

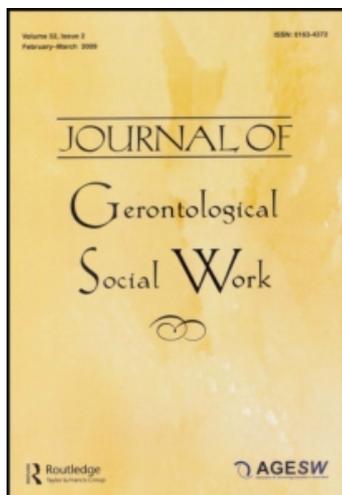
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Understanding Ambiguous Loss in the Context of Dementia Care: Adult Children's Perspectives

Sherry L. Dupuis, PhD

ABSTRACT. This study examined the experience of ambiguous loss for family members caring for a person with dementia living in a long-term care facility. Data for this study came from in-depth, active interviews conducted with 38 adult daughters and 23 adult sons caring for a parent with dementia living in a long-term care facility. The stories shared by the adult children revealed that ambiguous loss in the dementia context involves a long, on-going process of several phases including anticipatory loss, progressive loss, and acknowledged loss. The nature of the ambiguity shifts and the experience changes for families as they journey through the ambiguous loss process. Acceptance and avoidance were the two most common coping strategies used in dealing with acknowledged loss. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <getinfo@haworthpressinc.com> Website: <<http://www.HaworthPress.com>> © 2002 by The Haworth Press, Inc. All rights reserved.]

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KEYWORDS. Ambiguous loss, dementia, institution-based caregiving, caregiving career

INTRODUCTION

Studies conducted around the world suggest that approximately eight per cent of all people 65 years of age and older have some form of dementia (Molloy & Caldwell, 1998). Currently, dementia affects over four million Americans, the majority of those being 85 years of age or older (Gillick, 1999). With the growing population of older adults, however, it is estimated that the prevalence of dementia will increase dramatically over the next several decades (Molloy & Caldwell, 1998). Persons with dementia experience devastating consequences including progressive memory loss, loss in language abilities, and an inability to solve the problems of daily living (Gillick, 1999). Often, dementia culminates in the psychosocial death of the victim, a phenomenon "in which the psychological essence, individual personality, or self is perceived as dead, though the person remains alive" (Doka & Aber, 1989, p. 189; Sweeting & Gilhooly, 1997).

The illnesses that cause dementia also have detrimental impacts on the persons closest to those with dementia, especially their caregivers and family members. In fact, some research suggests that caring for a person with dementia can be one of the most difficult, frustrating, and distressing of all caregiving roles (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). One of the most painful experiences for family members in dementia care is watching the gradual deterioration and psychological loss of their loved ones (Dupuis, 1997). In later stages of illnesses causing dementia, family members also experience confusion regarding whether their loved ones still exist for them as well as great emotional distress and turmoil related to that confusion. This phenomenon has come to be known as ambiguous loss.

The concept of ambiguous loss was introduced by Pauline Boss in the mid-70s. It refers to a loss situation that remains incomplete, confusing, or uncertain for family members. Boss (1999) identified two types of ambiguous loss. In the first type, a person is perceived by their family members as physically absent but remains psychologically present because it is unclear whether the person is dead or alive. This type of ambiguous loss can occur in families of men missing in action and families with missing children. In the second instance, a person is perceived by family members as being physically present but psychologically absent. This type is often associated with families who have a relative with Alzheimer's disease or another related dementia, brain injury, stroke, or other chronic illnesses. In dementia, the loved one is perceived

to be physically alive, but gradually loses psychological presence in family members' lives as the level of cognitive impairment increases (Boss, Caron, & Horbal, 1988).

Ambiguous loss can result in boundary ambiguity, "a state in which family members are uncertain in their perception about who is in or out of the family and who is performing what roles and tasks within the family system" (Boss & Greenberg, 1984, p. 536). Further, the greater the confusion experienced in ambiguous loss situations, the more difficult it is to master the situation, and the greater the level of depression, anxiety, and family conflict experienced by the family (Boss, 1999; Boss & Greenberg, 1984). In fact, Boss (1991) proposed that it was the ambiguity and uncertainty in loss situations rather than the loss or event itself which predicted family stress, both for individual family members and for the family as a unit.

The phenomenon of ambiguous loss has been examined empirically in a number of different contexts, however, very few studies have examined ambiguous loss in the context of dementia. Nonetheless, the research that does exist supports Boss' theoretical premise and suggests that boundary ambiguity is a much better predictor of depressive symptoms in caregivers of persons with dementia than the severity of dementia displayed by the care receivers (Boss, Caron, Horbal, & Mortimer, 1990; Kaplan & Boss, 1999). It also suggests that ambiguous loss may be one of the greatest stressors associated with caring for a person with dementia (Boss et al., 1988). Ambiguous loss may become even more problematic when the care receiver is institutionalized and removed from the daily lives of their family members (Doka & Aber, 1989; Kaplan & Boss, 1999).

Although research suggests that ambiguous loss situations can have significant, negative consequences for family members, our understanding of the nature of ambiguous loss in the dementia care context remains quite limited. The purpose of this study was to examine the experience of ambiguous loss for family members caring for a person with dementia living in a long-term care facility. Pratt, Schmall, Wright, and Hare (1987) referred to institution-based familial caregivers as "forgotten clients." Meeting the needs of these forgotten clients demands a better understanding of the lived experience of ambiguous loss, particularly from the family member's perspective.

GUIDING CONCEPTUAL FRAMEWORK

This project drew on symbolic interactionism and the conceptual framework of the caregiving career. Symbolic interactionists maintain that individuals actively and creatively construct and modify their roles through interactions in

specific social settings based on the meaning they attach to actions or situations (Turner, 1962). As the disease progresses in the dementia care context, family member roles are constructed and reconstructed over time in a dynamic and fluid role-taking and role-making process. This process includes defining and re-defining the situation, interpreting and re-interpreting the behavioral gestures and expectations of others (such as the resident with dementia, other family members, and staff members), and ongoing negotiation processes (Blumer, 1969; Turner, 1962). Thus, family members' perceptions of reality at any point in time ultimately affect the meaning given to the situation, specifically to the loss, and the subsequent degree of boundary ambiguity and stress experienced by individual family members and the family as a whole (Boss & Greenberg, 1984).

In order to appreciate family members' perceptions of reality, it is important to understand the positionality of individual family members; that is, the unique personal circumstances or situations of family members (Jaffe & Miller, 1994). Family members bring to the dementia care context a unique set of interconnected characteristics and unique biographies of experience. These include, for example, stocks of knowledge at hand (Schutz, 1932/1967) such as knowledge from past experiences in the caregiving role, health and physical factors, and life circumstances (e.g., marital status, working status). These varied characteristics and "ordered experiences" are combined and re-combined in order to interpret meanings in particular contexts (Turner, 1988). Thus, because individual family members bring different sets of characteristics to the dementia care context, they may perceive the situation differently and, therefore, experience the situation in unique ways (Clair, Fitzpatrick, & La Gory, 1995).

Family members' perceptions of the situation may change several times as the disease progresses and, in turn, the nature of the ambiguity experienced by family members also may shift over the course of the disease (Boss et al., 1988). Thus, it is also important to consider the phase in the caregiving career. Researchers have described the multiple phases and transitions of the community-based caregiving career (e.g., Given & Given, 1991; Wilson, 1989) as well as the changeability of the role in the institution-based caregiving context (Dupuis, 1997; Rosenthal & Dawson, 1992). Aneshensel and her colleagues (1995) emphasized that each phase in the caregiving career represents only one piece of the entire caregiving career path. Further, "the meaning and impact of one's current caregiving experiences are shaped by what has passed before and by what is anticipated in the future" (Aneshensel et al., 1995, p. 19). Consequently, caregivers at different points in their caregiving careers may think about their situations, particularly the loss, differently and thus experience their roles in different ways.

As stated earlier, the general purpose of this study was to examine the experience of ambiguous loss for family members caring for a person with dementia living in a long-term care facility. Guided by the conceptual framework described above, this study was specifically designed: (1) to examine how family members describe their experience caring for someone with dementia living in a long-term care facility; (2) to explore whether the descriptions of the experience are different for family members at different stages in the institution-based caregiving career and, if so, how; and (3) to examine whether or not family members experience ambiguity in their caregiving roles and, if so, what the nature of that ambiguity is.

METHOD

The data for this study came from two data collection phases of a larger on-going research program focused on the roles of family members in long-term care facilities. The first phase examined the roles of adult daughters in long-term care facilities and the second phase focused on the roles of adult sons. A combination of selective sampling procedures (Schatzman & Strauss, 1973) and theoretical sampling strategies (Glaser & Strauss, 1967; Strauss, 1987) were used to determine which adult daughters and adult sons within one long-term facility in Southern Ontario, Canada would be asked to participate in the project. Initially, three criteria were used in the selective sampling to identify potential participants: (1) the family members were adult daughters or adult sons listed as a primary contact on the resident's admission form; (2) the family members were caring for a resident with dementia; and (3) the adult children were at different points or phases in their institution-based caregiving careers. Theoretical sampling was subsequently used to guide decisions concerning what other adult children should be included as the study progressed and new concepts, patterns, themes, and issues emerged that provided greater insights. For example, early in phase one it became clear that women with both parents living defined their roles differently than adult daughters with only one parent living. Thus, other adult daughters with both parents living were sought in order to explain their role perceptions and experiences further.

A total of 61 adult children agreed to participate in the two phases of the project of which 38 were adult daughters and 23 were adult sons (see Table 1). The majority of the participants were in their 50s or older, were married, and were working either full- or part-time. Almost three-quarters of the participants (73.8%) were caring for their mothers. The care receivers ranged in age from 66 to 95 years, with the average age being 84.2 years. Finally, based on previous work (Greenfield, 1984; Powell & Courtice, 1983; Ross, 1991),

TABLE 1. Characteristics of Adult Children

Characteristic	n	Percent
Relationship		
Adult Daughter	38	62.3
Adult Son	23	37.7
Age of Adult Child		
30 to 39 years	1	1.7
40 to 49 years	16	26.7
50 to 59 years	25	41.7
60 to 69 years	17	28.3
70 years and older	1	1.7
Marital Status		
Married/Common-law	51	85.0
Widowed	4	6.7
Separated/Divorced	4	6.7
Ever Single	1	1.7
Employment Status		
Full-time Homemaker	8	13.3
Employed Full-time	26	43.3
Employed Part-time	11	18.3
Retired	12	20.0
Other (e.g., long-term disability)	3	5.0
Parent Being Cared for		
Mother	45	73.8
Father	16	26.2
Caregiving Career Phase		
Early Career	19	31.1
Mid-Career	17	27.9
Later Career	25	41.0

31.1% of the adult children were considered to be in early phases of their institution-based caring careers (1 to 9 months), 27.9% were in mid-phases (10 months to 2 years), and 41% were in later phases (over two years). The average institution-based caregiving career was just over two years (mean = 25.13 months).

Within a grounded theory approach (Glaser & Strauss, 1967), each family member participated in an in-depth, active interview (Holstein & Gubrium, 1995) conducted by the author. Active interviews emphasize the collaborative and interactional process between the researcher and participants, and recognize that all knowledge is co-constructed. Thus, active interviews incorporate a variety of techniques different from a structured or semi-structured approach in the search for mutual understanding. For example, active interviews recognize that the interview is very much shaped by the interviewer and her or his research agenda, and therefore, the topic areas of interest to and the position of the researcher are made explicit to the participants. The active interview is much more conversational in style, capitalizes on the dynamic interplay between the researcher and participants, and involves mutual disclosure. Five of the adult sons and one of the adult daughters insisted that their spouses be involved in the interview process as they very much perceived their roles to be a shared endeavor. Thus, in these six instances both the adult child and their spouse participated in the active interview.

An initial interview guide was developed to explore a number of issues related to the institution-based caregiving role (e.g., the caregiving history, how family members thought about and described their roles within the long-term care facility, how the role was experienced by the family members, the impacts of the role on other aspects of the caregivers' lives, and how the role had changed over time). However, as key patterns and themes began to emerge, the interview guide was continually modified in order to explore those patterns and themes further. All but one of the interviews were audiotaped and interviews ranged anywhere from 45 minutes to three and a half hours, the typical interview being approximately 90 minutes in length.

In order to further enhance the credibility of the data collected, a modified member check was conducted (Kincheloe & McLaren, 1994; Lincoln & Guba, 1985); that is, once the tapes were transcribed, the author analyzed the narratives and added insights and interpretations as well as clarifying questions to the transcript. The transcripts were then sent back to the adult children and they were asked to respond to the author's interpretations of their experience, to answer the clarifying questions written in the margins, and to indicate whether or not the transcript accurately reflected their individual story or experience. They also were encouraged to expand on any issues they felt were important to

them. Any additional information or clarifications made by family members on their transcripts were used as data in subsequent analyses.

The data from the interviews were analyzed using a modified constant comparative method (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1990). Specifically, the author first conducted a line-by-line analysis using open coding to identify conceptual categories relevant to the meaning of caregiving and the experience of ambiguous loss for individual family members. The emergent patterns were then compared across individual caregivers and across groups of caregivers at different phases in the institution-based caregiving career to identify common patterns in the data as well as negative cases. Examples of common patterns at this stage of data analysis included unpredictability of future, anticipation of what was to come, pain of watching deterioration, and sense of helplessness. Through this process the author was able to identify the substantive codes specifically related to the experience and nature of ambiguous loss expressed by the family members at different phases in the institution-based caregiving career. Finally, theoretical coding (Dolan Mullen, 1985-86) was conducted to organize the substantive codes into a more integrated set of relationships or configurations. This is the stage of data analysis where the phases of ambiguous loss presented next came together and were developed more fully.

FINDINGS: THE PROCESS OF AMBIGUOUS LOSS IN DEMENTIA CARE

Although ambiguous loss has typically been conceptualized as a stable, single event or situation, the stories shared by the adult children highlighted the process of living through ambiguous loss. One of the adult daughters provided this exemplary comment during her interview:

... it was gradual and had to do with the, let's see, economics and necessity of keeping your life going. When I went every three days, obviously I hadn't accepted it. When I went every two weeks, I still hadn't accepted it. Then when winter would come, and it would be one month and two months, then it got to the point where it was three months. And, then after a while you stop feeling guilty every day. Then you realize that the man who is there isn't really your dad, and you kind of start to build up a memory base of your dad the way he was, as though he died. And, I guess it was a gradual thing.

The adult children's stories further suggested that ambiguous loss involves a number of phases that family members travel through as they deal with the

gradual loss of their loved ones. Examining how the experience changed over time for family members in later stages of their institution-based caregiving careers and comparing those in early stages with those in mid and later stages revealed that the nature of ambiguity shifted and the experience changed as adult children journeyed through each phase. The ambiguous loss process begins with anticipatory loss, moves through the progressive loss phase, and eventually culminates with acknowledged loss. Family members then cope with acknowledged loss in different ways.

Anticipatory Loss

For family members earlier in their caregiving careers and in the first phase of the process, anticipatory loss, the loved one is still very much psychologically present and remains “in” the family unit. Family members at this phase talked about how difficult it would be for them when their parent no longer recognized them. Thus, early in the institution-based caregiving career, the ambiguity is centred around what the future holds. Family members described two distressing aspects of anticipatory loss. Some adult children experienced great difficulty with the unpredictability or uncertainty of the future. As one adult daughter expressed:

I have got a bit, a fair bit of road to travel with mom. It's in darkness. I don't know what it's going to be like. I keep searching for some definition to this so I know what to expect. I'm not good with risk. I'm not good with the unknown. I want to know what lies ahead . . . so there's that worry that I don't know what I'll be called upon in the way of reserves to give to mom. But I hope I'll be okay with it when the time comes.

Another adult son early in his institution-based caregiving career described similar feelings when asked to talk about the most difficult aspects of caring for his parent. He said: “Well there's nothing really that difficult other than the anticipation of what's going to happen, when is it going to happen, and, you know, will I be prepared to handle it.”

Others observed what was happening to other residents day-in and day-out and anticipated that the same thing would happen to their parents. They experienced great distress in knowing what was ahead for them and their loved ones and not knowing whether they would be able to handle the deterioration, particularly the psychological loss, of their loved ones. One adult child stated:

When you come in and you visit and you see people that have been here longer and what happens as they go through this . . . and you know what's ahead for her [my mother], it's distressing.

Similarly, another adult daughter described her distress with knowing what was ahead, but not knowing whether or not she would be able to cope when the time came:

Mom is not vacant. . . . Mom has not reached the stage where there is nothing there, where she's a vegetable. She still can be kind of an eccentric and a very funny person. And, very sane-minded, but funny. But there's still a person there. One thing I often think is that I just started this journey of letting go with mom. I have a long way to go. Dear God how will I ever get the whole way. I see people out there visiting their parents or spouses and they are vacant. I think, oh God, I've got to do that yet. I hope I can do that. So there's that fear, that worry that I may not be able to handle that or I'll handle it badly.

Progressive Loss

As the level of cognitive impairment progresses, family members appear to move into the phase of progressive loss. This phase of the process often begins in mid-phases of the institution-based caregiving career and involves living through and dealing with the gradual loss of loved ones. Progressive loss is characterized by the pain of watching the deterioration and disintegration of the parent and thus the experience in the role becomes more and more difficult throughout this phase. When asked what the most difficult aspect of caring for her mother was, one adult daughter remarked:

I think watching her die mentally and not physically. It took me a long time to put it into words actually but you are watching them die mentally but not physically. And not being able to reach her is devastating. It is tough.

Another adult daughter described her experience caring for her mother:

Well with Mom, because of her dementia, it's just very difficult coming in and seeing [her]. She doesn't have any knowledge about, like she will spill something and she doesn't notice it and she'll have something on her plate and she doesn't notice it and this is a woman who I remember as a child would, she had a dress that she wore in the morning for doing the chores around the house and then she had another dress that she would get dressed up in the afternoon. Even if she wasn't going anywhere, you had a morning dress and an afternoon dress. She always had rings on and lipstick on and to come and just see the deterioration, that's very difficult. And, I think the other thing is, she was also someone who did a lot of reading. She was not well educated but she did a lot of reading. She was

interested in lots of things and just to be not making conversation and not making any sense is really, that's really disheartening to see day after day.

Progressive loss is also characterized by a sense of helplessness as family members struggle with what they can do to maintain some quality of life for their parents. One adult daughter described the helplessness she was feeling in her mother's care:

Feeling that if I knew what else I could do for her, there must be something else I can do but not knowing what it might be. Feeling that there's probably something I can do that would make her life have more meaning . . . but I don't know what it is . . . if only I knew something to give meaning to her life.

Visits become more and more difficult as progressive loss continues. One adult daughter expressed: "When I go and visit her, I'm a basket case for the rest of the evening I find. It's such a downer that it affects things. I just want to go to bed and cry." Adult sons expressed similar experiences as one adult son noted: "There's no conversation, there's nothing. It's just sit there and watch him drooling and it's like, oh my God, this is awful . . . As much as you try to get past the whole thing about, you know, that this is your father, it really hurts."

Despite the pain felt in visits during this phase, family members go to great measures to grasp for a connection with their parents. This involves trying to get some response in visits, trying to continue to include the parent in family events even when it becomes difficult as the resident is still perceived as being "in" the family unit, and trying to maintain the image of the parent as they were as long as possible. One family member explained:

Like mom gets her hair done weekly now . . . but as [my brother] and I both commented again, it's almost for our purposes that we do it because when she was in [another facility] her hair was just wild and straight and it wasn't, this was someone her whole life once a week had her hair done, and so it was very distressing for us to see her like that.

Another son described how it is important to keep doing things with his mother in an attempt to hold onto the past as long as possible:

When she was able to enjoy things, like I would come for their Christmas dinner and the Mother's Day thing and, you know, those kind of events. But that was because mom enjoyed it I think . . . it wasn't because I wanted to be here and eat a meal with her at the table because I, even then,

I found it upsetting . . . I guess I'm living in the past, I don't know. . . . I'm just trying to visualize the lady in there as being the same . . . I'm just trying to hang on to the past.

The nature of the ambiguity changes with progressive loss and family members find themselves struggling more and more with the ambiguity regarding the existence of their parents; that is, one day the parent is perceived as being psychologically present and the next visit he or she is not perceived as being "there." One adult son explained this:

There's times I've come in here, she's just been so mad, and just didn't want to talk to anybody. I remember one time I came and she was sitting in her doorway and I said well I'm just gonna go in and get you a glass of water. "No you're not going in my room." And, I'd walk around and she'd turn it the other way and she wouldn't let me anywhere near the room. I walked out of here and I cried and I thought oh man, like that's not mom, that's just not mom. But, then next time you come in to visit she's happy and bubbly and she still doesn't know who you are but I can take her outside and give her a cigarette, she's happy.

Another adult daughter described the first time she felt confusion regarding her mother's existence and the distress it caused her:

. . . once I didn't want to come because I had had such a terrible visit with [my mother] the week before. I can't even explain, it was just a feeling I had that it was hopeless. It was just the most useless time I've ever had in my life and that were we all kidding ourselves, and that had she really in reality died. And these are negative, negative thoughts that I hadn't even thought before. Like have we all been pretending that this woman is even alive? . . . Like has it all gone and vanished?

Acknowledged Loss

At some point, usually in later phases of the institution-based caregiving career, family members appeared to come to a realization that their parent no longer exists for them—they acknowledge the psychological loss of their parent. Some family members no longer refer to their parents as their mother or father at this phase in the process. For example, one adult daughter stated: "She doesn't know anybody, she doesn't respond to anything other than her own name. I don't call her mom anymore." Another adult daughter described her father as follows: "He is not my father anymore. He is this man who is sweet and looks like my father but he is not my father, he is not at all." At this stage, some fam-

ily members even talked about their parents as being dead. One adult son, described his mother as follows:

She lives, I think as comfortable as she could under the circumstances. When she was alive, we made sure that we involved her in many things we did. We'd have her over for dinner, we'd take her out for dinner, we'd go places with her, we'd take her on Sundays and go for drives and so on. I do that with [my wife's] mother because her mother's still alive and with it.

The language portrayed in the above quotation illustrates that, even in acknowledged loss, family members continue to deal with the ambiguity of the existence of their parents, at least to some degree. In the first sentence of the quote, the family member describes his mother as living—"she lives." In the very next sentence, however, she is no longer alive—"when she was alive."

Acknowledged loss often leads to a loss of the parent in family events, the loss of a valued relationship, and for some the loss of role identity. One adult daughter explained:

We used to have a parent-child relationship, even after I became an adult. After my father died, I became a more important part of her life. She needed me. We shared confidences and we became a regular part of each other's day-to-day lives. She was constantly on my mind; her loneliness, how she filled her days. I felt a need to spend more time with her. We became friends and I looked forward to and enjoyed her company. When she could no longer contribute to the relationship, I felt I lost a best friend.

When asked to talk about her role in her mother's care now, another daughter stated:

I don't know what I am. I'm not her keeper because she's not in my care. You could say you were her security but nobody's home, so you're not really her security. She doesn't know any different. I'm not her. . . I don't have to support her, she can self-support herself money-wise. I don't know. I'm the nobody.

In fact, at this phase the nature of the ambiguity changes yet again to uncertainty related to the family members' role in their parents' lives and confusion surrounding the consequences of their visits. Family members struggle with whether or not it is even necessary to continue to visit the parent and question the usefulness of their visits. An adult daughter with both parents still living—her mother in the community and her father in the facility—described her ambiguity about the visits to see her father:

I think the love is necessary for my mother. I don't know that it is . . . necessary for my dad as much. I still have difficulty comprehending that if I didn't show up or if my mother didn't show up, if that would be harmful for my dad. I don't know if we are doing it for him or if we are doing it for us. It is probably more for us than for him because he doesn't know us any more and he seems quite content even when we are there to take off with somebody else, like one of the residents, and wander and walk and forget all about us being there. So, I really don't know if it would make a difference.

Finally, the phase of acknowledged loss can result in family crises, particularly if individual family members reach this phase at different times or have different perceptions of the parent with dementia. This quotation illustrates the different family perceptions that two siblings held about their father:

One of my brothers did that, just like night and day. [He said:] "my father is no longer alive. I can do whatever needs to be done for this shell but that is not my father. My father died several years ago." Which I find fascinating. No, there are still characteristics, there are facial expressions, you can tell there is frustration at times, these are parts of his personality. He is also wanting to have hugs, his wanting to hold somebody's hand, his wanting for that tenderness, that is also part of my father. So no . . . he is still my father and he will be until the day he dies and yes he has this horrible disease but that doesn't take away the fact that he is my father. So, I feel very strongly about that actually.

Another adult daughter described the strain the situation had put on her relationship with her sister:

My sister's four years younger than I am and we've always been close but this has done the opposite. Now she and I have really had terrible arguments over stuff like this and I'm sad about that relationship and it's all because of this rotten disease . . . I think it's difficult for [my sister] when she's at a distance. In many ways, being able to face the situation has been more of a healing process but I don't think she's had a chance to go through that because she's not here. And, she was always my dad's favourite. Not favourite, but, you know, she spent a lot of time with him on his woodworking projects and all that kind of stuff. So, I think that she figured that we were jamming dad into a nursing home and we didn't really need to. . . . And, even this summer, my daughter got married this summer, and [my sister] went up to see [dad]. I knew that it would be awful because we knew how badly he had slipped. She was convinced that

he was drugged out of his mind at the nursing home. And, there wasn't anything that we could do to convince her that that wasn't the case (family member is crying through most of this and having a hard time talking).

Coping with Acknowledged Loss

Family members generally described two ways in which they coped with acknowledged loss. Both of these coping strategies represented attempts by the adult children to move on with their lives. Some family members coped through acceptance of the loss. They accepted the fact that their parents no longer existed in their lives, at least psychologically, or no longer existed as they once had, and reframed the situation in more positive ways. With this strategy, family members shifted their focus to reclaiming their own lives and improving their own well-being; that is, the focus shifted to a re-establishment of their own lives and to their own healing. One family member who described her mother as "no longer here" explained how she was able to move to this place of acceptance:

My mother and I got along very well and I don't have anything to make up for and I don't have any unresolved concerns. We didn't have any, we worked it all through. If I viewed myself as a very intense caregiver now, I am not sure how healthy that would be for me. I don't know that either of us would gain from that. I know that my mother can no longer help me . . . she can't do that. I need to acknowledge that and move on. We all feel that we were great when it was time to be great and we really can't help her any more than this.

Another adult son described how he came to accept the situation and reframe things in a more realistic way:

The fact is that I made the decision that the best thing I could do for her was to make her life as happy and full as possible regardless of the disease and that didn't mean maintaining her Winnipeg existence. It meant what can I do now. . . . Once I finally accepted the disease and the potential fate that lay ahead, I lost interest in trying to keep ties with "the old times." I decided to focus on what we could do to improve her standard of life. I really feel this is the way to go. My sisters are not as convinced and try to preserve the past connections. . . . It also helps to keep me from dwelling on how much we have lost or she specifically has lost from the old days.

Part of coming to a place of acceptance for family members also involved coming to a realization that they were doing the best they could in their roles. As one adult daughter explained:

Mother died five years ago, this is just a body and you try to make it as comfortable as you possibly can. I think I have learned after all of these last three or four years to try and accept that in yourself, to make yourself aware that you are doing everything you can.

Other family members coped with acknowledged loss through avoidance of the loss and focused on protecting themselves from the loss by avoiding the situation altogether. These family members visited rarely and rarely went to the facility alone. Some of these family members turned their focus to the other parent if both parents were still living. It was important to them to feel connected to that well parent. Others turned the focus to themselves and finding ways to heal from the loss. When asked to describe her role in her mother's care, one adult daughter stated:

I think I've defined my role as: I've left the facility to take care. . . . It probably sounds very non-caring. It isn't a case of non-caring. Once I lost my mother is what I call it, I find it incredibly stressful to go and see her. I guess it's because it's my mother and because my mother was widowed when I was 16 [and] we had a very, very close relationship and I haven't accepted it well, that's the bottom line. . . . I used to see her a lot and then toward the . . . when I could see her going down too, when she started mixing everybody in the family up and was never sure [who we were]. She knew we were family, but she didn't know who we were and I guess that's when it just hit me. My God, she doesn't even know me any more. . . and I think it just zapped me and it put me into a very defensive position for my own self and I just took the role that I can't handle this. I'm not doing well.

This particular family member rarely visited her mother, visiting every three months and often much less. Also, she only visited when her daughter could accompany her.

Not surprisingly, family members who coped through avoidance of the situation expressed much more pain and emotional distress in their roles than those who were able to come to a place of acceptance of the situation. They found it very difficult, if not impossible, to reframe the situation in more positive ways. Thus, these adult children found it much harder to move on than those who were able to accept the loss of their parents.

Because the loss of the parent occurs over a very long and gradual period of time, grieving begins early on in the process of ambiguous loss and continues throughout the journey. Most of the grieving happens while the care receiver is still living. One family member described the process as follows: "There's still a process that you have to work through and there's a whole grieving process, I mean all the way throughout this, about in essence the person isn't dead but in reality the person that you knew is gone." Once family members have gone through the acknowledged loss phase, many family members are ready for their parents to die physically or think that it would be less painful if their parents would die. One adult son explained:

[My mother] is very much in a way ready to leave this life. She would love to just go. She's actually old, it's nothing, bone, just skin over bones and she sits in the wheelchair . . . there's nothing there anymore.

Are you ready for her to leave this life?

Oh yeah.

Another adult son described the pain of watching his mother die:

I guess to me it's just, it would have been easier if she'd died one night in her sleep and that would have been the end of it. That's the way my father went. That's the way my grandmother went. My mother is the only living relative that I've got that's convalescent. Everybody else died quickly. And, to me that's the way it should be and that's the way I like it. Like just, because this to me is probably more painful than, than had she died and left this world.

DISCUSSION AND CONCLUSIONS

The findings in this study support previous research and insights on ambiguous loss in that it highlights the emotional stress and turmoil involved in dealing with such a loss. It also expands our understanding of the nature of ambiguous loss in caring for a parent with dementia living in a long-term care facility. The results suggest that dealing with ambiguous loss involves a long, painful grieving process. Some family members referred to it as "the long good-bye" or "the never-ending funeral." In dealing with ambiguous loss, family members go through at least three phases which involve anticipating the loss, living through the progressive psychological loss, and acknowledging

the loss. They then cope with the acknowledged loss of their loved ones using two different strategies, through acceptance or avoidance of the situation.

It became very apparent in the stories shared by the adult children that perceptions or definitions of the situation are critical to how family members cope and that these perceptions are altered and re-altered at different phases in the process. Further, as perceptions of the situation are re-defined, the nature of the ambiguity shifts and the experience of ambiguous loss changes. The most critical factor affecting these definitions of the situation was the progression of the parent's disease. That is, adult children's perceptions of the degree of cognitive impairment and particularly the perception of the parent's psychological presence were most important to the family member's experience in the caregiving role. Further, movement through the phases of ambiguous loss was more linked to the family member's interpretation and appraisal of the impairment than to time in the role itself.

In early phases of the institution-based caregiving role, family members often deal with uncertainty regarding what the future holds and whether or not they will be able to cope with what lies ahead. As the disease progresses and the institution-based caregiving career proceeds, family members deal with the gradual deterioration of their loved ones and watch them become more and more psychologically absent in their lives. Increasingly, they struggle with whether or not the parent still exists for them. At some point in the process and typically in later phases of the institution-based caregiving career, many family members realize that their parents no longer exist for them and acknowledge the psychological loss of their parents. Some uncertainty related to the "thereness" of the parent may continue, however, at this later phase family members struggle most with ambiguity regarding their role in their loved ones' lives and confusion over the usefulness of their visits.

Family members tended to cope with acknowledged loss through either acceptance or avoidance. The adult children in this study who were able to accept the loss and reframe the situation in new and positive ways coped much better in their roles than those who used avoidance as a coping strategy. This is consistent with previous research which suggests that avoidant-evasive coping strategies can be ineffective and more harmful than beneficial in dealing with the emotional demands of caregiving (Pruchno & Resch, 1989). Cognitive or appraisal-focused strategies (e.g., reframing/reappraising the situation, acceptance of situations that cannot be changed) appear to be the most effective strategies in dealing with the emotional stresses of caregiving (Williamson & Schulz, 1993). Acceptance may be particularly crucial in dealing with ambiguous loss associated with dementia care. In fact, researchers have suggested that acceptance is an important, and perhaps critical, final step in the grieving process. Through acceptance, family members seem to experience "maturation"

where they begin to accept their ill relative as being very different and also that it is unlikely that their loved one will return to the way they were before the illness (Ponder & Pomeroy, 1996). Family members then appear to experience a peace of mind with the situation and become better able to accept their limitations in the care of their loved ones (Teusink & Mahler, 1984). Research also suggests that as caregivers reach acceptance, both the intensity and the number of grief behaviors seem to decrease (Ponder & Pomeroy, 1996).

The insights from this study have numerous practical implications and may help social workers and other professionals to better meet the needs of family members caring for persons with dementia. The findings point to the importance of identifying the nature of the ambiguity at various phases in the disease process. Helping family members identify the type of ambiguity they are dealing with and assisting them in managing the ambiguity is critical in helping them cope with ambiguous loss.

The findings also demonstrate that family members may have different needs at different phases of the ambiguous loss process and highlight the importance of educational, supportive, and therapeutic programs for family members throughout the loss process. Those early in the anticipatory loss phase of the process, for example, may need educational programs focused on what they can expect as the disease progresses. Further, some family members later in their caregiving careers in this study recommended the use of caregiver mentors, particularly early in the institution-based caregiving career. They suggested that being matched with a family member who is later in the caregiving career may have helped them cope better with the stresses of anticipatory loss by providing them with a more realistic perception and better preparing them for what was to come. Those in the progressive loss phase may need individual counseling and support programs to help them deal with the gradual psychological loss of their loved ones. As family members move through acknowledged loss, they may need help in reframing the situation in more realistic ways and in moving to a place of acceptance. As Boss (1991) emphasized: "Only through the family members reframing of how they see the situation can change take place. We must therefore see the loss through their eyes before we can know how to support and guide their resolution" (p. 167). Avoidance of the situation leads to the loss of involvement of the family member in the life of the resident, which can be detrimental for both the families and the resident (Boss, 1999). By helping family members find a way to accept the loss of their loved ones, families can find ways to redefine their relationships and develop new roles and alternative ways to be involved in the resident's life (Boss, 1993). Family counseling may also be important at this phase, particularly for those families experiencing conflicts related to different

perceptions of the situation and the psychological presence of the care receiver.

The psychological death of a loved one can lead to a grief reaction as well as profound feelings of helplessness, guilt, and ambivalence as well as a tendency to view caregiving tasks and visits as useless (Doka & Aber, 1989). In this study, family members in mid and later phases of their institution-based caregiving careers described the difficulties they had during visits, the sense of helplessness they felt in their roles, and the longing for something meaningful to do while visiting and caring for their loved ones. Thus, as the disease progresses and process of ambiguous loss continues, family members also may need help in redefining their roles in their relatives' lives and in making visits easier, more meaningful, and less painful. Research suggests that therapeutic family leisure programs may be effective in enhancing family visits and alleviating caregiver burden for family members of institutionalized older adults with Alzheimer's disease (Dupuis & Pedlar, 1995). Family leisure programs appear to facilitate quality visits, provide meaningful roles for family members, and promote the development of social support networks, which together help to increase the coping capacity of caregivers. Dupuis & Pedlar (1995) argue that these factors may provide "buffering mechanisms" that may serve to moderate the impact of caregiver stress on psychological health and well-being and provide the opportunity for the re-establishment of meaningful relationships between caregivers and their care receivers. Whatever the case, strategies need to be developed that include family members in meaningful and creative ways in the facility and that enhance the visits for both the residents and their family members.

This study provides some deeper insight into the nature of ambiguous loss for adult children caring for parents with dementia living in long-term care facilities, but it is not without its limitations. The process of ambiguous loss was developed from cross-sectional data of family members' accounts of the history of their caregiving roles and from comparing family members at different phases in their institution-based caregiving careers. However, longitudinal research is necessary in order to verify the phases involved in dealing with ambiguous loss and to better understand the process further. This study also focused on adult children of persons with dementia and, therefore, it is unclear whether or not spouses of persons with dementia perceive their experiences with ambiguous loss in similar ways as adult children. Future research should explore the nature of ambiguous loss for other familial caregivers. Further, the focus of this study was on family members caring for a relative with dementia living in a long-term care facility. Thus, it is unclear at this point whether or not the process of ambiguous loss is similar for community-based caregivers. Research is needed that explores the nature and experience of ambiguous loss for

family members caring for a person with dementia living in the community. Finally, the process of ambiguous loss and how families cope throughout the process likely has enormous implications for persons with dementia. Yet very little is known about how various family reactions in ambiguous loss situations affect those with dementia. Much more research is needed in order to understand the relationship between ambiguous loss situations for family members and the impact of those situations and reactions on persons with dementia.

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