to other families that they get their relatives’ name on the waiting list as soon as possible. They also recommended that information about nursing homes and the entire transition process be more accessible to families.

Finally, prior to their relative moving to the facility, one family member suggested that both the caregiver and the older adult could spend a few days at the facility to get a feel for the new environment. For example, they could spend some time at the day program in order to feel more familiar with the facility.

**More Time to Move**

Another very strong recommendation made by family members was to allow more time for families to move their relatives to the long-term care facility. The transition can be very overwhelming, and becomes even more stressful when families are pressured to move in a very short period of time. Families felt they
needed more time to get prepared and get used to the idea of their relative moving to a long-term care facility. They also need time to prepare their relatives for the move.

*Individualize Care*

Family members recommended a number of approaches to individualizing the entire transition process to help them and their relatives feel more comfortable with the entire experience. They suggested that the facility:

- Allow admissions when it is convenient for families;
- After admission, allow residents to move at own pace through the day;
- Allow the person moving to the facility to bring their own items;
- Respect the personal preferences of the person moving in (e.g. baths vs. showers; a female resident not wanting a male caregiver);
- “Shift the rules” and let residents eat meals with whomever they wish; and
- Ensure there is a good matching of roommates.

Essentially, family members were asking for their wants and desires, and those of their relative, to be respected. As described by one adult daughter, “if I want to eat a meal with my Dad in his room, why can’t I… and don’t make me feel bad for doing it…just let us do what we like.”

Many suggestions were made by family members for ways to individualize the room their relative moved into. Families recommended that they be able to bring in their own items in order to personalize the room and that the room be cleaned and, if possible, freshly painted for new residents.
Welcome Families and Their Relatives

Families said they wished to be treated with a greater sense of welcome and as a “guest” when they moved to the nursing home. They suggested that family members and their relatives be welcomed and greeted as they arrive, that staff from the facility help family members move their things the day they move in, and for staff to “check in…” more often after the family arrive to ensure that everything is progressing smoothly. As one family member described it, caregivers and the new resident want a “family feeling” when they arrive at the facility.

Enhance Care by Staff and Volunteers

Family members recommend that in order to ease the entire transition experience of moving a relative to a nursing home, quality care needs to be provided. If quality care is not being provided, facilities need to make improvements. For example, family members suggested that more opportunities for baths for residents each week be provided, residents be taken to the bathroom more regularly, more meaningful activities for residents be provided, and continuity in terms of who is providing care to residents be maintained, particularly for those with dementia.

Family members also recommended that more staff and volunteers are needed to provide quality care. One family member also emphasized that conditions for staff need to be improved for example, by increasing their pay and decreasing their workload.
**Enhance Connection Between Community Services and LTC Facilities**

Suggestions were made by several family members for LTC facilities to make greater connections with services in the community, for example, with the local Alzheimer Society chapter and with local day programs. For one wife, it would have made the transition easier if her husband could have maintained his involvement in the day program after he moved to the nursing home, even if for a short period of time, to assist him in adjusting to his new residence. In the words of another family member, “nobody told us about the resources available to us” in the community. Families, therefore, recommended a stronger connection and collaboration between community services and nursing homes.

**Enhance Communication Between Families and Staff**

Enhanced communication would have made for an easier transition for several family members and for their relative. One family member suggested that staff at the facility could wear nametags to make it easier for families to approach them. Another family member recommended that the CCAC link family members directly to the facility instead of having to always communicate through the CCAC. Families want communication to be open enough so they feel at ease calling the facility to ask any questions they might have.

**Additional Recommendations Based on Findings**

**Educate Staff**

Educating staff about the complexity of the transition process for some family members would make staff more sensitive to the issues families face as they move
their relatives to a LTC facility. In addition, education for staff on the stress of informal caregiving would provide additional insight into the role of the family. Families and staff would benefit from this as staff would be able to respond to the needs of family caregivers more adequately, and families would become less frustrated with staff who do not understand their perspectives.

Provide Support for Families

Families should be provided with support services in order to help them deal with some of the emotions commonly experienced in relation to LTC placement of a relative. Issues that should be addressed include feelings of guilt, the deterioration of their loved ones, and the sense of loss some may be experiencing. Families would, therefore, feel less helpless and out of control in these situations.

Ease the Transition for New Residents

It is also important to ensure that the transition is as smooth as possible for the new resident. This could be accomplished through providing support for residents to deal with the loss frequently associated with moving to a LTC facility. Also, it is important to reduce the number of moves older adults must make from one facility to another, and from the community to various facilities. Finally it is necessary to conduct comprehensive assessments to ensure that all residents are placed in appropriate units/floors.
CONCLUSIONS

The transition experience is extremely complex. Once the decision is made to place a relative into a long-term care facility, a long process begins that involves much time, thought and emotion. While many family caregivers described the transition process as frustrating and overwhelming and felt a range of emotions from guilt to sadness, many also identified aspects of the process that provided support and comfort. Family caregivers have provided a broad range of recommendations for facilities to be a supportive force during this inevitably demanding time. Recommendations ranged from offering educational opportunities for all parties involved in the process to working to build stronger connections between long-term care facilities and other community services. The key findings and recommendations derived from this study are consistent with, and add to, past literature and strongly suggest continued exploration of this topic.
APPENDIX A
Interview Guide for Family Members

1. Could you describe the transition process of moving your family member to this facility – how did you go about moving your relative to this facility and what was involved in the process? How did the process work?

Questions about the Family member
2. How would you describe the experience for you of moving your family member to a long-term care facility? How did you feel during the process? Why do you think you felt that way?

3. What aspects of the entire transition process were most difficult, frustrating, or challenging for you? Why were these aspects challenging for you?

4. What aspects of the actual move were most difficult, frustrating, and challenging for you? Why were these aspects challenging for you?

5. What aspects of the transition process did you find to be the most supportive, comforting, or helpful to you throughout the experience of moving your relative to this facility? Why do you think these aspects were helpful to you?

6. What aspects of the actual move did you find to be the most supportive, comforting, or helpful to you throughout the experience of moving your relative to this facility? Why do you think these aspects were helpful to you?

Questions about their relative
7. How would you describe the experience of moving to a long-term care facility for your relative? How do you think your relative felt throughout the process?

8. What aspects of the entire transition process do you think were most difficult, frustrating, or challenging for your relative? Why were these aspects difficult for your relative?

9. What aspects of the actual move do you think were most difficult, frustrating, and challenging for your relative? Why were these aspects difficult for your relative?

10. What aspects of the transition process do you think were the most supportive, comforting, or helpful to your relative throughout the experience of moving to this facility? Why do you think these aspects were helpful to your relative?

11. What aspects of the actual move do you think were the most supportive, comforting, or helpful to your relative throughout the experience of moving to this facility? Why do you think these aspects were helpful to your relative?
**Questions about the Facility and the Process**

12. What could the facility have done differently to ease the transition process for you? What would you recommend to the facility that might make the move to a long-term care facility easier for family members?

13. What could the facility have done differently to ease the transition process for your relative? What would you recommend to the facility that might make the move to a long-term care facility easier for residents?

14. If you could change the entire process of moving to a long-term care facility, what would you change and why?
REFERENCES


Easing the Transition


