THE ROLES OF ADULT DAUGHTERS IN LONG-TERM CARE FACILITIES: ALTERNATIVE CAREGIVER CAREER PATHS

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ABSTRACT

THE ROLES OF ADULT DAUGHTERS IN LONG-TERM CARE FACILITIES: ALTERNATIVE CAREGIVER CAREER PATHS

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Although our understanding of issues faced by community-based caregivers has been expanding rapidly over the past decade, our understanding of the roles of family members within long-term care settings is quite limited. The research that does exist tends to conceptualise the term "role" as a uni-dimensional concept, to treat diverse caregiver samples as homogenous groups, and fails to take into account the broader context within which family member roles are played out. Employing a multi-dimensional conceptualisation of the term "role", and guided by a symbolic interactionist approach and the conceptual framework of the caregiving career, the purpose of this study was to gain a deeper and more comprehensive understanding of the roles of adult daughters in long-term care facilities from their perspectives. Specific techniques of the grounded theory approach combined with in depth, active interviews and personal logs were used as the primary research design procedures.

The analysis revealed that adult daughters' perceptions of their roles fell into five distinct yet not mutually exclusive "family caregiving role manifestations": *Active Monitors, Regular Visitors, Indirect Supporters, Unaccepting Relinquishers,* and *Accepting Relinquishers.* Key factors which help explain these role manifestations include temporal phase in the caregiving career, amount and nature of involvement within the facility, meaning or definition of the role, interpretations of their parent's "thereness" or psychological presence, pressure to be involved in care, the presence of both parents, satisfaction with care, the ability to accept the situation, and the experiences in the role. Common to all of the role manifestations was the inherent "changeability" of the caregiving role as well as the stresses and demands of the role and resourcefulness of the caregivers. An integration of a number of the above factors is used in the development of a substantive grounded theory on the alternative family member caregiving career paths in long-term care facilities. The dominant paths in this model are the "Coping Through Protection of Self Path", the "Focus on Other Path", and the "Growth Through Acceptance Path". Drawing on McCubbin and Patterson's Family Adjustment and Adaptation Response Model, a dialectic conceptualisation of caregiving career paths is presented.

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Finally, I would like to thank Bryan for his ever-present love, support, encouragement, patience, faith in me, and insightful advice. You are, and will always be my strongest mentor.

DEDICATION

This thesis is dedicated to my grandfather, Lennox Leroux, who passed away while I was finishing up this dissertation. The world has lost a remarkable man, but my family and I have gained one very special angel who now watches over us.

This thesis is also dedicated to the 38 women who agreed to share their stories with me throughout this project, and their parents. I feel privileged to have had the opportunity to have met with each of these women, if only for a brief amount of time. Because of the commitment of these women to the project, I believe we now have a much more comprehensive and deeper understanding of institution-based caregiving roles.

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"A favourite tape of mine by Shirley Eikhard has a song called *Emily Remembers*. It's about a woman with Alzheimer's but reminds me of Mom. If you have a chance to listen to this song it really captures how I feel" (Excerpt from one of the family member's Member Check, 1996).

Emily Remembers

Emily remembers
The dances at her high school
When she was young and carefree
Some forty years ago
Emily remembers
Standing on the bleachers
Cheering for the home team
Her hair all wet with snow

If she forgets today's her birthday
And if it's Tuesday, she's not sure
If she forgets to comb her hair now
I remember if for her…

Emily remembers
Her weekends in the country
Her walks down by the river
On Sunday afternoons
Emily remembers
Her holiday in Paris
Those evenings at the Ballet
Beneath an August moon

If she forgets that I'm her best friend
And how inseparable we were
If she forgets how much she needs me
I remember it for her
If she forgets how much she loves me
I remember it for her.
(Eikhard, 1991)

CHAPTER ONE
SETTING THE STAGE

While I was gathering data for my Master's thesis research in the summer of 1992, one of the family members of a resident involved in my project approached me one day and asked me a question that has stuck with me ever since. She asked me why I was not studying ***them***, meaning the family members of persons living in long-term care facilities. This particular family member was having a difficult time juggling all of her roles and was struggling to understand where she fit in within the long-term care facility in terms of her mother's care. Her question stuck with me while I finished my Master's thesis and started gnawing at me as I began working on my Ph.D. I found myself becoming more and more interested in issues related to family members of residents living in long-term care facilities.

I set out to review the literature. This review revealed that family members continue to have extensive contact and close emotional ties with their older adult relatives after institutionalisation (Brody, 1986; Montegomery, 1982; Moss & Kurland, 1979; Smith & Bengtson, 1979; Tobin & Kulys, 1981; York & Calsyn, 1977). As well, familial caregivers often place great importance on their continued participation in the care of their older adult relatives after long-term care placement and often actively assume responsibility for a number of care tasks (Bowers, 1988; Dempsey & Pruchno, 1993; Reisman, 1986; Rubin & Shuttlesworth, 1983; Schwartz & Vogel, 1990; Shuttlesworth, Rubin & Duffy, 1982; Zarit & Whitlatch, 1992). In fact, due to their often long-term, personal experiences in the primary caregiving role, "caregivers have moved far beyond viewing themselves merely as fonts of medical information and historical details" (Hasselkus, 1992, p. 75). Family members have moved towards considering themselves as vital members of the health care team (Duncan & Morgan, 1994) throughout their caregiving careers.

Nonetheless, while reviewing the literature, I also discovered that very little research has focused on the roles of family members in long-term care facilities. In fact, although our understanding of specific issues faced by community-based caregivers has been expanding rapidly over the past decade, very little is known about the perceptions, activities, and experiences of familial caregivers after placement of a relative into a long-term care facility. In surveying over 40 textbooks on nursing home management and nursing home care, Safford (1989) discovered "an almost total lack of reference to the family" (p. 2). Rosenthal and Dawson (1992) also noted the lack of research on families after placement of a relative into a long-term care facility. They concluded:

> Perhaps this neglect reflects an implicit assumption that following institutionalisation, families cease to be important because paid health workers take on the caregiving role (Rosenthal & Dawson, 1992, p. 400).

Although a few articles have appeared since Safford conducted his review of the literature, there continues to be a general lack of reference to, and research specifically focused on, the roles of family members of institutionalised older adults.

The research upon which this dissertation is based grew out of my discovery of this gap in the literature. Perhaps more importantly, not only was there a gap in our knowledge-base related to the roles of family members in long-term care facilities, but the family members' perceptions or "voices" related to how they view their roles were all but non-existent in the literature. An understanding of how family members themselves view their caregiving roles, what they do in those roles, their expectations for themselves in caregiving roles, and why family members think about or define their roles the way they do is crucial in facilitating strong staff/family member partnerships and ensuring quality care in long-term care settings. Further, Pratt, Schmall, Wright, and Hare (1987) referred to institution-based familial caregivers as "forgotten clients". Meeting the needs of these forgotten clients demands an understanding of family member roles, particularly from the family member's perspective.

STATEMENT OF PURPOSE

The general purpose of this study was to examine the roles of family members in long-term care settings. Several authors, however, have noted key differences in the responses and approaches to caregiving between male and female caregivers, between spouses and adult children, and between caregivers caring for persons with cognitive impairments and those caring for persons with physical impairments. Because situations differ for various types of caregivers, Harper and Lund (1990) recommended that more homogeneous categories of caregivers be considered in future analyses. Therefore, I chose to focus my investigation only on adult daughters of parents with cognitive impairment living in a long-term care facility. Family members caring for persons with cognitive impairments were chosen because these older adults make up the vast majority of residents in long-term care settings. As well, caring for a person with a cognitive impairment brings with it a unique set of experiences and consequences for these caregivers. Similarly, adult daughters were chosen because even though they represent the vast majority of familial caregivers in long-term care settings, few researchers have conducted in depth investigations of their perceived roles. Focusing on adult daughters allowed for a deeper and richer insight into the caregiving roles of this group of women. Further, recognising the limitations of excluding other family caregivers, as well as those caring for residents with physical impairment, I hoped that the relative homogeneity of the sample would "strengthen comparability within the sample as an aid to identifying similarities and diversity" (Luborsky & Rubinstein, 1995, p. 197).

Despite the fact that our current long-term care policies generally reflect a perspective which views familial caregiving as something which happens only in the community, "the careers of caregivers do not stop at the institutions door but continue in an altered, still stressful way. Caregivers do not give up their role; they shift their responsibilities" (Zarit & Whitlatch, 1992, p. 672). Evidence further suggests that these shifts in responsibility may continue over the caregiver's career in the long-term care setting (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Bitzan & Kruzich, 1990; Greene & Monahan, 1982; Hook, Sobal, & Oak, 1982; Rosenthal & Dawson, 1992; Ross, 1991). Using the conceptual framework of the "caregiving career" (Aneshensel et al., 1995), I further wanted to examine the roles of adult daughters in long-term care facilities at various phases or points in the institution-based caregiving career. Some researchers (e.g., Ross, 1991) have suggested that the most turbulent time for family members is the first six to nine months following the relative's placement. Family members, however, usually adjust to the placement of a loved one within a year (Greenfield, 1984; Powell & Courtrice, 1983). Nonetheless, very little is known about the caregiving careers of adult daughters after the placement of a parent into a long-term care facility.

Guiding Sensitizing Concepts

In most of the research conducted thus far, the term role has been conceptualised as a uni-dimensional concept. The task-assignment perspective has conceptualised roles as a set of expectations, specifically a set of tasks the family is responsible for in relation to the institution. The role perception or meaning approach has more broadly conceptualised roles as "more general gestalts and configurations of meaning about lines of conduct" (J. H. Turner, 1991, p. 426). This much less frequently employed line of inquiry has examined how family members themselves define or perceive their roles in long-term care facilities. Guided by R. H. Turner's (1968) conceptualisation of the concept role and the work of Margaret Ross (1991), I wanted to examine adult daughters' roles from a multi-dimensional perspective. Thus, the concept role in the present study was conceptualised as a construct consisting of both a subjective component – that is role meaning – and an objective component – that is role behaviour and role expectations.

The concepts role meaning, role behaviour, and role expectations served as sensitising concepts guiding this examination of adult daughter roles in long-term care facilities. Blumer (1969, p. 148) described the difference between definitive concepts and sensitising concepts: "definitive concepts provide prescriptions of what to see, sensitising concepts merely suggest directions along which to look". Further, sensitising concepts take into account the "the concrete distinctiveness" and the uniqueness of empirical events (Blumer, 1954, p. 8; van den Hoonaard, 1996). For example, the meaning of certain concepts or events may differ greatly across various social circumstances, groups, or situations making definitive concepts problematic. It is this "concrete distinctiveness" of events, happenings, situations, and circumstances that gives shape to the sensitising concept. Van den Hoonaard (1996, p. 2) explained this notion:

> Blumer summons for us the image of an unknown terrain which must be traversed. Our trained eyes require us to see the basic cartographic features on a map: the contours of mountains and rivers which allow us to speculate about possible passes or trails. The cartographic features allow us to get closer to the actual empirical instance, we discern further peculiarities of the terrain. Our tentative notions of the landscape sensitised us to the possibilities of travelling through the terrain. The particular, concrete expression of the landscape moulds our concept of it and, through the concept, allows us to find instances of it in other types of landscapes.

The "basic cartographic features" of adult daughters' roles in long-term care facilities which served as a starting point for me in the present study were the meanings of caregiving, the behaviours of caregiving, and the expectations of caregiving. The definitions of role meaning, role behaviour, and role expectations and how these ideas are thought about had to come from the adult daughters themselves. That is, I set out to explore the meanings, behaviours, and expectations related to the institution-based caregiving role as if they were "empty" concepts. The content of these concepts came from the adult daughters through their descriptions of their experiences. As these concepts grew and developed throughout the project, they served to point me down new paths by identifying other relevant concepts and insights that further helped explain the essence of adult daughter roles in long-term care facilities.

A final "basic cartographic feature" guiding the present study was the notion of "context". Drawing on the assumptions of an ecological perspective, I believed that the caregiving role meanings, behaviours, and expectations would be influenced by various characteristics of the long-term care facility. From this perspective, then, roles are both shaped by, and shape the "enduring environment" (Bronfenbrenner & Mahoney, 1975), particularly the immediate setting in which they are played out. Therefore, the degree and range of family member roles may be limited or enhanced by the institutional policies and availability of programs and resources which may or may not encourage family involvement (Brody, 1986; Dobroff & Litwak, 1977; Hansen, Patterson, & Wilson, 1988; Montgomery, 1982, 1983; Safford, 1980). As well, the meaning, behaviour, and expectations associated with those roles may vary depending on the philosophies and resources of various facilities. In the present study, therefore, context referred to a specific facility and its characteristics within which the caregiving roles were being played out. It was not my intent to compare adult daughters' roles across different institutional settings. However, it was important in this examination of roles to gain an understanding of the specific facility within which the caregiving roles were being played out.

In addition, ecological theory also emphasises the uniqueness of personal circumstances or situations of individual caregivers; that is, the "positionality" of the family member (Jaff & Miller, 1994, p. 53). Thus, context also referred to the unique personal positions and circumstances of the adult daughters at the time of the study. This meant that I had to gain an understanding of "who" the caregivers were and where the caregiving role fit into the rest of their lives.

Several researchers have employed Blumer's (1954) discussion of sensitising concepts to develop sensitising research questions (e.g., Murphy, 1992; Snyder, 1992). Unlike definite working hypotheses, sensitising questions serve as "points of reference that provide guidance for the researcher in approaching the empirical world" (Snyder, 1992, p. 48). They set out starting points for the researcher but do not provide definitive conceptualisations or relationships. The sensitising questions I used to guide my investigation of adult daughter roles in long-term care facilities are as follows:

1a. What does caregiving mean to adult daughters of institutionalised older adults living in a specific long-term care facility? How do adult daughters define their roles in relation to the staff? How do adult daughters think about and describe their roles?

1b. Does the way adult daughters think about and define their roles in a specific setting differ by their stage in the institution-based caregiving career?

2a. What do adult daughters expect of themselves in their role within the specific facility? What are adult daughters' perceptions of the expectations of others for them in their caregiving role?

2b. Do adult daughters' expectations for themselves in their caregiving role differ by their stage in their institution-based caregiving career?

3a. How do adult daughters describe their behaviours within a specific facility? What behaviours do they perform as part of their role?

3b. Do adult daughters' caregiving behaviours differ by their stage in the institution-based caregiving career?

4. What factors affect the way that adult daughters think about and act out their roles within a specific facility?

To summarise, the purpose of this study was to gain a deeper and more comprehensive understanding of the role meanings, behaviours, and expectations of adult daughters at various phases or points in the institution-based caregiving career within one setting. Gubrium (1991, p. xi) emphasised that: "A much ignored feature of the real world is that knowledge of it comes in the form of stories - ordinary narratives and tales of joy and woe about ourselves and others". This study was intended to explore the adult daughters' own constructions of their caregiving experiences and why they perceived their roles the way they did. It was designed to allow the women an opportunity to tell *their* stories.

MAKING FIRST-PERSON EXPLICIT

Before I continue, a note is warranted about the use of first person throughout this document. Discussions in the feminist literature (e.g., Fannow & Cook, 1991; Harding, 1987; Roberts, 1981; Stanely & Wise, 1983), the anthropological/ethnographic literature (e.g., Clifford & Marcus, 1986; Geertz, 1973, 1988; Stoller, 1989; Van Maanen, 1988), and the qualitative educational research (e.g., Lather, 1991; Peshkin, 1988) have all begun to consider how the social sciences, dominated by an ideology of science and a focus on objectivity, force the depersonalisation and suppression of the researcher's voice. Krieger (1991, p. 1) stated:

> The social sciences... are premised on a type of thinking that limits discussion of the self. We are taught to avoid attention to the authorial first person, whose view, and whose choices, a study represents. We learn to become invisible authors. If we cannot be objective, at least we should not call too much attention to the fact of our own subjectivity.

Consequently, our written and oral accounts of our work become what Friedrichs (1981) called "products of a disembodied intellect" (p. 217).

Several authors (Daly, 1997; Krieger, 1991; Stanley & Wise, 1983), however, have argued that the researcher's self is an important and integral component of all research endeavours and that the researcher's self cannot be removed from the work that we do, it can only be omitted. Stanley and Wise (1983, p. 262) emphasised this point:

> We see the presence of the researcher's self as central in all research. One's self can't be left behind, it can only be omitted from discussions and written accounts of the research process. But it *is* an omission, a failure to discuss something which has been present in the research itself. The researcher may be unwilling to admit this, or unable to see its importance, but it nevertheless remains so.

Our uniqueness, our idiosyncrasies, our personal experiences are in fact "at the heart not the periphery of the scientific enterprise" (Johnson, 1975; quoted in Bell & Newby, 1977,

p. 9). For these reasons, these authors recommend making the first-person explicit within our written and oral presentations of our work. Making the self explicit in our written works need not be problematic, but in fact is crucial in producing more truthful representations of the world and aspects of that world we are seeking to understand (Krieger, 1991). Making first-person explicit is also essential in obtaining trustworthiness and authenticity, the two sets of criteria for judging the goodness or quality of naturalistic studies.

Thus, for me, it was important to do what Eisner (1988) suggested and "sign" my work by having a strong authorial presence throughout the work. Researchers, as acting, thinking, and feeling beings, are an influential force at every stage of a research project (Daly, 1997); however, there are times when this force plays more of a role. What I have done in this work is to add more of a first-person presence at those places in the work where I feel my researcher "self" played more of a role in shaping this project.

ORGANIZATION OF THE DOCUMENT

A final note concerns how I have organised the remainder of this document. Before I present the findings of this study, I present much of the groundwork on which the study stands. In the next chapter, I provide a summary of the literature focused on institution-based familial caregivers as well as the limitations of this research. In Chapter Three, I outline in greater detail the guiding theoretical perspective which has informed me throughout this project. Chapter Four describes the specific methodological strategies employed in the data collection and analysis stages of the research. The final three chapters present the findings uncovered from this investigation -- the women's stories. In

Chapter Five, I present the women's perceptions of their roles within the long-term care facility and how those various roles get played out. Chapter Six discusses the demands of the caregiving role for caregivers and the various ways that the adult daughters in this study found to cope with the demands of their roles. Chapter Seven is primarily devoted to the development of a grounded theory on the alternative caregiving career paths of adult daughters in long-term care facilities and the dialectic nature of those career paths.

CHAPTER TWO
INSTITUTION-BASED FAMILY CAREGIVERS

THE FAMILIAL CAREGIVERS OF LONG-TERM CARE RESIDENTS

Very few studies have explicitly examined the roles of family members in long-term care settings. Consequently, our understanding of these roles is very limited. The research that does exist falls under three aspects or dimensions of caregiving: the experience or impact of caregiving on the caregiver, the visitation patterns and task performance of family members, and the role expectations and meaning of caregiving in long-term care facilities. I have organised the literature review around these three areas of research.

The Caregiving Experience Following Institutionalisation

The majority of the research on family members of institutionalised older adults focuses on the caregiving experience, particularly the negative consequences of caregiving. Some studies have suggested that caregivers experience relief from the emotional strains and burdens of caregiving (e.g., Harper & Lund, 1990; Zarit, Anthony, & Boutselis, 1987; Zarit & Whitlach, 1992). Aneshensel and her colleagues (1995), for example, found that family members experienced statistically significant decreases over time in levels of psychological distress, such as anxiety and anger, after the placement of their relatives into long-term care facilities. These family members also experienced significant declines in role overload and role captivity.

Many more studies, however, illustrate the considerable pain and anguish that family members often experience in dealing with the institutionalisation and gradual decline of a loved one. The majority of the research suggests that although the stresses associated with the day-to-day physical care of a relative are reduced with institutionalisation, the pain, anguish, and emotional strains of caregiving often continue (Dupuis, 1993; Pagel, Becker, & Coppel, 1985; Pratt, Schmall, Wright, & Cleland, 1985; Pratt, Wright, & Schmall, 1987; Riddick, Cohen-Mansfield, Fleshner, & Kraft, 1992; Stephens, Bridges, Ogrocki, Kinney, & Norris, 1988; Stephens, Kinney, & Ogrocki, 1991; Townsend, 1990) and may become more pronounced after institutionalisation (Carrilio & Eisenberg, 1983; George & Gwyther, 1984; Tobin & Kulys, 1981). Furthermore, researchers have found similar depression scores, morale scores, and levels of burden among both community-based caregivers and institution-based caregivers (Pratt, Wright, & Schmall, 1987; Stephens et al., 1991). Family members who institutionalise their relatives also experience significant elevations in guilt (Aneshensel et al., 1995) and often find visiting to be frustrating, painful, and difficult (Edelson & Lyons, 1985; Greene, 1982; York & Calsyn, 1977). Thus, institutionalisation does not eliminate the burdens of caring for a loved one, it merely shifts the distress to other areas. This literature emphasises that family members may have needs of their own as they go through the transition to institutionalisation and cope with the gradual deterioration of their loved ones. However, this literature also suggests that the caregiving experience may be very different depending on such factors as the caregiver's gender, familial relationship to the care receiver, and the care receiver's functional health status.

The Caregiving Experience: Gender Differences

Studies of both community-based and institutional-based caregivers have found that caregiving has a greater negative impact on women than on men (Fitting, Rabins, Lucas, & Eastman, 1986; Harper & Lund, 1990; Pruchno & Resch, 1989; Zarit, Todd, & Zarit., 1986). Consistently, women caring for an older adult relative report lower morale, greater levels of depression, and poorer health and well-being than men (Fisher & Lieberman, 1994; Galagher, Wrabetz, Lovett, Maestro, & Rose, 1989; George & Gwyther, 1986; Montgomery & Prothero, 1986; Young & Kahana, 1989; Zarit et al., 1986). Harper and Lund (1990) and Brody, Dempsey, and Pruchno (1990) also found gender differences in the factors associated with caregiver burden and mental health (i.e., depression, emotional effects).

Some researchers (e.g., Barber, 1989; Horowitz, 1985a) have suggested that women may experience greater burden than men because they approach their caregiving roles differently. For example, women tend to be more intensely involved in overall assistance to their older adult relatives than men (Horowitz, 1985b; Kivett, 1983; McAuley, Jacobs, & Carr, 1984; Reece, Walz, & Hageboeck, 1983; Stoller, 1983). Further, women are far more likely than men to provide “hands-on” assistance in the areas of domestic and personal care (Chang & White-Means, 1991; Dwyer & Coward, 1991; Horowitz, 1985b). Men, primarily adult sons, are more likely to provide assistance with home repair, financial management, and maintenance (Stoller, 1990). Other explanations for this gender difference in caregiver burden have been advanced including role conflicts (Brody, 1981), and the frustration of women’s desire for dealing with care receivers (Zarit et al., 1986). Nonetheless, these gender differences in the caregiving experience are particularly relevant considering that the majority of familial caregivers of residents living in long-term care facilities are women. Generally, daughters, followed by wives, represent the largest group of institution-based caregivers (Bowers, 1988; Duncan & Morgan, 1994; Safford, 1980).

The Caregiving Experience: Family Relationship Differences

Although spouses have been identified as the highest risk group for burden and distress among all caregivers (Cantor, 1983; George & Gwyther, 1986; Motenko, 1989; Quayhagen & Quayhagen, 1989), adult daughters are also deeply affected by caregiving responsibilities. In fact, the literature suggests that adult daughters are the second most affected group of all caregivers. In a study conducted by Grau, Teresi, and Chandler (1993), for example, daughters reported the second highest demoralisation scores (i.e., non-specific psychological distress related to anxiety, self-esteem, helplessness/hopelessness, and sadness) after spouses, and had significantly higher scores than sons. Riddick et al. (1992) also found that although spouses showed significantly higher levels of caregiver burden than daughters, spouses and daughters perceived similar negative emotions (i.e., guilt, sadness, anger, frustration with lack of control over relative's health, thoughts about own future health, and thoughts about own future living arrangements) surrounding the placement of their loved ones. Investigating family members of hospitalised "long-stay" patients, Rosenthal, Sulman, and Marshall (1993) found that although spouses had higher depression scores than adult children, the differences in levels of depressive symptomatology children did not reach statistical significance. The factors related to depressive symptoms, however, differed for spouses, adult children, and other relatives. Finally, Brody et al. (1990) noted significant differences in the effects of parent care when comparing adult daughters and sons of institutionalised older adults. Daughters experienced significantly higher emotional effects (e.g., helpless, frustrated, angry, emotionally drained, guilty, worried etc.) and levels of depression than sons. Daughters also reported significantly more time pressure as a result of caring for their parents than did sons. Similar to the Rosenthal et al. (1993) study, these authors also found that the predictors of depression and emotional effects differed for daughters and sons.

Brody (1981) introduced the concept of "women in the middle" to explain the greater distress experienced by adult daughters. The term refers to the competing demands that middle-aged women experience in their various roles (e.g., spouse, mother, employee, caregiver to aging parent, and so forth) which could result in role overload. Today women feel the pressures of family responsibility for care of their elderly relatives and at the same time may feel the competing pressure of working outside of the home and building occupational careers for themselves. Balancing multiple roles may lead to higher stress levels, particularly for women who are often forced to balance a number of different roles at the same time (MacBride-King, 1990; Martin Matthews & Rosenthal, 1993). Other researchers (e.g., Himes, 1994; Rosenthal, Martin-Matthews, & Matthews, 1996; Rosenthal, Matthews, & Marshall, 1989; Spitze & Logan, 1990; Stone, Cafferata, & Sangl, 1987; Stone & Kemper, 1989; Stone & Short, 1990), however, have found that the concept of "women in the middle" may not be a typical occurrence among middle-aged adults and that multiple family roles and responsibilities are not necessarily related to negative effects on caregiver well-being (Loomis & Booth, 1995). It is more likely that the differential approaches to the caregiving role by women and men are more important in explaining the greater distress felt by adult daughters than are the competing demands of multiple roles. In fact, combinations of roles may have positive outcomes for a caregiver's well-being and sense of self (Scharlach, 1994; Skaff & Pearlin, 1992; Stoller & Pugliesi, 1989).

The Caregiving Experience: Impact of the Care Receiver's Health Status

Research further suggests that the caregiving experience and its outcomes may differ by the care receivers' physical and mental health status (Birkel, 1987; Burtz, Eaton, & Bond, 1988; Ross, 1991). These authors suggest that caregivers of persons with physical impairments may have very different experiences in their roles and adjustment patterns than those caring for relatives with cognitive impairments or dementia. It is unclear, however, which type of impairment situation (physical or cognitive) is the most stressful for caregivers and the most difficult to cope with.

Some researchers suggest that although caring for a person with dementia can be extremely rewarding, it also can be one of the most difficult, frustrating, and distressing of all the caregiving roles (Brody, Lawton, & Liebowitz, 1984; Motenko, 1989). For example, George and Gwyther (1986) found that community-based caregivers of persons with Alzheimer's disease experienced three times as many emotional stress symptoms and were two to three times more likely to take psychotrophic drugs than other caregivers. In another community-based study, Birkel (1987) found that dementia was associated with higher levels of stress and that there were different mediating factors in cases involving caregivers of persons with physical impairments when compared with caregivers of persons with dementia.

Although studies focused on long-term care facilities suggest that frequency of visits is not related to the resident's health status, the quality or enjoyment of the visits for family members appears to show some relationship with the resident's cognitive abilities. In an institution-based sample of familial caregivers, York and Calsyn (1977) found a significant negative relationship between enjoyment of visits and level of cognitive impairment. No significant correlation was found, however, between enjoyment of visits and physical or sensory disabilities. Moss and Kurland (1979) reported similar findings.

Nonetheless, Ross (1991) found that wives of persons with cognitive impairments living in a long-term care facility appeared to cope better over time than wives of residents with physical impairments. Wives caring for husbands with physical impairments continued to be heavily involved in visiting and caregiving over time. Wives of husbands with cognitive impairment, on the other hand, were less involved in visiting and caregiving and felt less responsibility for the provision of care at the nine-month interview. Furthermore, wives "embracing new realities" showed significant decreases over time in depression scores and a significantly greater proportion of these wives reported being happier at the nine month interview. In comparison, those wives who were "holding on to the past" showed very small and non-significant increases in depression while their morale scores tended to remain relatively stable and substantially lower than those wives "embracing new realities". Perhaps a relative's cognitive impairment is more difficult to deal with early in a caregiver's institutional career, but is easier to adapt to over time. Nonetheless, the majority of residents living in institutional settings have an illness causing dementia

(German, Rovner, Burton, Brant, & Clark, 1992; Ontario Ministry of Community and Social Services, 1991). As Duncan and Morgan (1994, p. 236) pointed out, because of the large percentage of persons with cognitive impairment living in long-term care facilities, "the role of the family in caring for these patients takes on added importance".

Due to the emotional distress experienced by family members after the institutionalisation of a loved one, several researchers have stressed the importance of serving the family members as well as the residents as clients (e.g., Montgomery, 1982, 1983). Greenfield (1984), for example, emphasised:

> If quality service is truly an important issue to nursing home administrators, it becomes critical that institutional planning include intervention strategies … to expedite and facilitate the process of change in the most comfortable manner possible for both the resident and his or her family (p. 21).

These researchers have suggested several strategies which could help address the needs of family members. The need for family counselling services and supportive educational groups as well as support groups as part of a continuum of care for family members has been articulated by several researchers (Coen Buckwalter & Richards Hall, 1987; Hatch & Franken, 1984; Pratt, Schmall, Wright, & Hare, 1987). Cox and Ephross (1989) recommended the development of self-help family groups and stressed the importance of the "socialisation functions" of these groups. They suggested that a self-help group "provides a milieu in which new roles and behaviours appropriate to the institution are learned" (p. 61). Similarly, Brubaker and Schiefer (1987) emphasised the building of family social support networks which could be available to families of incoming residents. Schneewind (1990) discussed the institutionalisation process as a step in the normal family life cycle and encouraged the uses of rituals to assist families adjust to placement. Greenfield (1984) proposed the use of family group orientation meetings, on-going family support group meetings, and the inclusion of family members in therapeutic activities with the residents as possible therapeutic interventions. This literature suggests that the role of the family member as client may be important, at least from the long-term care facility's perspective. It is unclear, however, how family members perceive the client role within the long-term care facility and whether this is an important aspect of their role.

To summarise, much evidence demonstrates that the emotional strains of caregiving do not disappear after the institutionalization of a care receiver. Nonetheless, because of the different approaches to caregiving or the different caregiving situations, not all caregivers experience the caregiving role in the same way. Women, particularly wives and adult daughters, appear to be more intensely affected by the caregiving experience than men. Further, some evidence suggests that the care receiver's health status may also influence how a family member copes with the caregiving role. Greater awareness and recognition of the emotional distress experienced by family members after the institutionalization of a loved one has resulted in the development of intervention strategies to help family members adjust to their new circumstances and new roles. The differences in the caregiving experience highlight the problems with treating heterogeneous samples as homogeneous groups and emphasise the need for research which focuses on a specific group of caregivers.

Caregivers' Behaviours Following Institutionalisation

Role theorists have defined the concept of role behaviour as "the behaviour that emerges in interaction under the guidance of a role" (Heiss, 1981, p. 127). In his discussion of expectations, identities, and behaviours, Biddle (1979, p. 24) described overt behaviour as "the relatively transitory, overt activities of human beings". Sarbin (1968, p. 546) used the term "role enactment" to refer to "what the occupant of a given position *does* and *says*" (italics in the original). A small body of literature has examined the behaviour of familial caregivers in long-term care facilities. This research has focused primarily on the visitation patterns and the task performance of institution-based family members.

Visitation Patterns of Familial Caregivers

Evidence from the research on the role behaviour of institution-based familial caregivers consistently illustrates that family members continue to have frequent contact with their older adult relatives after placement into a long-term care facility. The majority of family members, in fact, visit at least once a week (Aneshensel et al., 1995; Bitzan & Kruzich, 1990; Hook et al., 1982; Moss & Kurland, 1979; Munichiello, 1988; York & Calsyn, 1977). Average frequency of visitation per week appears to range from once a week (Hook et al., 1982) to almost four times per week (Zarit & Whitlach, 1992), with a small percentage of family caregivers visiting daily (Hook et al., 1982; Moss & Kurland, 1979; Ross, 1991).

Family members also appear to spend substantial amounts of time with their loved ones living in long-term care facilities. Research suggests that family visits range in duration from an average of 3.4 hours on weekends to 6 hours on weekdays (Zarit & Whitlach, 1992). Aneshensel and her colleagues (1995) reported that family members spent anywhere from 0 to 30 hours during weekdays (or an average of 5 hours per week) visiting their relative in the nursing home. The duration of visits ranged from 0 to 12 hours (or an average of 2.5 hours per weekend) on the weekends. Ross (1991) found that the wives involved in her study reported visiting from ten to fifteen minutes to eight hours per visit. The majority of the wives visited for two to four hours at a time.

Very few of these studies have compared visitation patterns by the caregiver's gender, relationship to the care receiver, or the care receiver's functional health status. The scant research that does exist, however, suggests that women, specifically wives and adult daughters, may visit more regularly than men. For example, when Hook et al. (1982) compared the responses of adult sons and daughters, they found that daughters reported more daily and semi-weekly visits than did sons. Further, Ross (1991) found that the vast majority of the wives in her study visited several times a week if not daily.

Several studies suggest that the majority of family visitors to long-term care facilities are adult children, particularly daughters. In a study of residents in three homes, York and Calsyn (1977) found that in 64 of the 76 families interviewed, the family visitor was a child of the resident. In a study of 629 visitors of the residents of three rural nursing homes, Hook et al. (1982) again found that the residents' children made up the majority (41%) of the visitors. Kahana, Kahana, and Young (1985) reported similar findings. Residents also identify adult children as primary contacts or visitors. In interviews with 332 intellectually intact residents in 54 nursing homes, for example, Bitzan and Kruzich (1990) found that of the 90% of the residents who identified a person outside of the nursing home to whom they felt close, most (41%) named an adult child. Of the adult children, adult daughters outnumber sons as the primary caregivers in the institutional-setting by a ratio of between three and four times to one (Brody et al., 1900).

The literature also suggests that the number of family visits is not related to the amount of resident impairment (Greene & Monahan, 1982; Moss & Kurland, 1979; York & Calsyn, 1977). Nevertheless, the resident's level of cognitive impairment may significantly shorten the duration of family visits (Moss & Kurland, 1979). Again, it must be emphasised that most of the research thus far treats relatively heterogeneous caregiver samples as homogeneous groups or only examines one type of family caregiver, specifically wives. Thus, our understanding of differences in visitation patterns by gender, caregiver relationship to resident, and resident's functional status is extremely limited.

Our insights into the relationship between length of residence in a long-term care facility and the visitation patterns of familial caregivers are also limited. Some researchers have found no significant declines in visitation over a nine month period (Dawson, Rosenthal, & Ross, in review; Linsk, Miller, Pflaum, & Vicik, 1988; Ross, 1991) or over a one year span (Moss & Kurland, 1979; Spasoff et al., 1978). Ross (1991), for example, found that 71.3% of the wives involved in her study remained consistent in their visitation patterns over a nine-month period.

Other researchers, however, have reported a significant negative relationship between the length of time residents have lived in a long-term care facility and visitation frequency (Bitzen & Kruzich, 1990; Gladstone, 1994; Greene & Monahan, 1982; Hook et al., 1982). Bitzen & Kruzich (1990), for instance, interviewed residents with a length of residence in nursing homes ranging from 4 months to 21 years (Mean = 4.18). They found that those residents receiving daily visits had a significantly shorter mean length of residence than those residents who were visited weekly or monthly. The differences in findings could be attributed to the methods employed in the various studies. For example, all of the studies that found significant declines in family visitation over time employed retrospective, self-report questionnaires conducted at one point in time. In contrast, of those studies reporting relatively stable visitation patterns over time, all but the Moss and Kurland study were longitudinal.

The Task Performance of Familial Caregivers

A study by Glaser and Strauss (1965) was perhaps one of the first to demonstrate the substantial contribution family members make to the provision of care even after placement of a loved one to a medical or long-term care facility. They noted:

> A hospital visitor cannot remain at his [or her] dying kinsman's bedside for very long without taking on a role - other than that of relative or visitor - suggested by the situation, one that integrates him [or her] with the staff's daily work (p. 164).

Glaser and Strauss conceptualised family members as workers and observed the many ways families contribute to the care of their loved ones, in this case in a hospital setting. Family members monitored their relatives' care making sure to notify the nursing staff when deemed necessary. Viewing themselves as part of the medical care team, they provided hands-on care, performing such tasks as providing comfort measures for their relatives. Some family members even carried out most of the nursing care required and participated in, or took-over, decision-making responsibilities regarding their loved ones' treatment.

More recently, researchers have begun to refer to the role of family members in long-term care facilities as resources or partners in care. One of the earliest partnerships was developed at the Geriatric Centre in New York City in 1976 (Safford, 1980). This program originally began as an educational and support program for families of older adults with dementia in both the community and institutional settings. However, the Geriatric Centre also recognised the role that family members could play in the care system and provided an opportunity for family members to become legitimate partners in the organisation. "A basic premise of the program [was] that the needs of the mentally impaired aged in modern society can best be served by the sharing of responsibility for their care by the family and appropriate formal organisations" (Safford, 1980, p. 656). The program served the needs of family members through family support groups, and the needs of the institution and relatives through the development of a family council. The 200 members of the family council formed very active committees which took on the responsibility of providing a more enriched program of activities, serving as "resident's representatives", and developing a family visitor program.

Similarly, Coen Buckwalter and Richards Hall (1987) stressed both the importance of recognising the needs of family members in the institutionalisation of a loved one as well as the resource potential of family members. They advocated the active participation of family members on therapeutic teams in an "adjunct staff capacity". As well as participation in family support groups or family counselling, they proposed that family members could be trained to become group leaders in therapeutic strategies (e.g., remotivation, music, movement, and psychodrama therapies; reminiscence and life review; reality orientation; attitude therapy; sensory stimulation programs). These authors suggested that direct involvement of family members would benefit the residents, the family members and the staff alike.

Palmer (1991) also stressed the use of family members in therapeutic capacities, especially as co-leaders of family councils. She described some of the benefits of a family council in long-term care facilities:

> The council provides more than an opportunity to address family concerns. It is also a way to get families involved in the nursing home in a positive way. Family members bring many experiences and areas of expertise which often can be utilised by the facility...Utilising family members as a resource will ultimately benefit everyone involved and is well worth the time invested (pp. 124 and 133).

One of the primary purposes of the family council, then, was to forge a partnership between family members and staff in a "joint venture" in order to provide the highest quality of life for the residents. The family council established several sub-committees to address different concerns. The most unique feature of this program, however, was that it was co-lead by a family member.

The Resident Enrichment and Activity Program (REAP) was developed in the Dallas Home for Jewish Aged (Hansen et al., 1988). The primary goal of this home was "to provide support for residents' families and to involve them in the overall operation of the unit and the care planning for residents" (p. 508). REAP, thus, provided family members more active, legitimate roles on the special care unit and the opportunity to share in the caregiving responsibilities. Family members were recruited to become direct activity program leaders in the unit or to assist the program leaders in a variety of capacities and activities. Over an 18-month period, seven family members took on program leader roles and another 17 family members served as activity volunteers.

Believing that families are critically needed as partners in care in more than just a therapeutic capacity, Linsk and associates (1988) established the Alzheimer's Disease Family Care Centre program in order to investigate ways to involve families in the care of their institutionalised relatives. Part of the program involved contracting with family members the types of tasks they would perform during visits. Twenty-three family members developed contracts with the institution which could be re-negotiated at any time. Two-thirds of the family members contracted for interpersonal activities such as reminiscing (67%) and bringing favourite foods from home (61%). However, a substantial number of family members also contracted for some of the more direct hands-on types of care such as feeding (39%), toileting (22%), massaging the resident (35%), and walking the resident (44%). Several family members also contracted for activities related to the up-keep of the resident's clothing such as doing the resident's laundry (39%), keeping a clothing inventory (52%), and repairing the resident's clothing (44%).

At the end of the program, family members were asked to indicate which activities occurred most frequently during their visits. The most frequently performed activities were those that were most interactive with the relative such as talking to the relative, holding the relative's hand, touching, bringing gifts from home, taking a relative for a walk or grooming. Family members also reported talking to the staff as a frequent activity during visits to the home.

A few other studies (see Aneshensel et al, 1995; Gladstone, 1994; Moss & Kurland, 1979; Ross, 1991) focused on a variety of topics have asked family members what they do in their caregiving roles. Much of this research demonstrates that family members of institutionalised older adults provide both technical and non-technical types of care. In fact, Aneshensel et al. (1995) noted that after long-term care placement of a relative, family members continue to perform many of the same personal care activities that they had performed when the relative was at home. These studies suggest that family members provide hands-on assistance with grooming, dressing and undressing, feeding, and toileting. They bring in special or extra things such as plants and special foods for their relatives. Family members become directly involved in the maintenance of the residents' clothing by straightening bureau drawers, doing personal laundry, and labeling or marking clothing. Families also serve as emotional support systems by cheering up a resident, giving advice, talking with the resident, and spending time with the resident. In fact, when the wives in the Ross (1991) study were asked what the most important task was that they performed in their caregiving role, visiting was considered to be the most important caregiving activity they did for their husbands. In addition, the provision of love, support, and companionship were also viewed as important aspects of their role as well as performing specific tasks. Family members serve in a recreational capacity by taking the resident for walks or helping their relative get exercise, reading to the resident, getting a relative going in an activity, and by providing reading materials, radios, and televisions. Further, family members play a financial role by buying clothing and other needed items for their relative and by providing spending money. Family members also play advocate roles by making sure that the staff are made aware of their residents' concerns or needs.

Although very little research has examined how task performance changes over time, Ross (1991) found that the wives' high involvement in task performance remained relatively consistent over time. In fact, the average number of tasks performed by wives increased significantly over a nine-month period. Thus, although the overall patterns of involvement in the home did not reflect change but rather consistency, when change did occur, involvement in task performance increased over time rather than decreased. The increase over time in task performance may be due to the fact that family members are focused on their own needs upon institutional placement (Rosenthal & Dawson, 1991). In addition, familial caregivers may be tentative about becoming too involved initially, at least until they become more familiar and comfortable with the facility (Dawson et al., in review).

Few studies have compared caregiver task performance in long-term care settings by the care receiver's functional health status. However, some researchers examining community-based caregivers have suggested that there may be quantitative and possibly qualitative differences in the approaches to caregiving depending on whether or not the care receiver shows signs of cognitive impairment. Birkel (1987), for example, compared the activities provided by caregivers of older adults with physical impairments with those caring for persons with cognitive impairments. Although both types of caregivers were spending similar amounts of time in their caregiving roles, those family members caring for relatives with cognitive impairments demonstrated far more day-to-day variability in time spent caring than did caregivers of persons with physical impairments. Similarly, Jones (1994) found that almost 40% of the activities considered in her study showed significant differences by type of caregiver group (i.e., caregivers of persons with cognitive and physical impairments and caregivers of persons with only physical impairments) in terms of the types of activities the caregivers were likely to perform during the week, or the frequency or duration of those activities during the week. Nevertheless, whether or not the health status of care receivers influences the task performance of family members in long-term care settings remains unclear.

To summarise, much of the research reviewed suggests that a substantial number of family members are heavily involved in the care of their institutionalised relatives. They visit regularly and often stay for long periods of time. The research also demonstrates that family members of institutionalised older adults provide both technical and non-technical types of care. Further, when provided with the opportunity, some family members take on adjunct-staff roles within the institution. Nonetheless, the evidence from community-based caregiving samples suggests that the health status of the resident may affect the types of activities the family member performs in the caregiving role.

Caregiving Role Expectations and Meaning

A few studies have more explicitly examined the roles of family members in institutionalised settings and how these roles are developed. In these works, two approaches to conceptualising family member roles have been employed. Some researchers (Dempsey & Pruchno, 1993; Rubin & Shuttlesworth, 1983; Schwartz & Vogel, 1990; Shuttlesworth et al., 1982) have used a priori definitions of family member roles based on Litwak's (1977, 1985) structural-functionalist framework which he called the "Theory of Shared Functions and Balanced Coordination". Consistent with Litwak's framework, these authors conceptualised roles as a set of expectations, specifically a set of tasks, the primary group (e.g., the family) is responsible for in relation to the formal organisation (e.g., the long-term care setting). According to Litwak's model, the structural characteristics of the institution stress the maximisation of technical knowledge; thus, the formal organisation is best able to handle uniform, technical tasks and economies of large-scale. The structural characteristics of the primary group, on the other hand, stress the minimisation of technical knowledge, and therefore the primary group is best able to handle non-uniform, nontechnical tasks and economies of small scale. Quite simply, the division of labour approach to examining the roles of family members in long-term care facilities defines roles in terms of the tasks the family is *expected* to perform.

The concept "role expectations" generally refers to the "beliefs [or] cognitions held by certain persons in regard to what behaviours are appropriate for the occupant of a given position" (Sarbin, 1968, p. 546); that is, role expectations typically refer to the prevailing norms concerning what a person should do in their role. Sarbin (1968, p. 547) further suggested that "role expectations may be viewed as *actions* or *qualities* expected of the occupant of a position" (italics in the original). Thus, role theorists tend to use the concept role expectations to denote the prescriptive aspects of roles or the norms surrounding a specific role, status or position (Biddle & Thomas, 1966).

Research on Role Expectations

Of the studies investigating the tasks associated with each group structure (i.e., family member group versus organisation), Shuttlesworth and his associates (1982; Rubin & Shuttlesworth, 1983) examined the amount of congruency and variation in role expectations between nursing home staff and family members of residents. In both studies, very little variation both within the staff and family groups and between the groups was found for the majority of the tasks. However, a substantial number of tasks (i.e., 45 out of 100 in the first study, and 40 out of 100 in the second study) also showed considerable variation regarding who should assume responsibility for the tasks. In most cases where considerable ambiguity in responses was found, the referent item concerned a non-technical task where the staff assigned less responsibility to families than families assigned to themselves. The most problematic categories of tasks were personalised care, monitoring and ensuring the provision of care, clothing needs, grooming, and providing reading materials.

Schwartz and Vogel (1990) replicated the earlier studies but employed a broader based sample and modified the scoring procedure on the task-assignment instrument. In this study, congruency in ratings between staff and family members was found in 69 of the 100 tasks. Of these tasks, 36 were considered to be the responsibility of the staff and 7 the responsibility of the family. However, a substantial number of tasks (i.e., 26) were considered by both groups to be a shared responsibility. Physical health and safety security tasks were considered by both staff and relatives to be the responsibility of the staff. Special or extra services were assigned to the family. The four other clusters of tasks (i.e., regulator functions, cognitive/mental stimulation, emotional/spiritual/relationship, unclassified tasks) were generally considered by both groups to be of shared responsibility.

Schwartz and Vogel (1990) also found that caregivers of relatives who resided in a nursing home for less than 1 year or more than 3 years tended to assign responsibility more to the families than did those whose relative resided in the home for 1 to 3 years. They suggested several reasons for this finding:

> One might infer that initially (during the first year), families are more willing to assume responsibility because of feeling guilty at "putting the relative away" or possibly because the move to the nursing home is seen as temporary. A further inference could be made that as time progresses, the family relinquishes more responsibility to staff (or staff overtly assumes more responsibility). We might speculate that after 3 years of residence, families perceive the stay as permanent and therefore again assume more responsibility. It is also likely that families of longer staying residents are more knowledgeable about the nursing home and are more likely to perceive gaps in services provided and, in effect, begin to fill in where need is perceived (Schwartz & Vogel, 1990, p. 53).

Nonetheless, few studies have examined family member's role expectations or motivations at different times in a family member's caregiving career. Thus, our understanding of how these aspects of roles shift over the caregiving career is limited.

In contrast to the findings in the earlier studies, the wives involved in Ross' (1991) study consistently assigned more caregiving tasks as the responsibility of the family. Fifteen tasks from all five categories of task performance were considered to be the sole responsibility of the family. These activities included such things as providing special foods, arranging for hair grooming, providing plants and extras, supplying personal money, marking clothing, and doing personal laundry. Eleven of the 27 tasks were considered to be the primary responsibility of the staff. Some of the tasks assigned to staff included: clipping husbands' nails, grooming husbands, ensuring that the diets are followed, cleaning rooms, and providing wheelchairs. Interestingly, none of the recreational tasks were considered to be the responsibility of the staff. The wives assigned only one task (i.e., shaving husbands) as a shared responsibility.

Ross (1991) also found that the overall patterns of wives' expectations regarding who is responsible for various tasks remained relatively stable over the nine month period. However, a small but statistically significant increase in the number of care tasks assigned to the family from Time 1 to Time 9 was also noted. Further, there was much consistency between wives' expectations regarding task allocation and their actual task performance. Only seven tasks showed some discrepancy between reported expectations and actual performance of tasks.

Finally, Dempsey and Pruchno (1993) examined adult children's perceptions of who should be providing certain types of tasks in the long-term care setting as well as the predictors of technical and non-technical tasks. Family members assigned 9 of the 28 tasks (i.e., toileting, eating, bathing, dressing, helping in and out of bed, cleaning the room, giving medicine, using the telephone, supervising and reviewing medicine, and deciding which room the parent should be in upon admission) as the sole responsibility of the staff. Seven of the tasks (i.e., managing money, shopping, putting plants and extras in the room, writing letters, marking clothing with parent's name, giving permission for an operation and managing spending money) were considered the responsibility of the adult child. Overlapping responsibility or considerable ambiguity in assignment was noted for the remaining 12 tasks.

Significant predictors of the likelihood that adult children would perform non-technical tasks were more frequent visits, being female, and a greater number of parent illnesses. Significant predictors of assistance with technical tasks included more frequent visiting, more parent illnesses, an older parent, and more technical tasks done by staff. Dempsey and Pruchno (1993) also reported that neither the parent's mental status nor the length of stay in the long-term care facility were related to family involvement in either type of care. In addition, the work status, age and health of the adult child did not predict family assistance. Further, characteristics of the nursing home (e.g., home size, perception of staff), other than staff doing technical tasks, did not predict the involvement of an adult child in the care of their loved one.

The Meaning of Caregiving for Family Members

Other researchers have questioned the usefulness of a task-based conceptualisation of family caregiving and further questioned whether or not it is possible to differentiate roles simply by the specific behaviours or tasks associated with those roles (Bowers, 1987, 1988; R. H. Turner, 1968). They also criticised role theorists for failing to consider the more qualitative aspects of roles (Blumer, 1969; R. H. Turner, 1968). These researchers maintain that roles are "more general gestalts and configurations of meaning about lines of conduct" (J. H. Turner, 1991, p. 426). Thus, other gerontologists (see Bowers, 1987, 1988; Duncan & Morgan, 1994) employing more qualitative, inductive approaches have examined how family members themselves define their roles both in the community and in long-term care settings. These authors found that family members do not think of their roles in terms of the tasks that they perform, but viewed their roles in terms of the meaning or purpose they attributed to their role. A major purpose of the familial caregiving role mentioned by family members, for example, was the maintenance or preservation of the older relative's self (Bowers, 1988; Duncan & Morgan, 1994).

From the results of a study focused on middle-aged children caring for parents in the community, Bowers (1987) developed a purpose-based typology of caregiving activities. Family caregiving involved: (a) protective care (i.e., protecting or preserving the parent's concept of self and the parent-child relationship; (b) preventative care (i.e., preventing physical harm to parent); (c) anticipatory care (i.e., anticipating and preparing for what might happen to the parent); (d) supervisory care (i.e., co-ordinating and supervising the care provided by others); and (e) instrumental care (i.e., performing direct physical care tasks).

In a subsequent study focused on institution-based caregivers, Bowers (1988) again found that family members tended to focus on the purpose of family involvement and that the priority for these caregivers was on preserving their relative's sense of self.

Four types of preservative care, also focused on purpose rather than by associated tasks, were identified. These included: (a) maintaining family connectedness; (b) maintaining the relative's dignity; (c) maintaining the relative's hopes (generally for recovery); and (d) helping the relative maintain control of the environment. Maintaining family connectedness was considered the primary responsibility of the family members. However, family members felt that the other three types of care required collaboration between staff members and family. They emphasised that both groups should be able to perform both instrumental or technical types of care as well as the other three types of preservative care.

Duncan and Morgan (1994) examined the staff/family member relationship in long-term care settings from the family members' perspective. As in Bowers' (1988) study, family members placed much emphasis on their efforts to preserve their relative's identity. This endeavour involved monitoring staff behaviour, finding ways to get the staff to relate to their resident as a person, maintaining ongoing relationships with staff members, and serving as a role model for staff. However, unlike the caregivers in the Bowers' study, these family members were not interested in increasing their involvement in the range of tasks they performed but focused on increasing the social and emotional involvement of staff members. One of the reasons for this difference suggested by Duncan and Morgan may be that the majority of the family members in the Bowers' study were caring for persons with physical disabilities whereas the caregivers in the Duncan and Morgan study were all caring for a spouse or parent with Alzheimer's disease. Whatever the case, both studies emphasise the importance of purpose or the meaning of caregiving to family members.

Furthermore, the Bowers (1988) and Duncan and Morgan (1994) studies also illustrate that family members perceive high quality care as a "collaborative process" between family members and staff rather than a delegation of separate tasks. Conflict between staff and family members resulted from a lack of recognition on the part of staff of the expertise that family members possess and by overly rigid divisions of labour promoted by the staff. Conflict was avoided by developing ongoing, collaborative relationships with the staff (Duncan & Morgan, 1994). Nonetheless, family members represent a very heterogeneous group and there are also those family members who may not choose to be as involved in caregiving. These caregivers may define their roles very differently for themselves than do those who choose to be more intensely involved. Thus, not all family members may prefer a collaborative approach to caregiving.

Although very little research has examined how institution-based family caregivers define their roles within long-term care facilities, several alternative definitions or conceptualisations of the term "meaning" have been employed in other studies. Meanings, for example, have been presented "as broad themes that transcend time, place, and social context; as a set of concepts that capture some basic properties of how people think about something; or as situation-specific accounts for certain actions" (Jaffe & Miller, 1994, p. 52). Luborsky and Rubinstein (1995, p. 98) defined meaning "as the process of reference and connotation, undertaken by individuals, to evoke key symbols, values and ideas that shape, make coherent, and inform experience". Hasselkus (1988), in her investigation of the meaning of caregiving for family members caring for a relative in the community, adopted Hansen's (1979) definition of meaning. "Meaning was defined as those values, beliefs, and principles that people use to organise their behaviour and to interpret their experience" (Hasselkus, 1988, p. 686). Quite simply, these conceptualisations of meaning focus on the individuals' perceptions, views, descriptions, ideas, values, and understanding of the subject at hand.

Other researchers (Barkwell, 1991; Lewis, 1989; Mechanic, 1977; O'Connor, Wicker, & Germino, 1990; Taylor, Lichtman, & Wood, 1984) working in the stress, coping, and illness areas have defined "the search for meaning" or "found meaning" as the process of "finding a positive purpose", particularly when faced with negative events (Fife, 1994, p. 310). Farran, Keane-Hagerty, Salloway, Kupferer, and Wilken (1991), for example, employed an existentialist paradigm in order to examine how caregivers find meaning through their struggles and suffering. These authors all suggest that finding or assigning a sense of purpose to a difficult, threatening, or stressful event may serve as an important adaptive coping strategy (Farran et al., 1991; Fife, 1994). This definition is especially interesting given the family members' focus on purpose in the Bowers (1988) and Duncan and Morgan (1994) studies. In their search for meaning, assigning purpose to their roles may be an important part of the coping process for caregivers.

Some researchers (Allen & Walker, 1992; Fife, 1994; Rubinstein, 1989) have focused on the consequences or outcomes of events or the emotional responses to those events in their definitions of meaning. For example, Rubinstein (1989, p. 119), in investigating the meaning of caregiving for community-based caregivers, used the term meaning "to signify the often affectively laden array of significations and associations individuals attribute to the events they experience". Similarly, Fife (1994, p. 310), exploring the conceptualisation of meaning in illness, defined meaning "as an individual's perception of the potential significance of an event, such as the occurrence of serious illness, for the self and one's plan of action". Her conceptualisation included two dimensions of meaning: "self-meaning" and "contextual meaning". Self-meaning referred to the "perceived effect of the event on various aspects of one's identity" and contextual meaning referred to the "perceived characteristics of the event itself as well as the social circumstances that surround it" (Fife, 1994, p. 310). These authors focused primarily on how the experience either with caregiving or illness had affected the respondents themselves or different aspects of the respondents' lives.

Similar to this conceptualisation of meaning, Ross (1991) used fixed-choice and open-ended questions related to the wives' perceptions of their husbands' health and various aspects of the marital relationship to examine the meaning of caregiving for her participants. Two aspects of role meaning emerged from the wives' responses. First, the wives talked about the deterioration of their husbands and their growing "awareness of impending loss". This awareness was central to the wives' continued involvement in the care of their husbands after institutionalisation. Second, the caregiving role and the meaning associated with that role were found to be directly linked to the meaning associated with their marital careers. The quality of the marital relationship prior to admission, for the most part, remained consistent following admission. The quality of the marriage subsequently shaped the wives experience in the caregiving role.

To summarise, the majority of the research that has more explicitly examined the roles of family members in long-term care settings has focused on role expectations. In most cases, considerable ambiguity was apparent concerning who should be responsible for various caregiving tasks, the family or the staff of the long-term facility. In many instances, tasks were perceived to be the shared responsibility of both family and staff.

Fewer studies have examined how family members themselves define their caregiving roles within the long-term care setting. The studies that do exist, however, suggest that family members do not think about their roles in terms of the tasks they perform but rather in terms of the purpose they ascribe to their roles. A primary purpose for family members appears to be preserving their loved one's sense of self and dignity.

Limitations of the Research on Role Behaviours, Expectations, and Meaning

Although the literature on visitation patterns and task performance, role expectations, and role meaning provide some insight into the roles of caregivers in long-term care facilities, several limitations of the research were apparent to me. First, most of the studies focused on role behaviour employed structured, fixed-choice questions to measure visitation patterns or task performance. For example, Ross (1991) used a fixed-choice, 27-item list of tasks taken from the work of Rubin and Shuttlesworth (1983). Fixed-choice lists of tasks may not be able to capture all those activities that family members themselves feel are important for them to do – activities that may not be included on a fixed-choice questionnaire. Gladstone's (1994) work on spousal relationships following institutional placement is one of the few studies to employ an open-ended approach to identifying the types of assistance caregivers provide in long-term care facilities.

Second, all of the studies on role behaviour gathered retrospective accounts from family members to gain an understanding of their visitation patterns and task performance in long-term care settings. Retrospective or recall questions may yield overestimates of the frequency and duration of certain types of activities. None of the studies specifically examined what family members actually do in their role during or directly following caregiving activities. Such an approach might minimise the overestimations that may be introduced in retrospective approaches.

Third, the studies focused on family members of persons living in long-term care facilities either treated samples of diverse types of caregivers as homogeneous groups or only included one type of caregiver, particularly spouses. Very little research has specifically examined the role behaviour, role expectations, and/or role meanings of adult daughters in long-term care facilities. Given their different relationships to the care receiver and perhaps different life stages and situations, it is reasonable to assume that spouses and adult daughters approach their caregiving roles differently. Nonetheless, due to lack of research focused specifically on adult daughters, our understanding of the role expectations, role meanings, and the types of activities performed by this group of caregivers is limited.

Fourth, as mentioned in the introductory chapter, the majority of the studies conducted to date have conceptualised the term "role" as primarily a uni-dimensional concept. Researchers have either examined the family members' or staff members' expectations regarding the tasks family members should perform, or have examined family members' perceptions of their role. Interestingly, few studies have looked explicitly at what family members actually do in their role. In the work thus far, the term "role" is rarely, if ever, conceptualised as a multi-dimensional concept consisting of both meaning and behaviour (for an exception, see Ross, 1991). R. H. Turner (1968) noted the general lack of consensus with respect to the meaning of the concept "role" and identified the various ways in which the term has been used. Researchers have used the term to mean:

(a) expected behaviours, (b) conceptions of expected behaviours, (c) behaviour one learns to play in specific situations, (d) overt behaviours of persons, and (e) norms attached to statuses or positions (R. H. Turner, 1968). He argued that conceptualisations of role should not focus on any one of these attributes but should incorporate all into a unified conception of role. He also stressed the importance of considering the more qualitative aspects of roles. Further, symbolic interactionists stress that meaning and behaviour are integrally linked in that meaning both influences and is influenced by behaviour (Blumer, 1969; Fife, 1994). Thus, a more comprehensive understanding of roles involves an examination of the subjective meaning behind specific roles as well as the role behaviour and role expectations associated with those roles.

A multi-dimensional conceptualisation of roles is similar to Hughes' (1937, 1971) treatment of the concept of "career". Hughes defined "career" as having both an objective and a subjective component (see also Goffman, 1968; Layder, 1993; Stebbins, 1970). The objective aspects of career include the activities, the responsibilities and expectations attached to a status or position, as well as the more objective features of the social institution (Layder, 1993; Ross, Rosenthal, & Dawson, 1994). In contrast, the subjective aspects of career deal with "the moving perspective in which people see their lives as whole and interpret the meaning of various attributes, actions and the things that happen to them" (Hughes, 1971, p. 137). The subjective component, thus, refers to how individuals' themselves view their actions and their circumstances and how they feel at various stages in their career. Ross (1991) employed Hughes' concept of career to examine both the subjective and objective components of wives' caregiving careers.

Finally, as mentioned in the introductory chapter, none of the investigations to date have examined family member roles as part of a broader context or what Bronfenbrenner and Mahoney (1975) termed “the enduring environment”. Family member role perceptions or expectations have often been divorced from the settings in which these very roles are played out. According to the ecological perspective (Bronfenbrenner & Mahoney, 1975; Bronfenbrenner, 1979, 1989), the enduring environment within which these family member roles are played out will shape how family member roles are defined, the specific activities that family members may perform within the long-term care setting, the experience in those roles, and how family member roles are developed and change over time.

Related to this, Jaff and Miller (1994) argued that researchers need to consider the “positionality” and the “structural embeddedness” of both the researcher and the subjects being researched. Positionality refers to the unique personal positions or worldviews through which the world and aspects of the world are viewed. Jaff and Miller explained this notion in relation to the world of the aged:

> The world each of us sees is created from the social stuff that we all share, but it also varies because we are differently positioned or situated in reference to it. In other words, we may view the world of the aged through a lens that defines old age as a time of frailty and social irrelevance, but that lens is also coloured by our own age, class background, gender, education, and even our own experiences of aging (p. 53).

The unique combinations of these factors help shape the unique meaning that things have for individuals. Structural embeddedness is closely linked to positionality and refers to “the relationship between the phenomenon being studied and the broader social contexts of which the phenomenon is a part” (Jaff & Miller, 1994, p. 51). In order to understand the roles of family members in long-term care facilities, therefore, it is important to understand the family members themselves, how they themselves view their roles, as well as the immediate setting within which the roles are played out.

CHAPTER THREE
THEORETICAL GUIDING PERSPECTIVE

GUIDING PERSPECTIVE

The Use of Explicit Theory in Grounded Theory Approaches

Purists using grounded theory approaches have argued that preconceived notions of the phenomena of study should be "suspended in order to allow for the natural emergence of themes and categories" (Daly, 1992b, p. 105; Glaser & Strauss, 1967). More recently, researchers have argued that this approach ignores the unquestionable fact that trained researchers are "theoretically sensitised" and fails to recognise the important potential role that explicit theories may play in developing emergent grounded theory (Strauss & Corbin, 1994, p. 277). Thus, these researchers emphasise that a truly grounded approach begins with the taking stock of one's assumptions, experiences, and knowledge (Daly, 1992b; Lincoln & Guba, 1985). In this way, "tacit knowledge" (Lincoln & Guba, 1985, p. 198) is made explicit at the beginning of the research process.

The grounded theory process may also involve the utilisation of relevant theoretical and empirical literature "to stimulate theoretical sensitivity" (Strauss & Corbin, 1990, p. 50; Strauss & Corbin, 1994). Strauss and Corbin (1990, pp. 48-53) outlined how theoretical and empirical literature can inform research using grounded theory methodology. They suggest that technical literature and existing theories: (a) can provide a set of sensitising concepts and relationships that can be examined against actual data; (b) can provide ways of approaching and interpreting the data (e.g., a Symbolic Interactionist approach versus a Marxist perspective); (c) can stimulate or identify sensitising questions which in turn can be used to guide the development of interview questions; (d) can direct theoretical sampling; and (e) can provide supplementary validation for the findings.

Further, Murphy (1992) described the use of theoretical frameworks as guiding perspectives in grounded theory research:

> In grounded studies, theoretical concepts and hypotheses are derived from the data and verified in the data; that is, a theoretical framework is not used to derive hypotheses a priori. However, this does not preclude the investigator from entering the research setting with a sensitising perspective about the nature of the research phenomenon. Researchers using GTM most frequently have assumed a symbolic interactionist perspective but it is equally appropriate for investigators to come to a grounded study from a variety of other conceptual perspectives, based on the fit with their research questions (p. 150).

An examination of research using grounded theory approaches revealed the diverse theoretical and conceptual perspectives that have been used as guiding frameworks. For example, Murphy (1992) employed a life-span developmental perspective to guide the development of initial sensitising questions and to "maintain [her] awareness of the highly varied context within which sibling relationships develop" (p. 150). Matocha (1992) developed four domains of basic needs concepts using past experience, research, and theory to guide her study focused on caregivers of persons with AIDS. Detzner (1992) used continuity theory (Atchley, 1989) and family conflict theory (Sprey, 1979) to interpret the life histories of Southeast Asian refugee elders in his study of family conflict. Other researchers have used specific concepts as guiding perspectives. For example, Daly (1992b) employed the symbolic interactionist concept of "transformation of identity" (Strauss, 1959) as a set of sensitising concepts for approaching his study focused on the process of becoming adoptive parents. Lightburn (1992) used different definitions of the concept "mediation" to guide her research on special needs adoptive families.

Recognising the limitations of previous theoretical approaches to the study of family member roles in long-term care facilities and the contribution that other theories can make to this substantive area as well as to the development of substantive grounded theory, I developed an alternative framework which served to guide the present study. This framework integrates ideas and concepts from symbolic interactionism, an ecological perspective, and the conceptual framework of the caregiving career (Aneshensel et al., 1995). In the present study, this guiding perspective (as well as the empirical literature discussed in the literature review) was used to provide a set of initial sensitising concepts (e.g., meaning, behaviour, expectation, context) and relationships, to guide the development of sensitising questions and interview guide questions, and to provide "theoretical sensitivity" into the nature of roles and role development throughout the project.

The nature of the conceptual guiding framework I chose to inform my study was influenced greatly by my own experience working in a long-term care facility over a period of six years. Throughout that six-year period, I became increasingly aware of, and intrigued by, the undertakings of a specific group of people – a group of people who appeared to have a strong presence within this particular long-term care facility. Five years later, I still recall vivid images of specific individuals within this group. There was Helen, and I use pseudonyms, a talented artist who decided one day that she wanted to preserve the memories of the residents who lived in the home and set out to paint as many residents as she could before she herself became ill. Those resident portraits now decorate the walls of the facility. There was Thomas, who arrived punctually at 8:00 a.m., 12:00 noon, and 5:00 p.m., 7 days a week, to feed and visit with his wife. There was Margaret, a local hair dresser who would come and set her mother's hair once a week knowing full well that she could not possibly leave without also setting her mother's roommate's hair. And, there was Edna, who, two years after her husband's death, continued to volunteer at the home, ensuring that residents got to and from programs on time, and helping residents finish projects in the craft room. These people represent just a few of the family members of the older adult residents I got to know while working at the home.

Over the six-year period, close relationships developed between some of the family members and me. I remember, for example, spending hours, over several days and nights, sitting with one of these family members at a hospital while her father gradually passed away. We cried together and we supported each other, and we continued to have contact with each other after that episode. In fact, this particular family member still corresponds occasionally. Although I had never myself played the role of family caregiver to an institutionalised relative, I became very much aware of the presence of the family members in the home and gained first hand knowledge of some of their experiences and struggles in such a role.

In taking stock of my own assumptions and experiences related to institution-based caregivers, it occurred to me that those six years working in the long-term care facility had affected my life in many ways. That experience not only continues to influence the things, people, and situations I choose to research; those still vivid images also shape the way that I read and interpret the literature and were an ever-present influence throughout the development of this research project. As I conducted my literature review, for example, I was uncomfortable with the task-assignment approach which seemed to dominate much of the research on family member roles in long-term care settings. In my own experience working with family members, it seemed to me that family members developed roles for themselves based on their own unique circumstances and what they felt needed to be done. I also sensed that family member roles were closely linked to the individual family member's perception of the self. For example, Margaret, the hairdresser discussed earlier, developed a role within the institution based on her sense of self as a hairdresser and the skills she possessed related to her hairdressing career. Thus, family members performed a wide range of activities, technical and non-technical, depending on their own skills, their own sense of self, and on their own definitions of what their role should be in the care of their loved ones. The conceptual guiding framework informing this study, therefore, is more in keeping with the perception that I have of family member roles in long-term care facilities based on my experience working with them.

Conceptual Framework Guiding the Study

The Making of Roles

Unlike the conformist, task-based approach of Litwak's (1977, 1985) theory, this framework is centred around the Symbolic Interactionist's notion of the role making and role taking process (R. H. Turner, 1962). Symbolic interactionists maintain that humans, in this case family members, do not merely passively *conform* to others' expectations. Instead, humans actively and creatively construct and modify roles through interaction in specific social settings based on the *meaning* which they attach to actions or situations. Blumer (1969, p. 2) discussed the three premises which underlie a symbolic interactionist approach. First, human beings act toward things based on the meanings that the things have for them. Second, the meaning of such things is derived from, or arises out of, the social interaction that one has with others. And third, these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things she or he encounters.

From this framework, therefore, family member roles are constructed and reconstructed over time in a dynamic and fluid role-taking and role-making process (R. H. Turner, 1962). This role-taking and role-making process includes defining and re-defining the situation, interpreting and re-interpreting the behavioural and verbal gestures and expectations of others, and ongoing negotiation processes. Thus, the important factors here, which are different from the task-assignment approaches, are the focus on the *meaning* of the role for family members and the *interactive processes* by which meanings are developed, re-evaluated, and modified over time (Blumer, 1969; R. H. Turner, 1962). Further, meaning and behaviour, here, are integrally linked. The meaning that family members ascribe to their roles both influences and is influenced by role behaviour and the activities and tasks that a family member may choose to perform (Fife, 1994). Nonetheless, "the meanings that things have for human beings are central in their own right. To ignore the meaning of the things toward which people act is seen as falsifying the behaviour under study" (Blumer, 1969, p. 3).

The situation and meaning of the situation for the family member is continually defined and re-defined through interaction with others, both within the immediate situation and outside of the immediate situation, and through a complex "process of interpretation" (Blumer, 1969, p.5). Thus, the focus is also on the thinking or "deliberative capacities" (J.

H. Turner, 1988) of family members and how, using this deliberative capacity, family members actively seek, choose, take and make roles for themselves. This process of "interpretation of the situation" (Blumer, 1969, pp. 83-89) is also commonly referred to as the concept of "the definition of the situation" (Thomas & Thomas, 1928; Waller, 1970). Within this conceptualisation, family member roles cannot be differentiated simply by the types of tasks they perform, are never static, are certainly not pre-determined, but are based on meaning and are actively created and re-created in the context of different social interactions and ever-changing circumstances.

The Importance of Context: Positionality and the Immediate Setting

In order to appreciate the meanings that family members express, it is important to understand the contexts of both the behaviour and its interpretations (Sankar & Gubrium, 1994). Context, in this framework, refers to the "positionality" (Jaff & Miller, 1994) or the unique personal circumstances or situations of individual family members and the "immediate setting" (Bronfenbrenner, 1979) or the long-term care facility within which the roles are being played out.

Related to "positionality", family members bring to the caregiving situation a unique set of interconnected characteristics, some more stable than others, and unique biographies of experience. These characteristics and biographies of experience include: self-conceptions, stocks of knowledge at hand, personality and psychological factors, health and physical factors, temperaments, skills and capabilities, as well as sociodemographic characteristics.

One of the most important of these characteristics to roles and role development is a person's sense of self. Self-conceptions, similar to what Mead (1934) called "self", are defined as "a relatively enduring configuration of attitudes, dispositions, definitions and feelings about oneself that selectively filters the self-image in concrete situations" (J. H. Turner, 1988, p. 103). Zurcher (1983, p. 13) summarised the importance of self-conceptions in role development:

> ...self concepts, that is, the way we perceive ourselves (Hewitt, 1979; McCall and Simmons, 1966; Heiss, 1981; Strauss, 1959) ... provide us with a sense of personal continuity as we enact roles in diverse social settings. Within each setting, we negotiate with other people both our own and their identities (Stone, 1962; Goffman, 1969; Strauss, 1978) ... Some roles, because they are embedded in social institutions and organisations, are not very flexible. Nonetheless, we usually find ways to enact even the most structurally rigid roles in a manner consistent with our own self-concepts and with our interpretation of the social setting. If we are expected to enact a role only vaguely defined in a social setting, we usually find a way, guided by our self-concepts and through interaction with others in the setting, to establish a workable role for ourselves.

Due to the relevance of self-conceptions in the role making and role taking process, Silverman and Gubrium (1994) recommended that researchers gain an understanding of "who" the caregivers are before attempting to answer the "why" or "how" questions.

Another important factor in the role-taking and role-making process is a person's "stock of knowledge". Similar to R. H. Turner's (1962) "cultural frameworks" and "folk norms of consistency", Schutz (1932/1967) defined "stocks of knowledge" as "ordered past experiences". This complex set of cognitions help people structure their perceptions of, and orientations to, others in the situation (Schutz & Luckman, 1973). A "stocks of knowledge" warehouse includes knowledge of cultural frameworks, knowledge from past experiences in the specific role, knowledge from past experiences in other roles, and general inventories of role conceptions. These "ordered experiences" are combined and recombined in order to interpret meanings in particular contexts (J. H. Turner, 1988).

It is important to note that because family members bring different sets of characteristics to the situation, they may experience and define the caregiving situation differently and thus will develop individual, unique roles according to their particular situations. For example, adult children may be facing different circumstances (e.g., employment, parent of younger children) at the time they are involved in the caregiving role than spousal caregivers. Some adult children caring for older adult relatives may be dealing with very different life circumstances than other adult children caregivers. Also, spouses have different relationships with their husbands or wives than adult children have with their parents. "Since these structured relationships [and different circumstances] channel the caregiving experience, differences should be evident" (Clair, Fitzpatrick, & La Gory, 1995, p. 198). Further, those who have been caring for a much longer period of time will have a larger "stocks of knowledge" warehouse to examine their role through and to draw on than those who are relatively early in their caregiving careers.

Ecological theorists (e.g., Bronfenbrenner, 1979, 1989; Lerner, 1984; Lewin, 1931, 1935, 1951) and some symbolic interactionists (Fine, 1992, 1993; Stryker, 1980), however, suggest that knowing the person performing a certain role is not enough. They suggest that the person and the environment are interconnected and, therefore, in order to understand human behaviour and meanings, persons and environment must be considered jointly. The environment within which the person is located, particularly the immediate setting, will have a significant impact on the person and vice versa. Each immediate setting, in this case the long-term care facility, is made up of a distinct set of interconnected characteristics which include: the organisation's philosophy; its policies and procedures; its programs, activities, and supports available; its power structure; the physical structure of the setting and other physical factors; and the climate within the institution. As many have suggested, the degree and range of family member roles in institutionalised settings may be limited by the institutional policies and availability of programs and resources which may or may not encourage family member involvement (Brody, 1986; Dobroff, 1976; Dobroff & Litwak, 1977; Hansen et al., 1988; Safford, 1980). A long-term care facility, for example, which welcomes and encourages family participation and provides the opportunity for family member involvement in support groups, family councils, recreational programs, interdisciplinary team meetings, volunteer capacities, and so forth may foster very different family member roles than those facilities which are unable to provide similar opportunities. Fine (1992) referred to these structural constraints on action as the "obdurate reality".

Recognising the "obdurateness" or the objective reality of our world, Fine (1992) called for a "Synthetic Interactionism" which links micro perspectives with issues of structure. Fine (1992) emphasised that an understanding of meaning and the role-making process could not be understood apart from their broader contexts:

> Even an understanding of the definition of the situation that stresses the role of the agent in creating meaning must be understood with reference to institutional orders, if we wish to understand what definitions are possible and what effects can come about. I contend that this is not a merging of 2 separate approaches - one based on agency and the other on structure - but part of a seamless analysis of obdurate constraints. Agency is constrained at the same time as structure can be enabling (Fine, 1992, p. 93).

He, however, also stressed that because individuals come to a situation from different perspectives and circumstances (positionality), and because individuals have their own interpretive capacities, their understandings of the situation will vary. Due to different understandings, the impact of the objective reality will not be the same for everyone in the situation. Individuals use their understandings of the physical environment to determine how they will proceed in the situation and how they will interact with others (Fine, 1993).

Quite simply then, symbolic interactionists and ecological theorists emphasise the importance of knowing "who" the caregiver is and "where" the roles are being played out in order to understand the meaning, behaviour and expectations behind the caregiving role. As Luborsky and Rubinstein (1995, p. 99) noted: "Meanings and identities are fluid and changeable according to the situation and the persons involved". In the same way, roles are fluid and changeable according to the persons involved and the contexts within which the roles are played out.

Conceptual Framework of the Caregiving Career

Extending the work of Ross (1991), this study was also informed by the conceptual framework of the "caregiving career" (Aneshensel et al., 1995) to reflect the directions and patterns that the caregiving experience may take over time. As well as distinguishing between the objective and subjective dimensions of career, Hughes (1971, pp. 405-406, p. 125) defined career lines as the "significant phases of careers and the sequences in which they occur...the shifts from one weighting or combination of activities or pressures to another...a sort of running adjustment...the phases and turning points of one's whole life". A career includes the process and sequences of learning the techniques and purposes of the position, the progressive perception of the whole system and of possible places in it, and the accompanying changes in conception of the work and of one's self in relation to it over time. The joining of different life events, different adaptations, different decisions, different conceptions create each person's unique career.

Careers are characterised by specific qualities. Aneshensel and her associates (1995, pp. 18-19) outlined three characteristics of the concept of career. First, careers have a temporal component which is typically lengthy in duration. As the literature suggests, family members often care for elderly relatives in the community for years before their relative is placed into a formal care facility. After placement, family members continue to provide care for several more years. Second, careers involve change over time, usually towards growth or maturation in the role. As family members gain experience as caregivers, they acquire care-related skills, and develop and modify their role depending on the circumstances and what is required of them at various phases of the career. Finally, careers encompass a cumulative experience that converges into a complete entity; that is, the various activities and responsibilities involved at each phase of a career make up and represent a person's entire career path. Providing occasional care when needed to a parent or spouse in the community, to providing 24 hour care in one's home, to the transition to institutionalisation, to the death of a loved one and the subsequent readjustment together represent a caregiver's entire career. Some family members may begin their caregiving careers at different points or end their careers at different points, but the individual phases or sequences a family member goes through will represent her or his total caregiving career.

The concept of career has been extended beyond the occupational realm by several researchers. For example, using the concept of "status passage", Glaser and Strauss (1968, 1971; Strauss, Fagerhaugh, Suczek, & Weiner, 1985) employed a career perspective in their examinations of critically ill patients and families in hospital settings. Brody (1985) used the term caregiving careers to refer to the provision of successive care given to a number of impaired relatives by one caregiver. She emphasised the serial involvement of caregivers with several care receivers over time. Ross (1991) employed Hughes' (1971) concept of career to study the evolution of elderly wives' caregiving careers following the institutionalisation of their husbands.

The caregiving career in the community goes through several phases as the older adult's needs gradually shift and increase over time. Lewis and Meredith (1988) suggested that family members' caregiving roles usually begin with a period of "semi-care". This period involves relatively non-taxing tasks occasionally performed out of a sense of responsibility. As the older relative's needs escalate, the caregiving demands increase in a period of "part-time full care". Eventually, community-based caregiving involves "full care" with heavy demands placed on the caregiver. Only when caregiving becomes too burdensome for caregivers do family members seek long-term care placement and relinquish their primary caregiving role.

Other authors have described the multiple phases and transitions of the caregiving career in the community. Given and Given (1991), presenting what they refer to as the "natural course" of caregiving, discussed four stages that family caregivers go through. These stages include selection into the role, acquisition of care-related skills, provision of care, and cessation of care. Similarly, Wilson (1989) offered a three-stage career path: taking it up, deciding to become a caregiver; getting through it, enduring the unfolding sequence of problems entailed in providing care; and turning it over, relinquishing care and control to an institution.

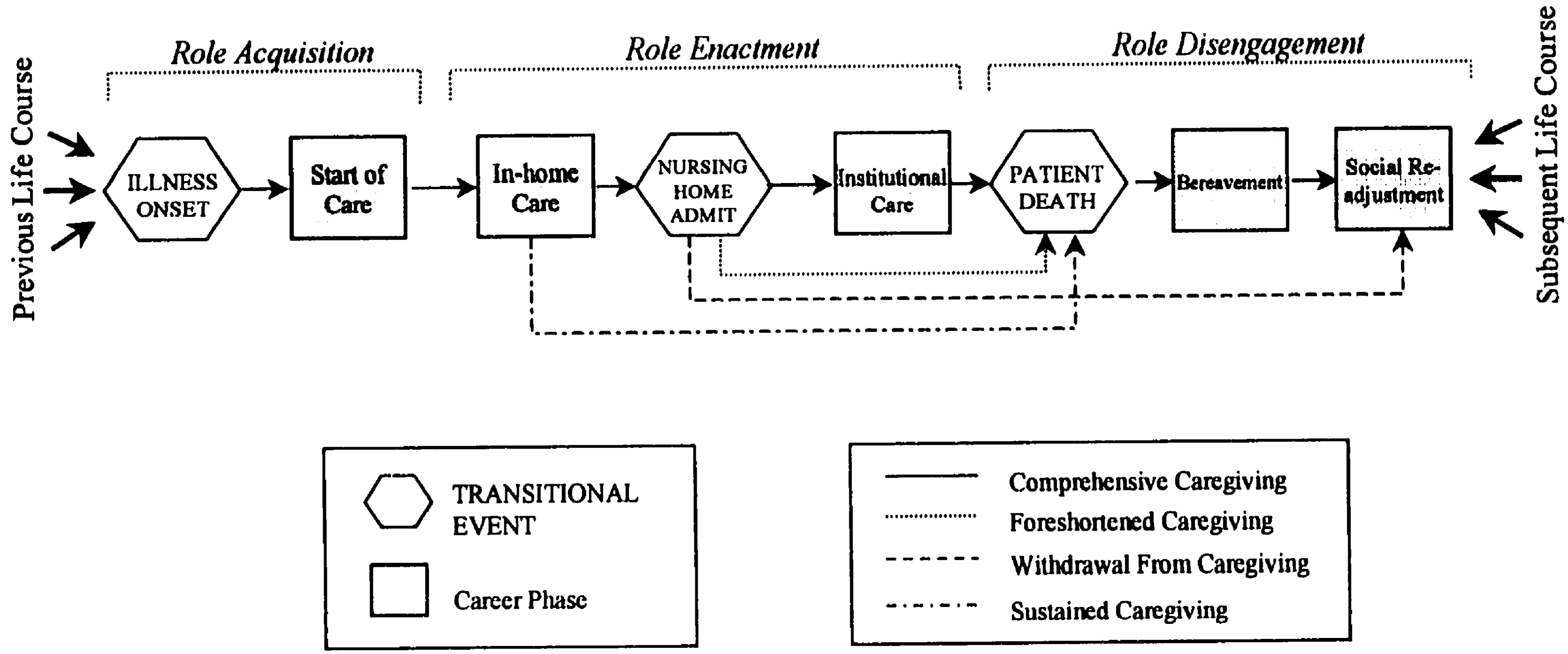
The institutionalisation of a care receiver further represents a pivotal point in a caregiver's career (Aneshensel et al.., 1995; Zarit & Whitlatch, 1992). Family members must again struggle to re-define their roles and adapt to sharing the care of their loved ones with staff members. Some researchers have suggested that family members may go through different patterns of caregiving as they learn to adapt to their caregiving role within the long-term care facility (Rosenthal and Dawson, 1992; Townsend, Noelker, Deimling, & Bass, 1987). Using the data collected in a large study examining wives of institutionalised husbands, Rosenthal and Dawson (1992) presented a four stage conceptual model of the process of family members' adaptation to the institutionalisation of a loved one. In their model, feelings of ambivalence and uncertainty as well as emotional and physical debilitation predominate in the first stage. As the mental and physical status of the caregivers improve, they become heavily, perhaps too heavily, involved in the care of their loved ones in the Assisting/Action Stage. As role clarity increases through negotiation with staff and as family members become more and more accepting of the situation, they relinquish some of the tasks and begin to redefine their roles much more realistically (Relinquishing/Augmenting Stage). By the final stage (Adaptation/Resolution), family members have positively adapted to the circumstances of institutionalisation and are better able to balance their own needs with the needs of their spouse or parent. Family members continue to restructure their roles within the institution based on their changing definitions of the situation and their abilities to cope with the situation.

Nonetheless, 38% of the wives in the Rosenthal and Dawson study did not appear to adapt as positively to their caregiving experiences. Thus, Ross (1991) suggested that two different patterns of caregiving reflective of different coping capacities and varied intrapersonal (patient's health, caregiver's self-rated health, depressive symptomatology, morale), interpersonal (marital closeness, perceived marital status), and institutional factors (satisfaction with unit, satisfaction with staff, and satisfaction with the overall arrangements for care) may emerge. The wives who did not appear to cope as well with the deterioration of a loved one over time were caring for husbands with physical impairments, reported no change in marital closeness, and were more dissatisfied with the unit, staff, and overall quality of care. On the other hand, wives who were caring for spouses with cognitive impairments, who reported a change in marital closeness over time, and who were much more satisfied with all aspects of care appeared to be significantly less depressed at the end of the nine month study period.

Other researchers have conceptualised the caregiving career as encompassing the entire career path of caregivers, from the early phases of taking on the role, to long after the care receiver has died. Aneshensel and her colleagues (1995) used a three-stage conceptualisation of career to examine the roles of family caregivers beginning in the community, through the transition to nursing home placement, and through the bereavement and adaptation process following their loved ones death (see Figure 1). The three stages in a typical caregiving career according to Aneshensel and her colleagues are:

> 1. *Role acquisition* - the recognition of the need for the role and the assumption of its obligations and responsibilities;
> 2. *Role enactment* - the performance of role-related tasks within the home and, for some, within the formal setting of a long-term care facility; and
> 3. *Role disengagement* - the cessation of caregiving and the returning to other venues of life that typically follow the death of one's impaired relative (p. 23).

Figure 1: Progression of Caregiving Careers



Source: Aneshensel et al. (1995)

My focus in the present study, however, was primarily on the institution-based caregiving career. Nonetheless, Aneshensel et al.'s (1995) conceptual model points to the importance of recognising that each single stage in a caregiving career represents only a piece of the entire caregiving career path. They further emphasised:

> The meaning and impact of one's current caregiving experience are shaped by what has passed before and by what is anticipated in the future. The caregiving career is not static: In addition to the present, each phase embodies a history and foreshadows a future (p. 19).

Also, although I found this research on the caregiving career important in its conceptualization of caregiving as a sequence of episodes and events which accumulate to make up the total experience rather than a single, self-contained episode, I found myself uncomfortable with the use of the term "stage" to describe the episodes or phases in the caregiving career. The term "stage" seemed antithetical to the essence of the concept of career and the dynamic nature of careers that Hughes (1971) so aptly described. Aneshensel et al. (1995), however, provided a definition of stage which was more in keeping with how I envisioned the notion of career. They stated:

> A stage is not necessarily a period of stability … all caregivers who are engaged at the same stage are not inevitably exposed to identical conditions; on the contrary, within each stage caregivers experience diverse circumstances. Moreover, the rapidity and direction of change and the timing and sequencing of transitions from one stage to another varies substantially among caregivers. Thus, we regard the stages of caregiving as heuristic devices that help us both detect the threads connecting each part of caregiving to its other parts and identify conditions that move caregivers along their career trajectories at different rates and at different psychological and material costs to themselves (Aneshensel et al., 1995, p. 23).

This definition of stage recognises both the commonalities in the caregiving experience as well as the individualistic aspects of the caregiving experience which serve to create unique and different caregiving roles and career paths. Further, this definition of stage does not view the periods and phases of caregiving as static but as fluid and dynamic dialectics in the caregiving career.

Thus, depending on their coping capacities, the family member role will change over the caregiving career as family members adapt to different circumstances, different pressures, and ever-changing definitions of the situation. A caregiver's unique career path will be a function of the different sets of characteristics both within and outside of the long-term care setting that will "turn them in one or another of many directions" one might take (Hughes, 1971, p. 406). As a caregiver travels through each phase and turning point in her or his career, one set of roles will be constantly created and recreated into another set of roles. The career line will thus reflect periods of stability and periods of instability or change. These roles, responsibilities, and behaviours will continue to shift over the caregiving career within the institutional setting. Caregivers at different points in their individual caregiving careers may think about their roles differently and, in turn, may have different expectations for themselves and may react differently in terms of their role behaviours.

Guiding Perspective: A Summary

The conceptual framework presented here has several basic assumptions which served to guide and inform the present study. First, family member roles cannot simply be differentiated by the types of tasks performed or by role expectations. Family member roles, instead, are based on the meaning and purpose that a family member ascribes to her or his "role" which both influences and is influenced by role behaviour, role expectations, and the role experience. In this way role meaning, behaviour and expectations are integrally linked. Further, family members do not merely conform to role expectations but actively create roles in dynamic interactions with others both within and outside of the long-term care setting as part of the role-taking and role-making process. Second, the role-taking and role-making process is shaped by both the circumstances and characteristics of the family member (i.e., the positionality of the caregiver) and the characteristics of the long-term care environment (i.e., the immediate setting in which the caregiver role is played out). Family members' self conceptions, stocks of knowledge at hand, as well as other factors important to the caregiver, influence and are influenced by the types of roles family members will seek to play, how those roles are developed and played out, and the family members' adaptation to the caregiving experience over time. Environmental features such as policies and procedures, the availability of programs and supports, and the physical structure of the facility can also limit or facilitate family member involvement and thereby shape family member roles and role behaviour. Finally, roles are uniquely and actively constructed and reconstructed over the caregiving career as family members adapt to the caregiving experience as well as to changes both within and outside of the setting over time. Thus, from this perspective, it is important to understand how family members think about themselves as well as how they think about their role in their specific and unique contexts. It is also important to understand the immediate setting within which these roles are played out.

This guiding framework is consistent with the sociological perspective of interpretivism (Guba & Lincoln, 1981; 1987). According to interpretive social scientists, "realities exist in the form of multiple mental constructions, socially and experientially based, local and specific, dependent for their form and content on the persons who hold them" (Guba, 1990, p. 27). The role of the researcher is to discover, describe, and understand lived experience through the participant's own understanding and interpretation of events, behaviours, and situations (Greene, 1990). Thus, my objective was to gain a comprehensive understanding of the roles of adult daughters in a specific long-term care facility from the perspectives of adult daughters directly involved within the institution.

It is important to stress, however, that it was not my intent in this study to test any of the assumptions presented in the guiding framework. The guiding perspective served to inform the present study; that is, it provided a framework from which to approach the study and interpret the findings (Strauss & Corbin, 1990). The framework presents a way of viewing the nature of roles and how roles are developed over time. It does not address the *content* of roles -- the characteristics, components, features, dimensions, or themes associated with the caregiving role. Guided by the cartographic features of role meaning, behaviour, and expectations, it is in this area that the present study can contribute to the development of a grounded substantive theory of family member roles in long-term care facilities; a grounded theory that addresses what institution-based caregiving roles look like and why they look the way they do from the family members' perspectives.

CHAPTER FOUR
METHODS

METHODOLOGICAL APPROACH AND RESEARCH DESIGN PROCEDURES

I chose to use a naturalistic, inductive methodological approach for the present study. A naturalistic methodology (Lincoln & Guba, 1985) was consistent with the interpretive nature of the conceptual framework guiding the study. Further, a naturalistic approached seemed the most appropriate for this study because such an approach allows for the emergence of multiple perceptions or meanings held by the participants themselves (Lincoln & Guba, 1985; Schwandt, 1994; Strauss & Corbin, 1994).

Lincoln and Guba (1985) described the characteristics of a naturalistic inquiry (see pp. 39-44 for a detailed description). Naturalistic studies are carried out in the natural setting in which the lived experience and meanings are embedded and involve the researcher as the primary data-gathering instrument. Naturalistic approaches recognise the contribution that intuitive and felt knowledge as well as propositional knowledge can make to our understandings of lived experience. Such approaches also emphasise that the participants' constructions of their own experience and the multiple meanings of events and situations for people can only be appreciated through the use of tacit knowledge. Naturalistic approaches employ methods and strategies that are more appropriate for tapping into and understanding lived experience. They employ: (1) qualitative methods and emergent research designs which are developed and modified as the research process unfolds rather than quantitative methods, (2) purposive/selective and theoretical sampling strategies rather than random sampling strategies, and (3) inductive data analysis and grounded theory rather than deductive data analysis and theory verification. Naturalistic inquiry recognises that participants are in the best position to understand and interpret their lived experiences within the specific contexts these experiences take place. Thus, naturalistic researchers often go back to the participants for verification, confirmation, and elaboration of the meanings and interpretations emerging from the data. Further, conventional criteria (i.e., internal and external validity, reliability, and objectivity) for judging the goodness or quality of a study are not applicable to naturalistic inquiry. Instead, naturalistic researchers substitute two alternative sets of criteria: trustworthiness criteria and authenticity criteria. The trustworthiness criteria include credibility, transferability, dependability, and confirmability (see Guba and Lincoln, 1981, 1994; Lincoln & Guba, 1985). The authenticity criteria include ontological authenticity, educative authenticity, catalytic authenticity, and tactical authenticity (see Guba & Lincoln, 1989, 1994 for a discussion of the criteria).

In designing the present study, I consulted and utilised the characteristics of naturalistic inquiry. Further, I employed the specific techniques of the grounded theory approach (Glaser & Strauss, 1967; Glaser, 1978) in order to gain a deeper understanding of the roles of adult daughters in long-term care facilities.

Grounded theory fits well with a naturalistic approach as it allows for the emergence of "multiple realities and makes transferability dependent on local contextual factors" (Lincoln & Guba, 1985, p. 205). As with other qualitative methodologies, data collection, the identification of important patterns and themes, the coding of all data and the analysis of the data are conducted simultaneously throughout the research process in a grounded theory methodology. However, the grounded theory approach differs from other forms of qualitative methods primarily in the strategies that are employed to code and reduce the data and in the ultimate goal of the analysis (Murphy, 1992). The goal of grounded theory is the development of inductively derived grounded substantive and formal theory about a phenomenon (Strauss & Corbin, 1990). Thus, in studies employing grounded theory methodologies, theoretical concepts and hypotheses both emerge from and are systematically verified in the data (Murphy, 1992). One of the strengths of grounded theory is that it not only identifies commonalities among participants but also accounts for the "negative cases" (Kidder, 1981; Lincoln & Guba, 1985). My goal in this research project was to develop grounded substantive theory pertaining to how adult daughters think about their roles in a specific long-term care facility, what they choose to do in those roles, what factors influence how the caregiving roles are defined, and how these roles might shift over the institution-based caregiving career.

Consistent with a naturalistic inquiry, I used in-depth active interviews with adult daughters and personal logs as the primary data collection strategies. The specific details of the interviews and the personal logs are described later in this chapter. Before I continue, however, a note is warranted about my approach to this chapter. I have often been disappointed in the methods sections of the written accounts of qualitative research projects. In much of the literature, it is difficult to get a complete sense of the research process, particularly the data collection process. In studies using interviews, for example, we typically report how many interviews were conducted or the sample "n", how the questions were asked, how information was recorded, and where interviews took place (Oakley, 1981). What is typically missing from our accounts, however, are factors such as those concerning how the research design decisions were made as the research progressed and what factors influenced those decisions. Further, those who use theoretical sampling procedures often identify that they were doing so, but rarely describe in detail how that process unfolded. As Oakley (1981, p. 31) suggested, qualitative strategies such as "interviewing [are] rather like marriage: everybody knows what it is, an awful lot of people do it, and yet behind each closed front door there is a world of secrets". Thus, "our presentations of research become research as it is described and not research as experienced" (Stanley & Wise, 1979, p. 360). I wanted my description of the research process to reflect research as it was experienced during this project.

Lincoln and Guba (1985) discussed the various techniques for establishing trustworthiness in qualitative inquiries. Audit trails are suggested for establishing both dependability and confirmability of a study. Although I did not have a formal audit trail conducted in this project, I felt that in order to address the auditability of the study, the methods section should include thick description (Geertz, 1973) of the methodological strategies used and how the emergent research design unfolded as the study progressed. Starting from the selection of a research site, therefore, I provide detailed description regarding what was done throughout the research process and the decisions that influenced how the research process unfolded.

The Research Site

In order to examine the roles of adult daughters of institutionalised older adults in a specific setting, I selected one long-term care facility in the Kitchener-Waterloo area for the study. The criteria for selection of a site were as follows:

1. Placement of a relative into a long-term care facility is often considered to be a permanent move. The stay of a relative in an acute care hospital or a chronic care ward in an acute care hospital, on the other hand, may be considered temporary and thus may be defined differently by caregivers than placement into a long-term care facility. Thus, to avoid these potential confounding factors, I decided that the facility should be a provincially regulated nursing home or home-for-the-aged providing extended, long-term care to its residents.

2. The present study was focused on gaining an understanding of adult daughters at different stages in their institution-based caregiving careers. In order to obtain adult daughters both in the early stages and in the more experienced stages of their careers, the facility had to be in operation for a minimum of three years, and had to have been admitting residents on a fairly regular basis over that time period.

3. Due to the potential differences in the caregiving experience depending on the care receiver's health status, the focus of this study was on those adult daughters of residents with cognitive impairment. In order to recruit a fairly large number of adult daughters caring for persons with cognitive impairment, the facility had to have a large proportion of residents with cognitive impairment.

The Nursing Home chosen met all the criteria listed above.

The administration of the home chosen also had a strong commitment to research, perhaps because the home is partly owned by a researcher. In an informal meeting with the Director of Nursing, before the home was chosen, it was stressed that an important future goal of the home was to become a teaching nursing home, much in the tradition of the teaching hospitals. The administration's commitment to research is also articulated in the homes Philosophy of Resident Care: "WE BELIEVE that the Administration has a commitment to promote education and studies in Gerontological care" (Facility Department Manual, p. 2). Two objectives related to the advancement of knowledge are also listed in the Philosophy of Resident Care Manual. The objectives of the home stated in the Manual are to:

> 1. Foster an environment which encourages creativity and inquiry and contributes to the advancement of knowledge in gerontology; and
> 2. Participate in studies which contribute to improvements in gerontological care and advancement of knowledge related to aging (p. 4).

Thus, conducting research and making links between research and practice were very important endeavours to the administration of this home. At the time of my project, there were two other research projects being conducted in the home; however, neither project involved residents' family members. When I chose the home, I had hoped that this commitment to the advancement of knowledge would allow me easier access to the family members and the documents in the facility relevant to the study. As expected, the administration of the facility was very receptive to my research and very supportive and co-operative throughout the project. Nonetheless, I should also note that because of their commitment to research, this home may not represent a typical nursing home environment.

Gaining an Understanding of the Immediate Setting

Guided by the theoretical framework informing this study, particularly its focus on context, it was important for me to understand the roles of adult daughters within the specific immediate setting in which the roles were being played out. This meant gaining an understanding of the long-term care facility. Once the facility was identified and permission was obtained from the administration of the home to conduct the research project in the facility, I began my examination of the facility itself. This involved examining facility documents such as the Philosophy of Care as well as documents handed out to the family members as part of the orientation to the home. As part of this phase of the project, I also conducted open-ended, formal interviews with three key members of the administration (i.e., the administrator, the director of nursing care, and the activity director). These interviews were tape-recorded with the interviewee's consent and then transcribed verbatim. A list of the questions that were included in the interviews with the administration are presented in Appendix A. Specifically, the purpose of these strategies was to uncover how the institution was run; the mandate, policies and procedures of the institution and the philosophy of the administration, particularly in relation to family member involvement within the institution; and the programs and supports, if any, specifically related to family member involvement within the institution (e.g., family member involvement on care teams, support groups, counselling programs, educational programs, family/resident activity programs, family volunteer programs and so forth).

The information obtained from this phase was used primarily to provide a thick, detailed description of the long-term care setting; that is, to place the adult daughters' stories and the findings of the study in a specific context. The information also served to frame the ongoing analysis of the data and interpretation of the findings.

Description of the Research Site

The facility chosen for the study was a large provincially regulated, family-owned nursing home with 95 extended care beds. Thirty-six of the extended care beds were located in a Alzheimer's Unit specifically designed to meet the specialised needs of persons with Alzheimer's disease or with other illnesses causing dementia. The home also provided accommodations in private, semi-private, and two-roomed retirement suites for 20 residents who require less care than those living in the nursing home. The relatively new facility was in its fifth year of operation in its present location at the time of the project. It also was part of a growing multi-level care community with the goal of eventually providing a continuum of long-term care accommodations to seniors in the area.

A Board of Directors oversees the operation of the facility, and a committee of senior administrative staff runs the day-to-day operations. The senior administrative staff includes the Acting Administrator, the Director of Nursing Care, the Activity Director, the Director of Food Services, and the Director of Residential Care. The facility also has a Chaplain on staff and employs approximately another 100 staff members.

History of the Home - The facility was originally opened in the early 1960s in a different location than where the present home is now situated. The Administrator explained the history of the facility during my interview with him:

> [The original site of the facility] was on Woolwich Street in Kitchener and it existed there, I guess, for close to 30 years...The original building was actually a residence. In the 1940s and 1950s, a lot of the really nice homes in the Kitchener-Waterloo area were in Waterloo, were in that area along Woolwich Street. It was a rural area and they were rural estates. And, so one of the more prominent families in Kitchener owned that house, I can't remember who it was offhand and so it was originally a personal residence that was then converted into a nursing home with an addition on the back of it. In any event, the home was purchased in 1987 from the original owners and then in 1991 the nursing home beds, 52 nursing home beds were moved from [the old location to the new location]....43 beds were won on tender, this was back in the days when we were expanding the total number of long-term care beds and so they would say there were X number of beds available and they'd entertain offers for those beds. We won an additional 43 beds.
> ***So, in 1987 the home was bought by your family?***
> That's right.

The Alzheimer's Unit was a unique feature added to the building structure of the new home, and 36 of the 95 extended care beds were reserved for residents needing this specialised type of care.

Facility's Philosophy Regarding Family Member Involvement - The Philosophy of Resident Care as stated in the Department Manual of Nursing Policies makes reference to the family in one of its nine philosophy statements. The specific statement related to the family states:

> We BELIEVE that excellence in health care is predicated on an holistic approach and is achieved through collaboration and co-operation of the multi-disciplinary team, the resident, and his/her family (p. 1).

The Administrator further articulated the home's philosophy toward family member involvement in the facility:

> Our philosophy, and we hope it's borne out in our practices is that families do play an active part in the home, not only in terms of active participation in the care of a resident, that is in terms of being appraised of the resident's health changes or their existing condition and what treatment we're trying or planning to try, but also in terms of their visiting. Although we can't require that, we certainly encourage it. And, we encourage it not only indirectly but through active means such as family nights and family dinners and special events and that sort of thing. So, we attempt to involve them as much as possible. We find that from a psychological standpoint, there's only so much we can do for residents. We can't substitute for family. We can certainly go a long way towards their psychological and emotional health but we can't substitute for family so we recognise the family as an important element of the overall care of the person. Therefore, we try to encourage their participation. That has met with success in some cases and not success in others but we do what we can.

He also emphasised that the home had a responsibility to the family as part of their clientele: "They're, on one hand, part of our clientele and then, on the other hand, very much a part of the caregiving." The Director of Nursing Care and the Activity Director both shared similar perceptions of the facility's philosophy regarding family member involvement in the home. For example, in my interview with the Director of Nursing Care, she stated:

> Our philosophy of care is very much holistic, from the nursing point of view. It is not just washing and dressing and keeping people clean. We try to meet their social needs, their emotional needs, and their spiritual needs as well. So, as a result the families are a vital part of that because they are part of the social background.

The Administration of this particular home believed that family member involvement within the home was an important component in the provision of quality care to the residents. Thus, during interviews with The Administrator, The Director of Nursing Care, and the Activity Director, each of them spoke at length about the various ways they formally encourage family member involvement. This process began at the Admission Care Conference. The Director of Nursing Care explained the procedures and purpose of this Conference:

> On admission we have what we call an Admission Care Conference in which the families are invited, all the members of the family are welcome to attend and at that care conference we ask the families [about their resident's] social background, their educational background, we get as much history as we can, their health background as well because often times a doctor will forget to write in things that happened during their lifetime that the family will remember. So the family is very involved in giving us that initial information, package of information. From that conference of information, we set up our plan of care for the resident. So they are involved right from the beginning in giving us the history for the care plan, for the plan of care and that usually takes us about an hour to gather up that. It is an inter-multidisciplinary conference because activation is there, pastoral care is there, dietary is there, as well as nursing and the Administrator. So that is where the families are first introduced.

The administrator stressed the importance of involving family members in that Admission Care Conference:

> In terms of the Admission Conference, they're [the family] the most important part of the conference. That's why we have them there. Quite frankly, it is to get as much information from the family as we can and also to give them as much information about [the home] as possible.... We tell them about our visiting policy, which is basically wide open. We tell them about their ability to take the resident out of the building at any time, as long as they sign them out so we know where they are. We tell them about the quarterly care conferences that will be held so that they can come and be part of that information trading session. We tell them about the fact that we inform them on an ongoing basis if the resident's health changes or if we need to get more information from them or just to let them know about how they're [the resident] doing. So, it's the philosophy, we don't necessarily specifically say, this is our philosophy, but we do talk about those various things which probably embody the philosophy without directly talking about it. So it's [the Admission Care Conference] really completely an information sharing session where we answer whatever questions they have and tell them as much as we can about ourselves and they tell us as much about their family member [moving into the facility] as possible. So they're highly important.

Every three months the home also conducts a Quarterly Care Conference for every resident. The Director of Nursing Care explained this conference to me:

> Every three months, we have what we call a Quarterly Care Conference. So everybody in the building is done every three months and that is to coincide with the nursing home regulations that we must do a nursing assessment of that person's progress every three months.. But as a result we invite the families in to attend that conference and we ask them if they have any concerns about the resident's progress. So, every three months they are welcome to come and discuss with us what our goals are for the person, have we attained any of the goals, are our goals unrealistic, should we redefine the goals and the families participate in those conferences as well.

The family members are informed about the Quarterly Care Conferences at the Admission Care Conference. The Director of Nursing Care told me that the schedule for the Quarterly Care Conferences for the entire year for each resident is set up during those initial meetings with family members. Yet it was unclear whether or not family members were reminded of the up-coming Quarterly Care Conference for their resident closer to the date. The Administrator explained that the families usually do not participate in the Quarterly Care Conferences:

> The Quarterly Care Conference occurs irrespective of the family's involvement. Often times families won't participate simply because they're during the day and they can't come but we do try to inform family, especially, [the Director of Nursing Care] will if there's a burning issue with a particular resident, or if she knows the family is keenly interested in coming to one, or she knows they want specifically to talk about something, she'll make sure they get informed. But, on balance, families don't come to care conferences because they're not very long, they're ten or fifteen minutes and the purpose of that is for the departments to sit down because it's a multidisciplinary session and go through the person's total care plan. The family would be more of a participant, more of an observer and that sort of thing although they certainly would be free to comment but I know their involvement isn't nearly as high as the admission conferences.

As far as the day-to-day care is concerned, the Director of Nursing Care told me that family members were also encouraged to participate in the direct care of the residents, but only if they wanted to. She stressed that there was "a fine line between making them [family members] feel obliged to do it and making them feel involved." Her sense was that those family members who were involved in the day-to-day care such as feeding were involved because of guilt. She stated: "Sometimes I think they [the family] come because they feel guilty if they don't come. You know, they have a sense that they need to be here when they [the resident] really could be fed without [the family] being here. They really would not have to be here." Thus, the nursing staff does not discourage family member involvement in day-to-day care unless they feel that either the resident or the family member is at risk. The Administrator explained his thoughts on this to me:

> A family member, like a spouse or someone's in here and trying to lift the [resident] on the bed, well that could be a problem, so we keep our eye on that sort of thing. It doesn't happen a whole lot, very few circumstances where we have to tell a family member that they shouldn't be helping mom

> or dad or wife, whatever....If a family member is doing too much, we'll tell them, we won't discourage it if they, because some family members need that, they need to feel that they're still helping and they can give the little extra care that isn't possible with our resources so we don't want to discourage that. We only discourage it if we feel that they're putting themselves at risk and the resident at risk.

The three senior staff members also talked to me about the recreational activities in the home, particularly the special events that are developed specifically to encourage family member involvement in the home. The Activity Director explained many of these activities and how family members are kept informed of up-coming events:

> When family members come for the care conference then I direct them as to where the calendar is kept every month at the main nursing station and we have a large calendar outside the activity room door and they're welcome, they're encouraged to pick up a calendar when they come in and they can come to anything that they want. Of particular interest to them is our monthly newsletter. Through communication through that there's special events that we highlight for families. We have a donut thing once a month, where families can come in, free of charge, and join their family member. Friends or family can come in for that. We have a monthly birthday party with entertainment that they can come in to and we have quite a few families that come regularly to that as well as any special event parties or special event days. Families are very encouraged to come to that. Also, if families are here and visiting or what have you during an activity time, then we try to make them feel included and share goodies with them and take a few minutes to talk with them so they feel included in what's going on with the [resident]...We've had quite a few family members even sit in on our discussion groups and enjoy that and get an idea of what we're doing. We also have a special care unit sing-a-long every Wednesday. The volunteers help us with that program, to run it, who play piano and sing. Those volunteers are family members of the special care unit residents.

The Director of Nursing Care also spoke enthusiastically about all the special events the facility hosts every year:

> In activation, we have the special celebrations where families are really involved. They are encouraged to attend all our activities but especially, for example on Mother's Day, we have a family dinner where the families come in and sit down with table cloths and candles and a fancy menu and they have a meal with their resident. We do that, I guess, twice a year at

> Mother's Day in the summer and Christmas we do it. The staff, we dress up, all the staff volunteer and all the ones on duty dress up in black and white like waitresses, so we wear black skirts and white blouses. We act as waitresses then to serve them their meals. So, the families really appreciate that, those are big dinners for them. And we have, Christmas we make sure that every resident has a gift that Santa gives the resident. But there are always residents who don't have family close by so we put everybody's name on a tree and they [the family members] pick the angel with the name [of their resident] on it and they buy a gift for $5.00 and those are the gifts that Santa gives out. So each resident's name is on an angel and they tag the gift from Santa Claus. But a lot of resident's families get involved because they will buy gifts for residents who don't have family that they get to know. So, there's a lot of family involvement in those special activities. Some time in the summer, in June, during nursing home week, we always have a family barbecue so that is another [opportunity] where the family are involved socially.

The Administration of the home seemed to take great pride in the different activities they provided to ensure that the residents continued to feel part of a family unit. However, no mention was made to whether or not the facility also recognises non-Christian holidays and celebrations and if so, how.

The facility serves the family members by providing an educational, informative series and an Alzheimer's Support Group for family members in the Special Care Unit. The sessions in the educational series are called Family Nights and these sessions have been going on quarterly for about a year and a half. At these sessions they have had guests discuss such topics as obtaining power of attorney, and death and dying. I was also invited to one of these sessions before my research project began to discuss the use of music therapy with older adults and to run a music therapy program.

Recognising that the family members caring for a loved one with Alzheimer's Disease had unique and important needs that were not being addressed by the other programs, the administration in the home developed the Alzheimer's Support Group. The support group was a new program for family members when I first began investigating the home. The group meets monthly with a mandate "to provide a support group where families in like circumstances can congregate to discuss common concerns and modes of coping and address certain feelings of guilt and that sort of thing" (Interview with Administrator). It is organised and run by the Director of Nursing Care and the facility Chaplain. The Director of Nursing Care discussed some of the things they have done in the support groups:

> It is mainly just for the family members to discuss their feelings and we have had about three meetings I think. We have had the Alzheimer's Society come and talk on the benefits of a support group. The we decided to have a support group and we have talked about guilt, we have talked about touch, and now we have [a doctor] coming to speak to us on the disease process [Alzheimer's Disease] and how it is developing.

During my investigation of the home, I was invited to attend one of the support groups and to introduce myself and my research project to the family members of the group. In addition to the support group, the Administrator told me that the Chaplain was also available for personal counselling for those family members who were having a difficult time coping with the situation.

The senior administrative staff also felt that various policies within the home reflected their philosophy regarding family member involvement. For example, when asked about the policy regarding visiting hours for family and friends, all three of the administration members interviewed stressed the open visitation policy within the facility. The Director of Nursing Care, for instance, commented:

> I always say that our visiting hours are wide open, basically nine to nine. But if they stay after nine nobody kicks them out. We don't have an announcement that our visiting hours are over, you must leave. They [visitors] just leave when they are ready to leave or when the resident is

> ready to sleep. Most often it is regulated by when the resident is ready to sleep. They are welcome to come in the morning any time, basically most of them come after nine because that is when breakfast is over and they are dressed and ready for the day.

It was stressed in the interviews that the administration wanted the facility to feel as much like a family home environment as possible. The Administrator emphasised this point:

> We will have the doors locked, we lock them at 9:00 o'clock at night for security purposes, so we encourage them [family members] to come before that so they can get in but it's essentially wide open. If they want to come at 10:00 o'clock and knock on the doors, someone will let them in. But, realistically, most of our residents go to bed by 9:00 but we tend to leave it wide open. My thinking is that this is very much their home just like a house in the suburbs would be or just like an apartment or a condominium would be or whatever and therefore they should enjoy the same benefits and the same uses as if it were their home, well not as if it were, because it is their home. The only difference is that this is a setting within which they can receive care support [which can help] keep them active and independent as long as possible. So just as they could entertain guests at their own home any hour of the day that they so chose, they can do that here.

Nonetheless, there did seem to be preferred visiting times among the staff for families, such as after breakfast, but my sense from the interviews was that the staff maintained a relatively open approach to family visitation.

Another informal policy that both the Administrator and the Activity Director identified in their interviews was related to staff taking time to speak with, spend time with, and support family members. Supervisors were continually reinforcing to staff that they supported staff spending time with families, especially in palliative care situations. When I asked the Administrator about how their philosophy towards family member involvement was communicated to the staff, he suggested that it occurred more informally by the supervisors rather than in in-services or in staff orientations. In discussing the Director of Nursing Care's approach, he stated:

> She not only supports [staff spending time with families] but encourages that sort of behaviour so it's reinforced on an ongoing basis as compared to, I think, talking about it at orientation.

The Activity Director also spoke of her commitment to staff supporting family members:

> ***So would you say that the facility's mandate includes family members as well as residents?***
> Yes, and I encourage the staff that I work with, that if family members need a few minutes to talk, that that's just as important as the time that we're spending with residents because residents, you know tend to be from a family group and so it's very important to maintain their family group and usually a few minutes can assist in that.

Given the strong commitment to family member involvement in the home, I did find it interesting that there were few areas within the home where family members could visit privately with their resident. "Quite often the resident's families use the board room or the activity room especially if they are having [family] meals or parties" (Interview with the Director of Nursing Care). When I spoke about this with the administrator, he stated that he felt that the lack of a private place for family members to visit with their loved ones was a big problem for him and that they were currently working towards rectifying the problem.

> ***Does the facility have a room or specific locations where residents can visit with their family members other than their rooms?***
> That's actually an issue that we're dealing with. Currently, technically no. There are the two TV rooms but those may or may not be available at any given time for visitation purposes. I know the TV room on the North wing that before [one of the Research Projects] was set up was used quite extensively for family meetings. We had to usurp that space unfortunately. Right now, other than the TV room, they have to meet in their rooms which is a problem for residents who live in a semi-private ward. What we're talking about for the next phase [of the complex] is, and it's interesting that you asked the question because we were just talking about this at the last board meeting, was the board room is actually moving downstairs in the next phase so this room is going to be recovered for activation space and one of the uses is going to be a family lounge or family meeting room so if they come, if the family come and meet with the

> resident they don't have to stay in the room, they can take them to a separate room and meet. So, I guess the answer is, we sort of have one, although we don't call it one but we will have one, we hope to have one in the next phase.

It became clear after this interview and some informal comments made by family members, that the home had once had a TV room that was used often for family visiting. With the commitment to ongoing research in the facility, however, this room was transformed into a research office for one of the projects being run in the home. The needs of a research project had outweighed the needs of the family members. The administration's commitment to research had major implications for family visitation within the home. Thus, at the time of the research project, family members did not have a private place where they could meet with family members. During the warm weather, family members could take their relatives outside to visit with them. In fact, the Alzheimer Unit has a beautiful, protected, secure garden outside where family members could take their relatives to visit with them away from the Unit. During the cold weather, family members had to make do with the residents' rooms, the front lobby, or the TV room, dining room, or activation room if they were not in use.

I found this issue related to balancing family member needs with the needs of researchers interesting and incredibly bothersome. My perspective was that long-term care facilities were the homes for the residents and thus should meet the needs of the residents and their family members first. Although continued research endeavours are very important in long-term care facilities, especially given the lack of research in these contexts, researcher projects and researchers should never become intrusive, and certainly the research projects' needs should be met without negative implications to the residents and their family members. Taking away a valued space where residents and family members can visit together privately in order to provide space for an on-going research project was problematic to me. As more and more research is conducted in long-term care facilities, this issue could potentially have further implications for family members and may warrant further investigation in the future.

To summarise, the documentation reviewed and the staff's perceptions of the facility suggest that the home has a family-oriented care policy similar to the model that Montgomery (1982, 1983) referred to as "the family as client" model. In such an orientation, the facility has a strong commitment to the resident as part of a family unit. There is a general openness to family visitation and participation in facility activities. Staff members are encouraged to visit or talk with family members and efforts are made to communicate with family members. There are several opportunities for family member participation within the facility. There are greater efforts made to recruit family member involvement in the home. And, finally, such an orientation recognises that family members may have needs and desires that should be met and thus provide ways to address some of these needs (Montgomery, 1982. 1983). Nonetheless, despite the administration's strong commitment to the family as well as to the residents, this particular facility had few private spaces for family visitation.

Sampling Procedures and the Participants

Once my examination of the facility was completed, recruitment of family member participants began. I used a combination of selective sampling procedures (Schatzman & Strauss, 1973) and theoretical sampling (Glaser & Strauss, 1967; Strauss, 1987; Strauss &

Corbin, 1990) in order to determine which adult daughters would participate in the study. Selective sampling is similar to purposive sampling and "refers to a decision made prior to beginning a study to sample subjects according to a preconceived but reasonable initial set of criteria" (Sandelowski, Holditich-Davis, & Harris, 1992, p. 302). Initially, three criteria were used to identify potential participants for the study: (1) family members had to be adult daughters of residents listed as a primary contact on the resident's admission form; (2) the adult daughters had to be caring for a relative with cognitive impairment; and (3) the adult daughters had to be at various points or phases in their institution-based caregiving careers.

An important characteristic of the caregiving career is the temporal component (Aneshensel et al., 1995); that is, the duration of time an individual has been in the caregiving role. Another important characteristic of the concept of career is that careers involve change, hopefully growth and development, over time (Aneshensel et al., 1995). Some researchers (Greenfield, 1984; Powell & Courtrice, 1983; Ross, 1991) have suggested that caregivers may experience the caregiving role differently depending on how long they have been in the role. According to these researchers, the first six to nine months following the relative's placement are the most distressing months of the institution-based career but family members usually adjust to the placement within a year. It was also assumed that those who have been in the caregiving role for a longer period of time would potentially have a larger "stocks of knowledge" warehouse about the role to draw on than those who are relatively early in their institution-based caregiving careers. This more experienced knowledge about the role may differentially influence the way that family members think about their roles and how those roles are played out.

I wanted to be able to examine adult daughter roles at various temporal phases or points in the institution-based caregiving career and to compare the role perceptions of caregivers at relatively the same temporal phase, as well as the role perceptions of caregivers at different temporal phases or points. Simply, I wanted to group all of those family members who were in the same phase of their institution-based caregiving career. Then, I wanted to compare their perceptions of their roles with others in the same temporal group and with those at other phases of the caregiving career looking for consistencies and inconsistencies in their role perceptions. This meant that I had to include adult daughters in various phases of the institution-based caregiving career, from those relatively new to the role to those who had been in the institution-based role for a number of years.

For sampling and analysis purposes, I decided to define the temporal characteristic of the institution-based career by the length of time the parent had been living in the facility. Thus, those who had a parent living in the facility between 1 and 9 months were considered to be in an early phase of the institution-based caregiving career. Adult daughters who had been caring for a parent in the institution between 10 months and 2 years were considered to be in a mid-career phase. Finally, those who had parents living in the facility for more than two years were considered to be in a more experienced, later phase of the caregiving career. I should stress that this temporal component of the caregiving career represents only one characteristic or feature of the objective aspects of career. In my examination and development of caregiving career roles and paths, a number of factors, including the temporal component, emerged as important to the concept of career for the women involved in the study. These other factors will be discussed in Chapters Five, Six and Seven.

Theoretical sampling "refers to a sampling design made on analytic grounds developed in the course of a study" (Sandelowski et al., 1992, p. 302). Theoretical sampling is directed by the emerging incidents, themes, patterns, questions, and theory throughout the project, not by the persons (Strauss, 1987). However, it is in the lived experiences of the participants that these incidents, themes, patterns and so forth are grounded (Strauss & Corbin, 1990). Thus, the people to include in the study becomes a central focus of qualitative endeavours (Dienhart, 1995). Theoretical sampling typically continues until no new concepts, patterns, or themes emerge in the data collection process; that is, until theoretical saturation (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1990) is reached.

In the present study, theoretical sampling was used to guide me in the decisions of which participants to include in the study, and to gain further insight into specific situations, categories, or issues that emerged as important factors during the study process. For example, early in the interview process, some of the participants talked about the important role that other siblings, particularly sisters, played in the care of their parent. Given this information, I decided that, in order to gain a comprehensive understanding of the roles of adult daughters in long-term care facilities, I needed to interview other adult daughters within the same family and how they defined their role in the care of their parent. Further, in talking to an adult daughter who had both of her parents living (i.e., her mother in the community and her father in the long-term care facility) it became clear that she defined her role differently than other adult daughters. I then set out to interview other women in similar circumstances to see if the same patterns of role definitions emerged for them. Quite simply, as new categories or incidents emerged throughout the research process, adult daughters meeting these new criteria were selected and included in the study.

Initially and with the assistance of the Director of Nursing Care, all daughters who were caring for a parent with cognitive impairment listed as a primary contact on the resident admission forms were identified. Adult daughters were first informed about the project through an information letter that was sent out with the monthly newsletter. At the same time, I was invited to attend an Alzheimer's support group sponsored by the home as well as to conduct a music therapy session for residents and family members. These three venues allowed me the opportunity to introduce myself, to describe the research project to potential participants, and to let adult daughters know that I might be calling them to participate in the project.

In mid-October, I began telephoning adult daughters in various phases of their institution-based caregiving careers to explain in greater detail the purpose and nature of the research project and invite family members to participate. Those who agreed to participate in the study were sent a written explanation of the project, and a date and time for the interview was set up. The women contacted showed great interest in the project. Over a course of four months, 41 adult daughters were approached and asked to participate in the project. Only three of those women declined to participate, explaining that they were having an extremely difficult time coping with the situation and did not feel emotionally able to meet with me at that time. For the same reason, another adult daughter did not want to meet with me in person, but agreed to share her role definitions and perceptions with me over the telephone. All together, thirty-eight adult daughters took part in the study and shared their insights with me about their perceptions of their role within the long-term care facility. Their stories told to me in the active interviews and in their logs became the data used for analysis in the study.

Each of the family members involved in the study (except for the woman who agreed to talk to me over the telephone) filled out a *Family Caregiver Demographic Profile*. A copy of the profile form is presented in Appendix B. Only basic demographic information was collected such as age, marital status, and work status of the adult daughters; the number of siblings the adult daughters had and how many of these siblings lived within a 60 minute drive to the institution; the age of their parents living in the long-term care facility; and the number and ages of children under 18 living at home. I also used the demographic profile to ask family members how they described themselves in the care of their parent; that is, as the primary family caregiver, sharing equally in the care with one other family member, sharing equally in the care with two or more family members, as a secondary family caregiver providing support when needed to the primary family caregiver, or not at all involved in the care of their parent. This information was used in combination with the interview data to gain an understanding of the contexts of the adult daughters.

A Description of the Participants

Table 1 presents some of the demographic characteristics of the adult daughters who agreed to share their stories with me. The adult daughters who participated in the study were white, and for the most part, were middle-class women. All of the women lived within an hour's drive of the facility. The adult daughter's parents living in the institution ranged in age from 66 years to 95 years of age, the average resident age being 84.24 years. All of the parents had moderate or severe cognitive impairment. Five of the women

Table 1
Characteristics of the Adult Daughters

Characteristic	*n*	*Percentage*
Age		
30 to 39 years	1	2.7
40 to 49 years	10	27.0
50 to 59 years	14	37.8
60 to 69 years	12	32.4
Marital Status		
Married/Common-law	30	81.1
Widowed	4	10.8
Separated or divorced	3	8.1
Employment Status		
Full-time homemaker	8	21.6
Employed full-time	12	32.4
Employed part-time	10	27.0
Retired	7	18.9
Parent Caring For		
Mother	30	78.9
Father	8	21.1
Sibling Network		
No siblings	3	8.1
One sibling	10	27.0
Two siblings	14	37.8
Three siblings	5	13.5
Four or more siblings	5	13.5
Sibling Network in Area		
No siblings	10	27.0
One sibling	16	43.2
Two siblings	6	16.2
Three siblings	2	5.4
Four or more siblings	3	8.1
Caregiving Temporal Career Phase		
Early Career	13	34.2
Mid-Career	11	28.9
Later Career	14	36.8

were sisters of other family members participating in the study and six of the women had both parents still living, one in the community and one in the facility.

The temporal component of the institution-based caregiving careers ranged from 3 months to 54 months, with the average duration in the institution-based caregiving role being 21.84 months or almost two years. Thirteen of the adult daughters fell in the early caregiving career phase (i.e., 1 to 9 months), 11 had been caring between 10 months and 2 years so were considered to be in their mid-career phase, and 14 were in later phases of their institution-based caregiving careers, caring for more than two years.

When the family members were asked on the demographic profile to indicate how they described themselves in terms of the care they provided their parent, the majority (n=20, 52.6%) indicated that they considered themselves to be the primary caregiver for their parent. Another 9 (23.7%) adult daughters indicated that they were sharing the care of their parent with one or more of their siblings. Finally, 9 (23.7%) of the adult daughters considered themselves to be the secondary caregiver, supporting the primary caregiver when needed.

Data Collection Strategies

Within a naturalistic, grounded theory approach, I chose two data collection strategies which I felt were most appropriate for uncovering the concepts, themes, and personal meanings important to the family members themselves: semi-structured, in-depth interviews and personal logs. The specific details of each of these strategies are outlined next.

Family Member Interviews

I initially chose to use in-depth, semi-structured interviews in order to collect rich and detailed data from the adult daughters. Several researchers have pointed out the strengths of using semi-structured interviews and open-ended questions (Kaufman, 1994; Layder, 1993; Snyder, 1992). Most importantly, semi-structured interviews allow researchers to ask questions relevant to them and at the same time allow respondents the freedom to respond in any way they choose and to discuss issues that are most important to them. "In this manner the individual's own interpretations and meanings are allowed to surface in the interview data" (Layder, 1993, p. 41).

However, very early in the study I became very aware that the adult daughters perceived that WE (the participants and me) were involved in a co-construction of meaning about institution-based caregiving roles. The women in the study very often defined our relationship as something which existed beyond the limits of question asking and answering, and as a more collaborative endeavour. From my first telephone contacts with the potential participants, it became very clear to me that these women had many questions they expected me to respond to, questions they were struggling with in order to sort out their own definitions of their caregiving roles. I felt uncomfortable expecting them to share so much with me, information that was very personal and often very painful to discuss, while I shared very little with them. For example, some of the adult daughters wanted to know how I came to be interested in the area I was studying, what I thought the role of family members was in long-term care facilities, and how I defined the concept of caregiving which I found out was not a term typically used in their own vocabularies to describe their role. Furthermore, several of the women saw our relationship and their responsibility to the project as extending beyond the interview stage and thus I received several subsequent phone calls from various participants, particularly when adult daughters lost their loved ones. They telephoned not only to inform me of the death of their parent or spouse, but also to reflect more about their experience and how the death had changed the nature of their caregiving role and their lives. Two family members insisted on loaning me books they felt would help illuminate for me how they perceived their experience. From these and other circumstances, I realised early on in the project that we were sharing a mutual search for understanding about the caregiving experience, that together we were immersed in a collaborative, meaning-making process that could not have been unravelled or as deeply understood in any other way.

In working with the emergent design of the study, therefore, I decided to modify my semi-structured, in-depth interview approach to incorporate the philosophy of active interviews as outlined by Holstein and Gubrium (1995). Holstein and Gubrium argued that the objective approach with its emphasis on distance fails to recognise the unavoidably collaborative, interactional, mutually interpretive nature of qualitative techniques such as in-depth interviews. According to them,

> [B]oth parties in the interview are necessarily and unavoidably "active". Each is involved in meaning-making work. Meaning is not merely elicited by apt questioning nor simply transported through respondent replies; it is actively and communicatively assembled in the interview encounter. Respondents are not so much repositories of knowledge - treasures of information awaiting excavation - as they are constructors of knowledge in collaboration with interviewers (p. 4).

Thus, active interviews incorporate a variety of techniques different from a structured or semi-structured interview approach in the search for mutual understanding.

Holstein and Gubrium (1995) outlined the ways in which the active interview process differs from a more structured interview. First, in an active interview, it is recognised that the interview is very much shaped by the interviewer and his or her research agenda. From the initial contact, the topic areas of interest to the researcher as well as the position of the researcher are made explicit to the participants. Second, the active interview is much more conversational in style and capitalises on the dynamic interplay between the researcher and the respondents. This approach is quite different from the traditional hierarchical approach in which the researcher's job is to ask the questions and the participant's role is simply to answer them (Oakley, 1981). In active interviews, "[c]onversational give-and-take [by both the researcher and respondents] around topics of mutual interest is a way of conveying to the respondent that the interviewer is sensitive to, and interested in, the ongoing line of *talk*" (Holstein & Gubrium, 1995, p. 77; emphasis added). Third, the interview guide in active interviews is just that, a guide. Holstein and Gubrium (1995, p. 77) describe it as "more of a conversational agenda than a procedural directive". In some interviews, it will be followed relatively closely. In other interviews it may be abandoned totally or partially as respondents develop their own stories based on what is important to them and their lived experience. Finally, active interviews involve mutual disclosure, a sharing of information and insight in the meaning-making process. This approach means sharing background information or personal experiences with respondents. Introducing background information or describing personal experiences can be a very useful way of providing concrete contexts or reference points on which respondents can contemplate and explore their own situations and experiences. Information from prior interviews becomes important background information to be utilised in subsequent interviews. Holstein and Gubrium (1995, p. 46) state:

> Whereas the standardised interview would try to limit informational "spillage" from one interview to another, active interviewing takes advantage of the growing stockpile of background knowledge that the interviewer collects in prior interviews to pose concrete questions and explore facets of respondents' circumstances that would not otherwise be probed.

In the active interview, therefore, the interview process involves mutual disclosure where interviewers and participants together explore and attempt to more fully understand areas relevant to the research project.

The active interviews in the present study were designed primarily to elicit information regarding: (a) how family members think about and describe their role within a specific long-term care facility; (b) the behaviours family members feel are associated with their caregiving role; and (c) the expectations that family members have for themselves in their role as well as their perceptions of the staff's expectations for them. Related more specifically to context and positionality, I also explored with participants: (d) the factors (both outside and inside the institution), if any, which constrained adult daughters from performing the roles the way they would have liked; (e) the factors (both outside and inside the institution), if any, which enabled them to perform the role the way they would have liked; and (f) the adult daughters' perceptions of themselves as well as their perceptions of how their caregiving role fits into the rest of their lives. These questions were intended to place the role aspects being discussed into the specific contexts of the individuals involved.

An initial interview guide was prepared for the interviews and an attempt was made to ask the same general questions so that comparable data were available across cases (Detzner, 1992). Consistent with the active interview approach, however, when other issues or areas of interest were raised by the adult daughters that were more important to their individual experiences, the interview guide was set aside while we discussed and explored these alternative paths of inquiry. As patterns and themes began to emerge, I added questions to the interview guide so that I could explore the presence and importance of these patterns and themes more fully with other participants. For example, it became very clear to me after the first two interviews that the adult daughters avoided my first question on the original interview guide until they could give me a sense of history of their parents' illnesses and how they came to be where they were in terms of the caregiving role at the time of the interview. Thus, after the second interview, I added a question to the beginning of the interview guide which was designed to explore the history of the parent's illness and the caregiving history of the adult daughter. I also chose to introduce issues or concepts by indicating to the adult daughter that other participants had spoken about the issue and that I was wondering how they felt about it in the context of their experience. Or, consistent with the active interview approach, I explained to the adult daughter that in my early analysis of the data gathered thus far, it occurred to me that a specific issue or a relationship between factors may be important. I then asked how they felt about my interpretation in relation to their own experience and their own definitions of their role. When an adult daughter indicated that the issue was not particularly relevant or important in her experience, I made no attempt to explore this area of inquiry further. However, when an adult daughter did indicate that the pattern or theme was important to them, probes were used to seek further information about the issue. The original interview guide is presented in Appendix C1. Examples of questions that were added to the interview guide are presented in Appendix C2.

At the beginning of each interview, I again explained to the adult daughters that I was interested in how adult daughters think about or define their role within the long-term care facility, and what types of things were important for them to do in that role. I also re-articulated to the participants what their involvement in the project would entail. Following this explanation, I then asked the adult daughters to read through the letter of consent and encouraged them to ask any questions that they had about the project. Often at this point the adult daughters would ask me why I was interested in this topic and I responded by telling them about my experience working in a long-term care facility and my concern for what I perceived to be the unmet needs of family members of residents living in long-term care facilities. By disclosing pieces of my own story, I hoped that family members would feel more comfortable in their disclosures of their stories (Douglas, 1985).

Oakley (1981) provided a summary of how methodological textbooks have warned us about the threats to objectivity when the interviewer or the interviewee become too involved in the interview process; that is, when they go beyond what is considered proper interview etiquette. She identified numerous examples of rules or strategies that authors (e.g., Galtung, 1967; Selltiz, Jahoda, Deutsch, & Cook, 1965; Sjoberg & Nett, 1968) have suggested interviewers use to avoid "leading" participants. For example, Goode and Hatt (1952, p. 198) advised:

> What is the interviewer to do, however, if the respondent really wants information? Suppose the interviewee does answer the question but then asks for the opinions of the interviewer. Should he [sic] give his honest opinion, or an opinion which he [sic] thinks the interviewee wants? In most cases, the rule remains that he [sic] is there to obtain information and to focus on the respondent, not himself [sic]. Usually, a few simple phrases will shift the emphasis back to the respondent. Some which have been fairly successful are 'I guess I haven't thought enough about it to give a good answer right now', 'Well, right now, your opinions are more important than mine', and 'if you really want to know what I think, I'll be honest and tell you in a moment, after we've finished the interview.' Sometimes the diversion can be accomplished by a head shaking gesture which suggests 'That's a hard one!' while continuing with the interview. In short, the interviewer must avoid the temptation to express his [sic] own views, even if given the opportunity.

Interviewers must avoid discussing their perceptions, feelings, experiences, or opinions otherwise they may bias the interview by "leading" the respondent (Oakley, 1981). To me, the idea of leading questions did not give credit to our participants as active, interpretive humans in their own right. It is assumed that if they disagree with something we say, they will not tell us so or will alter *their* perceptions of their experiences to fit *our* perceptions. My sense from the interviews I conducted was that my active involvement in the interview and the back-and-forth dialogue actually helped participants to gain a clearer understanding of what their own ideas and perceptions about their experiences were. As Daly (1992b, p. 110) also found, "the deliberate use of the self in the research process help[s] to unravel the experience of the other". Several adult daughters disagreed with statements I made or re-worked ideas I presented which had emerged in other interviews to more accurately fit their experience. I do not believe that the collaborative nature of the interviews threatened the validity of the information I obtained. On the contrary, I believe that this approach is necessary in achieving in-depth, rich, quality information (Daly, 1992b; Rapoport & Rapoport, 1976).

I continued the interview by asking the adult daughters if they were comfortable with the information on the consent form and, if so, they were asked to sign the form. If an adult daughter expressed concerns about anything in the consent form, we discussed the specific issue and came up with a compromise or a way of wording the form that was more comfortable for that adult daughter. For example, one family member was quite anxious about her interview being tape-recorded. After discussing her concerns, we decided that I would not tape-record her interview but that I would take detailed notes during the interview instead. The consent form was modified to reflect this and the family member agreed to sign the form. In other instances, some adult daughters felt that there was no need for them to complete the personal log component of the study since they would not be involved in any caregiving activities over the two-week period following the interview. While pursuing this issue further, I became aware of the fact that this situation was consistent with how these family members defined their roles for themselves; that is, they did not feel the need to be regularly involved in their parent's care. Thus, together we decided that the personal log would not be appropriate in their particular circumstance and modified the consent form accordingly. These adult daughters were still encouraged to take the log home with them in case the situation changed, but most declined stating that in their regular routine they would not be involved in caregiving activities over the two weeks following the interview.

With the family members' permission, all but one of the family interviews were audio-taped. I transcribed the first three interviews myself, and then in order to get transcripts back to family members fairly quickly after the interviews, I hired four women experienced in transcription to transcribe the remainder of the tapes. All the tapes were transcribed *verbatim*. Once tapes were transcribed, I proofed each transcript against the tape. The purpose of this exercise was to check the accuracy of the transcripts but also to add annotations about the affective tone (e.g., laughter, crying), the flow (e.g., pauses, flow of the conversation) and of the interviewee's and my speech (Dienhart, 1995). For example, in many instances family members broke down crying during interviews and where this occurred was noted on the transcript. These completed, annotated transcripts served as the textual data for analysis in the present study.

Two steps were taken in an effort to enhance the quality and credibility of the interview data. First, to verify and clarify the information gathered from the participants in the interviews, a modified member check was conducted. Lincoln and Guba (1985, p. 314) suggested that "[t]he member check, whereby data, analytic categories, interpretations, and conclusions are tested with members of those stakeholding groups from whom the data were originally collected, is the most crucial technique for establishing credibility". The traditional member check typically takes place near the end of the data collection and analysis phases of the project. However, I wanted to use the member check in this study as an on-going meaning-making, meaning-clarifying, and meaning-verifying process. Thus, after each interview tape was transcribed and I had a chance to go over the transcript and add my insights and interpretations as well as clarifying questions, I sent the individual transcript back to the respective adult daughters. I told the participants that it was very important to me that I present an accurate representation of *their* stories, *their* perceptions, and *their* lived experiences and encouraged all family members to complete the member check. The adult daughters were asked to indicate whether they agreed or disagreed with my interpretations of their experience, to answer the clarifying questions written in the margins, and to indicate whether or not the transcript accurately reflected their story or experience. The adult daughters were also encouraged to elaborate on or clarify issues raised in the interview that were important to them. Family members were also encouraged to express any concerns, criticisms or comments about my preliminary insights or the research process in general. A stamped self-addressed envelope was enclosed as a means of encouraging feedback. Six of the adult daughters indicated at the end of their interviews that they did not want to see their transcript. Most of these women were having a difficult time coping with their parents' deterioration and institutionalisation and felt it would be too painful for them to read their transcripts of the interview. I respected their wishes and these women did not receive the member check.

Second, field notes and a research journal were also maintained throughout the study. Specific observations noted during the interviews were documented in the field notes both during and directly following each interview. Observations noted in the field notes included the family member's demeanour during the interview, important facial and body expressions related to specific responses, a description of where the interview took place, and any other factors or situations that arose during the interview that I thought were potentially relevant to an understanding of the information obtained from the interview.

I maintained a research journal similar to the approach suggested by Lincoln and Guba (1985) to document my insights, reactions, and self-analysis throughout the process as well as information about methodological decisions. Lincoln and Guba (1985, p. 327, italics in the original) suggested that a research journal should include three separate sections:

1. the *daily schedule and logistics of the study*;
2. a *personal diary* that provides the opportunity for catharsis, for reflection upon what is happening in terms of one's own values and interests, and for speculation about growing insights; and
3. a *methodological log* in which methodological decisions and accompanying rationales are recorded.

Several researchers emphasise the importance of self-reflection throughout the research project in order for the researcher to remain true to the participant's experience (Daly, 1992a; Kleinman & Copp, 1993; Lincoln & Guba, 1985; Lofland & Lofland, 1984; Maguire, 1987). The interviews were often quite emotional for both the participants and myself and I wanted to ensure that my emotional reactions did not colour my understanding of the adult daughters' lived experiences. Therefore, these emotional consequences and responses were documented in the research journal and taken into consideration throughout the process (Daly, 1992a, 1992b; Reinharz, 1983). The researcher's own personal meanings, interpretations, or responses may also block the researcher's openness to unexpected results. An on-going process of self-reflection maintained in a researcher journal is a crucial component of qualitative research necessary in order to take account of the researcher's experience and interpretations throughout the project, and to identify and separate the researcher's personal agenda from the research agenda (Daly, 1992a).

Further, because qualitative grounded theory designs often develop, take shape, and change over the research process, it is also important to report information regarding methodological decisions made throughout the process. Maintaining a record of how the actual study takes shape, the decisions related to method that are made and the rational behind those decisions, and the day-to-day logistics of the study are particularly important to the "dependability" and "confirmability" of the project (Lincoln & Guba, 1985). When decisions pertaining to the method were made in the present study, such as questions that were added to the interview guide, these decisions were recorded in the research journal as well as a rationale for the decision. Dates, times, and places of all interviews were also documented in the journal. Finally, it became apparent in the first couple of recruitment telephone calls, that family members began thinking about their role in the long-term care facility during those initial telephone conversations. Many started sharing some of their insights with me during this initial contact. I began taking notes during and following recruitment telephone calls and this information was added to the research journal.

Personal Logs

Most studies focused on the roles of family members have examined family members' perceptions of their roles or role expectations but have not investigated their actual role behaviour. For example, Shuttlesworth and his associates (1982; Rubin & Shuttlesworth, 1983) explored the question of who should be expected to perform certain "essential tasks" within the institution using a 100-task inventory. What they were not able to determine was whether or not these expectations were fulfilled behaviourally. Similarly, Dempsey and Pruchno (1993) asked their respondents to identify which of the 28 tasks they currently performed, the staff currently performed, or were shared responsibilities. Again, this approach examined family members' perceptions of who should be responsible for tasks determined *a priori* by the researchers. The approach, however, was not able to capture the range of activities that families actually perform in their role in the language of the family members themselves. Ross (1991) also used a 27 item list based on Rubin and Shuttlesworth's (1983) caregiving activity inventory. Wives were asked to indicate whether or not they were currently performing each task.

In order to identify the behaviours associated with the caregiving role and allow the adult daughters to label and describe those behaviours themselves, all participants were asked to keep a personal log for a two week period. Layder (1993, p. 116) noted that personal logs or diaries can be used to record: (a) valuable qualitative information about the degree and type of contact that people have with each other in various kinds of settings; (b) the incidence and type of event that a participant is experiencing; and (c) the participants' own feelings and thoughts during the period of relevance to the research. Personal logs provide sources of information about what it is really like and what it entails being a familial caregiver of an older adult living in a long-term care facility. They are often able to capture the "day-to-day flow of experience" (Berman, 1994, p. 212).

The personal log approach used here was adapted from Larson and Csikszentmihalyi's (1983) experiential sampling method (ESM). In research using an experiential sampling method (also known as beeper studies), respondents are asked to carry electronic pagers around with them and are randomly signalled throughout the day for a period of a week or two. The respondents are asked to complete a experiential sampling form (ESF) every time their pager emits a signal. These forms typically include a series of open- and close-ended items indicating what they are doing, the social and physical context of the activity, and how they are feeling about the activity (Mannell & Dupuis, 1994). "The goal of the [ESM] procedure is to sample representative instances of experiences that occur naturally within participants' day to day lives" (Voelkl & Brown, 1989, p. 36). The strengths of the ESM are: (a) that it allows researchers to examine both the objective and subjective aspects of behaviour in the natural context of the experience (Altman & Rogoff, 1987; Georgoudi & Rosnow, 1986; Voelkl & Birkel, 1988; Voelkl & Brown, 1989); and (b) that it obtains information about individual behaviour and experience during or directly following the activity minimising the potential distortions that may be introduced in retrospective approaches (Hnatiuk, 1991).

For the purposes of this study, participants were not paged, but instead were asked to fill out their personal log immediately following every direct or indirect contact with the facility. Direct contact included those occasions in which the family member made contact with the facility (e.g., visiting, participating in activities within the facility, communicating with someone at the facility by telephone and so forth). Indirect contact included those activities that the family member performed in their caregiver role which did not involve direct contact with the facility (e.g., preparation for a visit by baking for the family member, picking up or doing laundry for the older adult relative, shopping for the relative, arranging doctor or other medical appointments, thinking about an activity that has to be done, and so forth). I emphasised to the daughters that it was important that what they chose to document in the log came from them. They were told that if they considered a particular activity to be part of their caregiving role, then they were to document it in their personal log. Quite simply, the adult daughters were encouraged to fill out the personal log every time they were doing something they felt was part of their caregiving role.

All adult daughters who agreed to take part in the study were asked to fill out a personal log. However, as stated earlier, eleven of the women declined to participate in the personal log component of the study. Those who did not complete personal logs were either: (a) not heavily involved in the care of their parent and indicated that they would not be performing any caregiving activities over the two week period following the interview; or (b) were not coping well with the situation and indicated that they felt the log would be too difficult for them to complete, or that because of their difficulty coping they would not be involved in any caregiving activities over the two week period following the interview.

Twenty-seven adult daughters agreed to complete the personal logs. The logs were maintained over a two-week period (beginning immediately following their interviews). Using an example of a completed personal log entry, I explained the personal log procedure to the participants following their interviews. The adult daughters were also given my home telephone number and encouraged to call me should they have any questions or concerns during the two-week period. As a reminder to the adult daughters to complete their personal logs, I sent out a note to each participant a few days following the interview. In this note I thanked the family members for the insights they shared with me during their interviews and reminded them about completing the personal logs encouraging them again to call me should they have any questions.

I was interested in what adult daughters did in their caregiving roles from their perspectives and in their words. The personal log, therefore, consisted of primarily open-ended questions (see Appendix D). The questions in the log were designed to elicit information regarding: (a) the specific behaviours or activities performed, (b) the length of time the caregiver spent on certain behaviours or activities, (c) the location of the behaviours or activities, (d) the other people present during the behaviours or activities, and (e) why the behaviours or activities were performed. The personal log was also used to examine role meaning from a different perspective, mainly the affective aspects of their role. Further, it allowed adult daughters the opportunity to describe their role and their experience in their role in relation to concrete, real behaviours and situations.

Several researchers have advocated the use of triangulation to improve the credibility of the research findings (Howe & Keller, 1988; Lincoln & Guba, 1985; Madley, 1982; Patton, 1990; Reichardt & Cook, 1979). When different data collection strategies are used for the same purpose, the two methodological procedures can build upon each other to provide insights that neither one alone could provide. In summarising what many authors have found, Henderson (1991, p. 30) stated: "The value of multiple methods is that they lead to multiple realities". The use of multiple data collection strategies can broaden the opportunities for discovery, for understanding, and for verification and support for one's findings (Patton, 1980; Rossman & Wilson, 1985). I hoped that by using both the active interviews and the personal logs, I would gain a more comprehensive and deeper understanding of the multi-dimensions (i.e., role meaning, role behaviour, and role expectations) of adult daughter roles in long-term care facilities from their perspectives.

To summarise, the primary data collection strategy in this study was the in-depth active interview. This component was employed to examine role meaning, role expectations, and adult daughters' perceptions of their role behaviour. The interview was also used to try to gain an understanding of the identity and lives of the individual caregivers (positionality) in order to place the caregiving roles in context. Information gathered on the personal logs was used to supplement the information gained during the interviews. The personal logs primarily were used to collect information about actual role behaviour and the temporal and contextual features of those behaviours. In order to verify and elaborate on the information related to meaning obtained during the interviews, however, the personal logs were also used to examine role meaning, particularly the affective aspects of role meaning. Appendix E presents a summary of the key sensitising concepts, the research questions, and how the concepts were being operationalised.

Data Analysis

"The discovery of themes begins most appropriately during the interviews and fieldwork using direct discussions and observations, not just during armchair review of completed field notes, transcripts, or other media" (Luborsky, 1994, p. 202). Thus, my data analysis process began when I started to make initial telephone contact with potential participants. My analysis began here because very early in the study it became clear to me that the meaning-making process for both my participants and myself did not begin at the interview but began with the initial telephone contact when I first introduced the project to potential participants. It is at this stage that the women began to share some of their initial thoughts with me on their experience. My analysis process continued throughout each of the individual interviews as well as following each interview in my self-reflections. The use of tacit knowledge and intuition were important components throughout the entire analysis process, however, they played a particularly important role for me in these early stages of the project. Moustakas (1990) described the importance of intuition in seeking to understand a phenomenon:

> Intuition is an essential characteristic of seeking knowledge. Without the intuitive capacity to form patterns, relationships, and inferences, essential material for scientific knowledge is denied or lost. Intuition facilitates the researcher's process of asking questions about the phenomena that hold promise for enriching life. In substance, intuition guides the researcher in discovery of patterns and meanings that will lead to enhanced meanings, and deepened and extended knowledge (p. 23).

During initial telephone contacts and during individual interviews, I relied very much on my intuition to help illuminate important preliminary meaning categories that required further investigation.

Once an individual interview was completed and transcribed, I immersed myself in that participant's story as told in the transcript and tried to gain a comprehensive understanding of that women's perceptions and experience in the institution-based caregiving role (Moustakas, 1990). The important meaning categories that emerged at this level of analysis were documented on the individual transcript as were questions that I needed the participant to address. At this point, the individual transcript with my initial interpretations and further questions was shared with the participant "for affirmation of its comprehensiveness and accuracy and for suggested deletions and additions" (Moustakas, 1990, p. 51). At the same time, I made a note of emerging meaning categories and the suspected relationships between various other categories, patterns and themes in my research log. This analysis process was completed for each participant involved in the project until I had gained an individual understanding of each participant's experience (Moustakas, 1990).

Following the collection of all of the interview and personal log data, I again immersed myself into the raw data and began a comparison of each of the women's experiences. The purpose of this exercise was to develop a composite depiction that represented the common meaning categories and themes that embraced the experiences of the adult daughters (Moustakas, 1990). At this particular stage in the analysis process, I formally analysed the data from the interviews and the personal logs using a modified constant comparative method (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1990). This process involved: (1) coding all the data by sector or group, (2) identifying common and variable patterns by sector or group, (3) comparing emergent patterns across sectors or groups, and (4) identifying central themes or issues which are further explained by the patterns (Lord & Hearn, 1987). The emergent patterns and themes are then compared with the existing literature. In this grounded theory approach (Glaser & Strauss, 1967), the theoretical findings emerge from and are grounded in the people and context studied (Patton, 1980).

The constant comparative method is particularly useful in studies with multiple sources of data. Inconsistencies and consistencies found in various data sources are explored in order to verify the findings. Further, "the method supports the researcher's focusing in on key issues (themes) that emerge from the data and become categories of interest" (Snyder, 1992, p. 52). In the present study, the method allowed for comparisons between, and the identification of similarities and differences among, the individual adult daughters as well as between adult daughters at various phases in the institution-based caregiving career.

More specifically, I first re-analysed each interview transcript separately. The data for each adult daughter were organised according to their relevance to meaning, behaviour, or expectations. I also used this stage of the analysis to re-examine the presence of preliminary meaning categories which emerged in my initial analysis procedures. I began this process by conducting a line-by-line analysis of the transcribed interviews using open coding (Strauss & Corbin, 1990) in order to identify conceptual categories relevant to meaning, behaviour, and expectations. I then analysed these open codes with a focus on identifying common patterns or the repetition of words or phrases in the text. These common patterns became the "substantive codes" related to meaning, behaviour, and expectations. Substantive codes "conceptualise the empirical substance of the area of research" (Glaser, 1978, pp. 55-57). The relationships between the patterns or "substantive codes" identified were then investigated in order to identify broader categories or themes that emerged frequently in the women's stories. Dolan Mullen (1985-86) described this process as "theoretical coding". The goal at this point was to organise the many concepts and patterns into a more integrated set of relationships or configurations. These patterns and themes were then compared across all adult daughters to identify similarities and differences in individual experiences, and reasons for the similarities and differences were explored. The positionality of the caregivers and its relationship to individual experiences was also considered at this stage.

Five overarching patterns or approaches to the caregiving role in the institution-based context emerged from this analysis. I eventually came to refer to these various approaches as "caregiving role manifestations". The idea of manifestations seemed to capture for me the essence of these roles; that is, how a combination of a number of features or qualities (patterns and themes) come together and make themselves known or manifest themselves to explain the nature of a phenomenon -- these various roles (Oxford English Dictionary, 1981). I then set out to compare the patterns and themes that explained each of these overarching caregiving role manifestations. I first conducted a comparison across individuals whom I perceived to be in the same role manifestation and then I conducted a comparison between the five different role manifestations. The purpose of this process was to verify in the data the existence of the role manifestations and to examine the similarities and differences among individuals in each of the manifestations as well as between the five manifestations. I was specifically looking for negative cases (Lincoln & Guba, 1985) or individuals who overall "fit" into a specific manifestation but who also had aspects of their experience that were different or inconsistent from the other adult daughters in the same group. At this point, then, I was examining how the role meanings, behaviours and expectations differed between the five role manifestations and for individuals within the same manifestations.

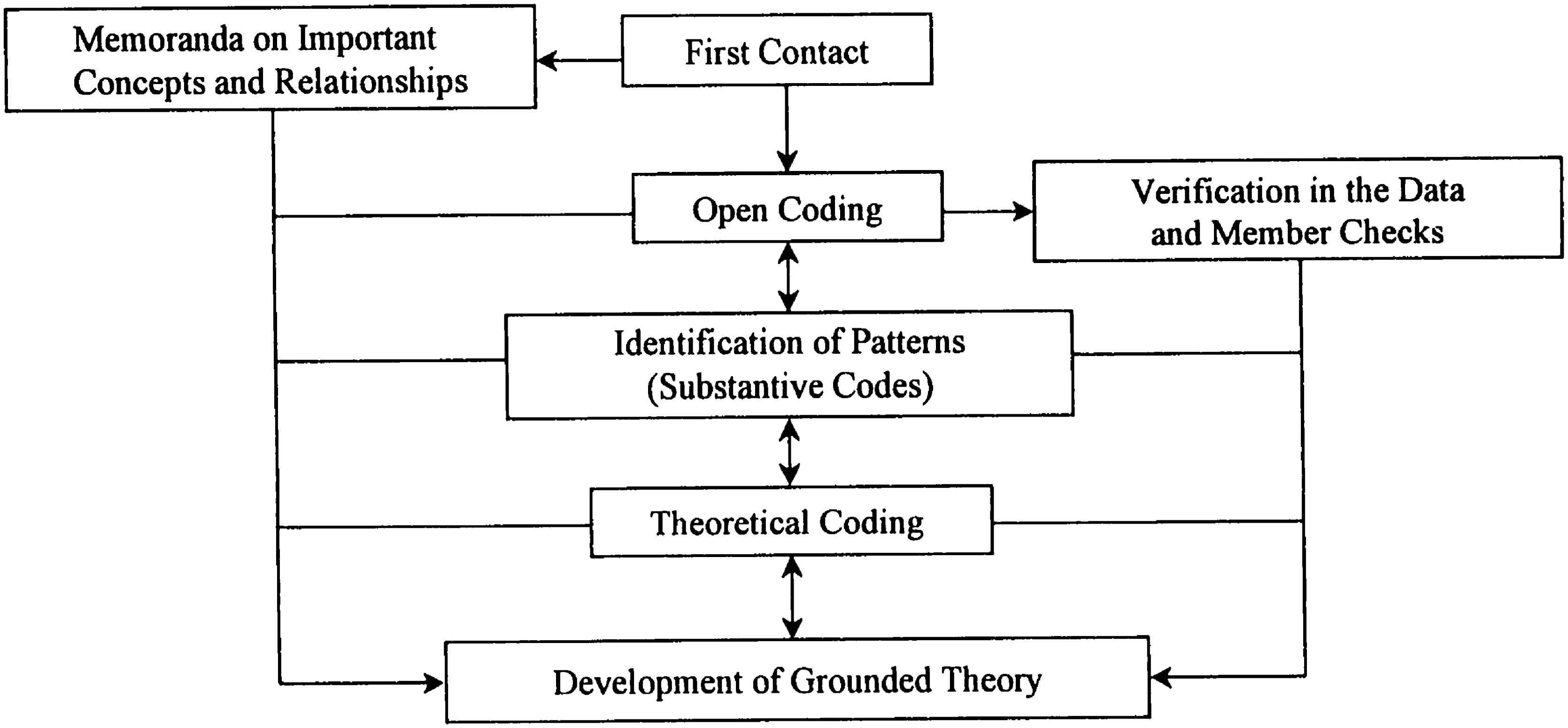
I then turned the focus of my analysis of the interview data to whether or not institution-based temporal career phase played a role in the construction of role meanings, behaviours, and expectations. I began this stage of the analysis by comparing those women in early phases of their institution-based caregiving careers, with those in mid-phases and those in later phases. Again, I was looking for common and variant patterns and themes within each group and across the three career groups. I was looking for patterns in the data which signified a shift or shifts in the caregiving role. Once this analysis was completed, I went back to the five overarching role manifestations that had emerged in the initial analysis and examined each of those groups in relation to commonalities and differences in temporal career phase. I compared the career phases of the adult daughters within each of the five manifestations separately to determine if the individuals in those groups were at similar points in their institution-based caregiving temporal careers. Similarities in career phase were noted and negative cases within each role group related to career phase were explored to try explain these individual differences. This part of the analysis ended with a comparison of the predominant temporal career phases of the adult daughters across the five caregiving role manifestations. I wanted to determine if the manifestation groups differed in relation to temporal career phase and, if so, how they differed.

Initially, the data from the personal logs were coded and analysed apart from the interview data but in a similar fashion. This analysis focused primarily on determining the types of behaviours associated with the family member caregiving role, the frequency of each behaviour, and the context of the behaviours (e.g., where the activities took place and who the adult daughters interacted with while performing caregiving activities). However, I was also interested in how the adult daughters described what they did in their personal logs.

Once I had coded the data from the personal logs, I used SPSS for Windows to organise the log data. In inputting the data into SPSS, it was never my intent to conduct a statistical analysis of the data. Instead, I used the computer package primarily to organise the data in various ways so that I could look for patterns, commonalities, and variations in the data related to the types of activities the caregivers were performing in their roles. A total of 90 different caregiving activities were listed by the adult daughters in their logs. These activities were collapsed into 10 activity categories (i.e., recreational-type activities, personalising care, monitoring care activities, clothing needs, financial and record keeping activities, ADL activities/grooming, housekeeping activities, affection-type activities, family manager activities, and support activities for "other" parent). I then organised the activities and activity categories according to caregiver and examined separately the types of activities each adult daughter performed, comparing activities listed in the log with the activities mentioned during the individual interviews. Next, I conducted a comparison across adult daughters in order to look for any patterns that might emerge related to the types of activity categories most predominant for these caregivers. The data were then analysed according to the five overarching caregiving role manifestations to determine if the role behaviour differed by role manifestation and, if so, how. Finally, I examined the log data to identify any patterns in role behaviour related to the caregiving temporal career. Specifically, I wanted to determine whether or not the types of activities the caregiver performed shifted over the caregiving temporal career and, if so, how.

A final and important step relevant to the development of grounded theory involved linking and comparing the findings from the present study -- that is, the emergent patterns and themes and their relationships -- with the major theoretical constructs appearing in the literature (Detzner, 1992). Questions I continually asked myself at this stage in the process were: (1) how do my findings differ from the findings of other relevant studies? (2) do my findings support any of the findings in other relevant studies, and, if so, what are the similarities in my findings and the findings of others? and (3) considering my findings and the findings of others, how might I conceptualise the roles of adult daughters in long-term care facilities and how those roles are developed? These questions served to guide the development of my grounded theory presented in Chapter Six. Figure 2 summarises the analysis process I used throughout the project.

Figure 2
Analysis Process for Developing Caregiver Role Manifestations



CHAPTER FIVE
ALTERNATIVE ROLE PERCEPTIONS

MANIFESTATIONS OF CAREGIVING ROLES

Although family members of residents in long-term care facilities are often considered, or at least treated, as a homogeneous group, it became very clear early in my investigation that there were several different, conflicting perceptions of the types of roles the adult daughters were playing or not playing in the facility. The stories told to me in the interviews represented a variety of ways that adult daughters viewed their roles in the care of their parents. In an attempt to understand how the role perceptions differed, I began to look for "dominant themes or descriptors" (Dienhart, 1995) within the women's stories that would help explain the essence of the various role perceptions. In comparing the dominant patterns and themes across all 38 adult daughters, particularly looking for similarities and differences, I was able to categorise the role perceptions of the adult daughters into five family member role manifestations. These alternative role manifestations were based primarily on how the adult daughters defined their roles in the care of their parents. The women's expectations for themselves in the caregiving role as evident in their stories told to me (which tended to be similar to how they defined their role), and their behaviour in the role revealed in their interviews and the personal logs were also used to develop the dominant caregiving role manifestations.

I called the family member role manifestations which emerged from the women's stories the *active monitors*, the *regular visitors*, the *indirect supporters*, the *unaccepting* *relinquishers*, and the *accepting relinquishers*. A large majority of the women (23) fell into the regular visitor role manifestation, another five of the women were active monitors, five were indirect supporters, three were unaccepting relinquishers, and two were accepting relinquishers. These numbers, however, are somewhat misleading. For example, although each of the role manifestations is distinct in many ways from each other, the manifestations are not mutually exclusive and overlap one another. That is, the women in any one of the five manifestations may also share characteristics of the women in any of the other manifestations. Therefore, a woman categorised as an indirect supporter may also have a few characteristics similar to the women in the regular visitors role type. Her perception of her role within the long-term care facility, however, "fits" more closely with the indirect supporter group. Further, the women in any one of the role manifestations are not all at the same place in the manifestation. Many of the women in the regular visitor role manifestation, for instance, appeared to be in transition from the active monitor stage to the regular visitor stage or moving from the regular visitor role to the accepting relinquisher role. What the women in each group share in common is the *dominant* way that they define or think about their role within the facility.

In addition, each woman who participated in the study brought a different set of circumstances to her experience in the long-term care facility. These individual life situations shaped the women's perceptions and experiences in very unique ways. Thus, although the role perceptions of the women in each of the five family member role manifestations are presented here as distinct, individual women's situations within any one role manifestation are, in many cases, quite diverse.

In my portrayal of the five caregiving role manifestations, I wanted to be able to capture both the distinctiveness of each group but also the uniqueness of the individual women's lived experiences within each of these roles. My presentations of the five role manifestations first include a description of the core features (the patterns and themes) which explain each of the role manifestations. Using the women's stories, I then provide two profiles for each of the five role manifestations. These profiles are used not only to provide illustrations or examples of the various roles and the core features of the roles, but to provide a thick description of the real women in these roles and the real situations they have found themselves in. This approach to presenting findings, particularly in retaining as much of the individual participants in the depictions as possible and presenting participants' experiences as a whole, is similar to a heuristic research approach and what Moustakas (1990) called "creative synthesis". Due to lack of space, I could not provide profiles on all the women involved in this study. Rather, in selecting the women for the profiles, I relied on Moustakas's (1990, p. 54) advice and chose women whose stories were "exemplary portraits" of the role manifestations, particularly in how their stories "vividly" and "comprehensively" illustrated the core features of the manifestations. I also wanted to illustrate the differences in the experience for the women involved and so for the second profile in each role manifestation I chose women whose stories reflected a somewhat different experience in their role. This was not difficult since all of the women's stories and experiences were unique in one way or another. In order to ensure confidentiality and to protect the anonymity of the women involved in the project, I use pseudonyms in all of the profiles.

Before I present the caregiving role manifestations, I want to acknowledge and again emphasise my presence in the analysis and writing processes. Daly (1997) challenges the traditional assumption or emphasis in qualitative research of the idea that our findings and our theories "emerge from the data" (Glazer & Strauss, 1967). He argues that our findings and theories do not emerge from the data but they emerge from the researchers; that is, they are drawn out of the data by those who collect it. He further emphasises that our stories, our reports, and our theories can therefore only ever be "second order stories". They are always our interpretations about our participants' interpretations at one point in time. Krieger (1991) calls for the recognition and acknowledgement of this fact:

> I think it is important to try to grasp experiences that are not one's own. However, such attempts ought to not to be masqueraded as other than what they are: they are attempts, they grasp only small pieces of experience, and they are always impositions of an authorial perspective (p. 54).

Although I took several precautions to ensure that I was accurately understanding the experiences and stories told to me by the women involved in the study, the stories I am about to present are still my interpretations of the adult daughter's narratives.

Core Features of the Role Manifestations

Several core features or characteristics (themes and patterns) related to role meaning, behaviour, and expectations came together to help explain the women's varied roles in the long-term care facility. I used these core features to develop the caregiving role manifestations. A summary of the core features of each of the five role manifestations is presented in Figure 3. The dominant core features include:

- *temporal caregiving career phase* - Temporal career phase was primarily defined as the duration of time the parent had been living in the long-term care facility and the length of time the adult daughter had been involved in the institution-based context. Although time in itself may be important, time here seems to be more important in how it changes the context of the situation. For example, the longer the parent is in the facility, the more likely they may be to have more severe levels of cognitive impairment. Also, the more experience an adult daughter has within the institution, the more time she has to get a sense of how the facility operates and what is expected of her. She can use this knowledge from experience to re-define and re-create her role within the institution.

- *visitation patterns/involvement in the facility* - This feature has primarily to do with how often the adult daughters visit, and whether or not adult daughters feel a need to be involved in the facility in their parents' care.

- *role definitions* - Role definitions emerged as the most important feature in the development of the role manifestations and have to do with how the adult daughters define or think about their role in the long-term care facility.

- *focus of support* (if any given) - The notion of support came up regularly in the stories of the women in three of the five role manifestations (active monitors, regular visitors, indirect supporters). Where the support was targeted was a core feature in defining some of roles. Focus of support is also important in explaining the types of activities or tasks the family members perform in their roles.

- *perceptions of the "thereness" of the parent* - This core feature has to do with how the adult daughters think about their institutionalised parents and whether or not they believe their parents still exist, particularly personality-wise. For example, some adult daughters talk about their parents as being gone mentally, no longer existing for them anymore. Others still very much think about their parents as being vital human beings and still being the parents they remember from before the parents became ill.

- *pressure to be at the facility* - The women's stories had an element within them which had to do with how pressured they feel to be at the home regularly. In the stories where this sense of pressure was evident, the pressure generally has three sources: it could come from the daughter herself and her own sense of duty and obligation to the parent, it could come from the perceived expectations of the parent, or it could come from how comfortable the adult daughters are with the care their parents are receiving. Other adult daughters expressed no pressure to be at the facility regularly.

Figure 3
Summary of Caregiver Role Manifestations

Active Monitors

- early temporal career phase
- visits parent more than regularly
- role definition in terms of 3 purposes
  - →maintaining normalcy
  - →monitoring care
  - →preserving self
- support focused on both parent and staff
  - →part of the care team
  - →provide direct, hands-on care
- parent still there personality-wise
- intense pressure to be at facility
  - →not as satisfied with care
  - →pressure from parent
  - →pressure from self

Regular Visitors

- mid or later temporal career phase
- visits parent regularly
- role definition in terms of 3 purposes
  - →maintaining normalcy
  - →monitoring care
  - →preserving self
- support focused on parent
  - →extension of staff role
  - →emotional aspects of care
  - →direct, hands-on care not important
- parent still there personality-wise
- peace of mind that parent well cared for

Indirect Supporters

- all temporal career phases
- presence of both parents
- support focused on *other* parent living in the community
- role definition in terms of 2 purposes
  - →assisting other parent with caregiving role
  - →monitoring other parent's health/well-being
- most cases, institutionalised parent no longer exists personality-wise
- parent being well cared for by other parent and facility

Accepting Relinquishers

- later temporal career phase
- relinquished care to facility/other
  - →physical care
  - →emotional care
- visits facility irregularly (once per month)
- role definition in terms of overseeing care
  - →assesses how facility operates
  - →assesses how people interact in facility
- acceptance of situation
  - →focus turned to own lives and needs
- do not define themselves as caregivers
- parent no longer exists personality-wise
- very satisfied with care

Unaccepting Relinquishers

- moving into, or in, later temporal career phase
- relinquished care to facility/other
  - →physical care
  - →emotional care
- visits parent irregularly (once per three months)
- role definition in terms of experience
  - →pain
  - →sense of helplessness
- unacceptance of situation
  - →avoid visiting
  - →never visit alone
- do not define themselves as caregivers
- parent no longer exists personality-wise
- very satisfied with care

- *acceptance of the situation* - An important core feature of some of the role manifestations, especially as told in the accepting relinquisher's and unaccepting relinquisher's stories, is the idea of coping and acceptance of the situation. These women talked about their ability or inability to cope with situation and how they came to that acceptance or how they cope with their inacceptance.

These core features will be described further in the discussions of each of the role manifestations and examples of them will be illustrated in the adult daughter profiles.

Level of involvement in the facility is one of the most basic distinguishing features of all five family member role manifestations. The active monitors are the most intensely involved, at least within the facility, and the accepting relinquishers and the unaccepting relinquishers are the least involved of the five groups. The indirect supporters are also very involved, however, their roles are focused outside of the facility. I have chosen to present the role manifestations beginning with the two groups that are most involved within the facility (the active monitors and the regular visitors). I then describe the two role manifestations which represent the women who are the least involved within the facility (the accepting relinquishers and the unaccepting relinquishers). I finish my presentation of the role manifestations by describing the group of women who are quite intensely involved, although sometimes invisibly so, outside of the facility (the indirect supporters).

Family Members Involved in the Facility: Active Monitors and Regular Visitors

The Three Purposes of Caregiving

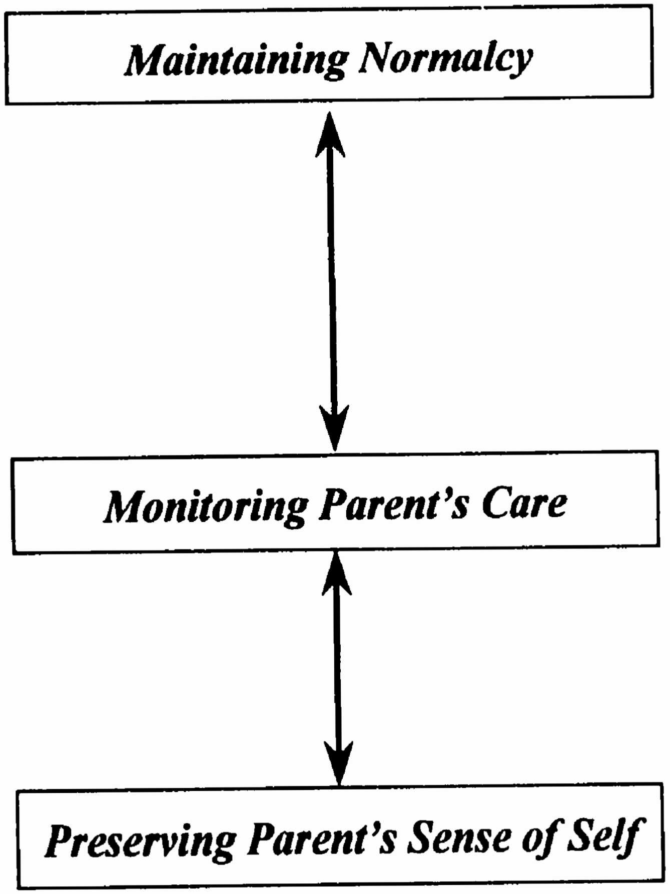
Those adult daughters who are more heavily involved in the care of their parents living in the facility fall into two caregiving manifestations: *Active Monitors and Regular Visitors*. Consistent with the role meaning perspective (Bowers, 1988; Duncan & Morgan, 1994), these adult daughters describe their role primarily in terms of their purpose within the facility. Three purpose themes or categories emerged from the women's stories. Figure 4 summarises the three purpose themes and patterns associated with those themes.

The most consistent purpose identified by both active monitors and regular visitors was *to maintain some sense of normalcy* in their parents' lives. Above all, maintaining normalcy involves providing a familiar presence in the facility for the parent and, in some cases, for the staff. It is very important to these family members that the parent knows they are cared for, that they are loved, and that they are not forgotten. These adult daughters also feel that their presence in the facility demonstrates to the staff members how important their parents are to them. Many of these women feel that if they did not have a regular presence in the home, their parent would not receive the care they now receive. Interestingly, this motivation for involvement within the home expands on the sense of motivation perceived by the Director of Nursing Care. According to the Director of Nursing Care, those who take more of an active role in the facility are there primarily out of guilt. Although, some of the adult daughters I spoke with were definitely feeling a sense of guilt for having to admit their parents to a long-term care facility, what was also emphasised to me was how the family members' presence within the home ensured quality care.

The adult daughters maintain normalcy in several ways. First, these adult daughters place great importance in "just being there" or visiting their parents regularly. For many of these adult daughters, this simply represents a continuation of their involvement or participation in their parents' lives and continuity of the daughter role. In "being there" on a regular basis the family members can provide a familiar face for the parent. In their

Figure 4

Purpose Themes and Patterns Described by Active Adult Daughters Within the Facility



- being there/visiting regularly
    - →familiar face and context
- maintaining parent as part of the family unit
    - →family manager/organiser
- serving as emotional support system
    - →showing affection
    - →providing companionship
- continuity of important and familiar activities
- link to past and present

- visual thing/observe parents, facility and staff
- regular communication with staff
    - →advocate/voice for parent
    - →keep informed of parent's condition
- providing direct care

- maintain as much of parent as possible
    - →physical appearance
    - →mental functioning
    - →parent's sense of who they are
- parents treated as adults/dignity, respect, control

stories, many of the family members talked about the guilt they feel for taking their parents out of a context which was familiar to them. Being a familiar face within the institution is how the family members now provide a familiar context for their parents. Deborah described her thoughts on trying to maintain normalcy in her mother's life:

> She is here and I guess, this is getting pretty difficult, I feel like I need to be here because I feel guilty for her being here. I feel that I have deprived her of some normalcy in her life by placing her here and so I feel that that kind of is my role, by coming in, providing somebody familiar and talk about things you know, that she might relate to. So, I guess I feel that I am here for her, and for me too I guess, but to try and make her life as normal as it can be while she is here.

An aspect of maintaining normalcy involves ensuring that their parents have whatever they need to be comfortable and content within the home. Visiting their parents and the home regularly helps family members identify what the parents' needs might be and take steps to address those needs on a regular basis.

Second, adult daughters maintain normalcy by ensuring that their parents know they are part of a family unit and by continuing to involve their parents in the larger family system. For example, Jennifer, a regular visitor, stated:

> I would call it a fact of life, I guess. It is just a part of my life. I think it is still trying to keep him as part of the family. I think that is it. I don't want to exclude him, that is the word that I am looking for. I don't want to exclude my father from anything.

In visits, adult daughters talk about family events or family news and keep their parents up-to-date on what is happening in their lives and the lives of other family members. The daughters' stories told in their interviews and in their logs also revealed that these women often serve as family managers. Organising family events for special occasions and keeping other family members informed of their parent's condition represents a large part of their caregiving role.

Related to reminding parents that they are important members of the family unit, adult daughters also serve as an emotional support system for their parents, making sure their parents know they are loved and not forgotten. Adult daughters discussed how it is important to them to openly show affection towards their parents by hugging, kissing, caressing, and holding their parents during visits. They also appreciate it when the staff show affection towards their parents. In her interview, for example, Hazel began talking about how she and her mother appreciate the affection the staff demonstrates towards her mother. When I asked Hazel if she felt that showing affection was an important part of her role, she responded: "Oh God yes. Yes, she [mother] looks forward to the hug and kiss very much, even holding hands, just holding hands, sitting there holding hands". Nonetheless, showing affection can sometimes be difficult for family members as they often feel there is little privacy in the facility and that their interactions with their parents are constantly on display in the home.

Companionship was another important aspect of their emotional supportive role. Another regular visitor, Sheila, described how important it was for her to provide her mother with regular companionship:

> I would say that there's really not a lot that I do for her every day here because the staff here are involved in that. I'm not here to do it. I think probably as someone to keep her company, probably that's the important thing, somebody to actually sit down and in mom's eyes as having a conversation with her and listening to her.

The adult daughters hope that their regular companionship will help lessen their parents' loneliness or anxiety within the home.

Fourth, family members maintain normalcy through the continuity of activities that are important or familiar to their parents. For example, if a parent regularly attended church services, the adult daughters often find ways to either take the parent out of the facility for church on Sunday, or arrange their visits on days when the facility church service is held so that they can accompany their parent to the mass. Candace explained this notion to me during her interview:

> [My mother] was brought up in the Salvation Army which has a band and they have the songs and the choir and everything and she really enjoys that. Well the Salvation Army does a service the last Sunday of every month up there. They have a bit of a brass ensemble that comes in and I try and be there to take her up. Some Sundays she just sits there and other Sundays she will hum a few bars and once in a while she will say a word or two. And, she seems to enjoy it most times and other times it is just kind of, she just sits there and you are not sure if she is enjoying it or not. But it is worthwhile for me to take her even if she hums a bar, you know because there is not too much that she can interact with any more.

Family members also bring in special treats they know their parents always loved. These items may not be available in the facility but family members see them as important to maintaining continuity and normalcy in their parents' lives. Providing newspapers, plants, and music are other examples of how family members try to provide some continuity in their parents' lives.

Fifth, family members see themselves as not only a connection to the past for their parent but also a link to the present. Adult daughters feel the need to keep their parents in touch with things familiar from the past. They reminisce with their parents about past events, trying to get them to remember significant occasions or people who were important to the parent. They bring in photograph albums and other familiar items to share with the parent during these reminiscence sessions. In comparing her role with the role the staff members play in the care of her mother, Pauline noted:

> [My role is] probably more trying to get her to remember things or conversations or pictures or more sort of trying to keep her in touch with her own family and our own families.

Adult daughters also keep their parents informed of important happenings, dates or events in the present. In addition, some family members bring in seasonal decorations to place in their parents' rooms to make sure their parents know what time of year it is. All of these activities are done for the sole purpose of providing some continuity in their parents lives, some sense of normalcy to a situation and setting they perceive to be anything but normal.

The next purpose communicated throughout the women's stories (both active monitors and regular visitors) was *to monitor the care* their parents were receiving in the long-term care facility. This purpose involves making sure that the parent is being cared for the way they would care for their parent if they were at home. Some of the women described this purpose category in terms of a "protector" role; that is, they were there to watch over and protect their parent much like a parent protects a young child. Adult daughters monitor care in three general ways: observing their parents, the facility, and the staff; maintaining regular communication with the staff; and providing direct care if needed.

The adult daughters described one component of monitoring care as "a visual thing". In their visits, they would observe their parents, aspects of the facility itself, and the staff members within the facility. In terms of their parents, the adult daughters check to make sure their parents are kept clean, dry, and properly groomed. They watch their parents' body and facial expressions to make sure they are not in any pain. They also observe their parents to ensure that they are getting proper rest within the facility, and that they are well fed and receiving proper liquids. For example, Elizabeth, a regular visitor, described her role in monitoring her father's care:

> Well, I don't really think, as far as caregiving goes, that it's anything in depth, my role caring. Concern and keeping an eye out for anything that we feel, that I feel is necessary...You know if I notice that he needs a t-shirt or clothing or any little needs that might make him a little more comfortable. But as far as health care or bathing him it would be, it's just more of a visual thing, you know, what we see or, you know, is he comfortable, asking questions. The actual doing of it, no.

Adult daughters also take note of the maintenance of the facility particularly in terms of the cleanliness and upkeep of the home. Some family members, for instance, check their parents' linen when they visit the home. These women also watch the staff when they are at the facility. For the most part, they observe how various staff members interact with other residents and they use those observations to gage how their own parent is being treated in the facility when they are not there. Another regular visitor, Candace, reflected on her role in monitoring her mother's care:

> ...ultimately I am responsible for the care that she [my mother] gets or doesn't get whether I am doing it personally or not and I have to make the final decisions on her care if there is anything beyond the norm...Making sure she is in a good place is part of it, making sure that the staff carries out what they said they are going to do, not that I have to be right on top of them but whenever I go and visit just seeing that the place is clean and my mom is clean and her clothes are clean, that she is well fed and she has her liquids and everything. These are all things they do but I still think it is my responsibility to make sure that it is being done for her but they do the actual caregiving I think, I just kind of make sure it is being done.

Monitoring their parents' care also involves regular communication with the staff of the facility. This regular communication serves two purposes. First, it allows family members to serve as advocates or a "voice" for the parent. This role is particularly important when the parent is no longer able to communicate their thoughts and needs for themselves. Serving as an advocate for the parent, the adult daughters will make sure that staff members are made aware of any concerns they may have concerning their parents' care. Evelyn explained how the loss of her mother's ability to communicate has led to a change in her role:

> Well, [my role] has changed in that my mother can't communicate at all any more. I feel like I have to speak out for her. If her hands are dirty or her floor is dirty or her walls are dirty or there is something that doesn't suit me and I know would not suit my mother I would, I feel that I should speak up for her and I realise that in an institution that things aren't quite the same as at home. They wash the clothes very roughly and that kind of thing. Yet, as a person on the outside paying the monthly fee that they charge for clothing washing and that I come here and her sweaters are three inches by three inches and her slacks are all wrinkled. I am thinking, surely they can do a better job and my mom is not, she is at a stage now where she would not say anything because she can't. Yet my mom was very, very particular about her hair, her feet and her clothing. She was always so particular about them. She always looked so nice and she still looks nice. I am not saying they don't do a good job because they do. But when things start to slide is when I think, oh I have got to say something because my mother can't.

As the parent's voice, these women provide tips to the staff on how to care for their parent based on their more personal and historical knowledge of their parent. For example, a daughter might inform staff members about her parent's likes and dislikes, and the way the parent prefers to have routine tasks done.

Second, regular communication serves to keep an adult daughter informed of her parent's condition. These women check with the staff regularly about their parents' health status. For instance, Janet described for me how she makes a point of "questioning the nurses on her [mother's] health and eating habits" each visit and phones if she is unable to visit the facility to check with the nurses on her mother's condition. Family members also inquire whether their parents might have specific needs, healthwise or otherwise, they should be looking into. Some family members also take part in care conferences to keep abreast of their parents' progress. These women may also attend special medical appointments so they can check on their parents' conditions first hand. Keeping informed about what is happening with their parents also might involve learning about a particular disease process by obtaining information from experts in the field, for example, from the Alzheimer's Society.

Finally, monitoring care also involves providing direct care or hands-on activities such as dealing with problems themselves if the staff do not address the problem quickly enough. For example, Helen talked about how upset she was with the odour and mess in her father's bathroom within the facility. So, this adult daughter visits the home regularly so she can mop up her father's bathroom and also has other siblings checking on this when they visit. Another active monitor, Eva, described in her story how concerned she was about the bruises the mechanical lift occasionally left on her mother's legs. She took it upon herself to put together a padding device and attached this device onto the lift to protect her mother from being hurt further:

> The lift that they use on her, it's a big [machine], it goes in between her legs and that was always coming down on her leg and hurting her. So I went and I got a pad about that long and I took a shoe lace from home and I tied it around [the lift] and now it doesn't hurt as much if it comes down if the nurses don't see it right away. At least it's not the same pressure on [her leg]. So that helped. It doesn't look too good but every once and a while it's taken off and I say how many shoelaces am I going to need. So, now I leave one in her closet at all times. Now some of the nurses, oh not very many, just one or two might, didn't figure it was necessary. But, then the others said to me: "[Eva] that was a great idea, that's really wonderful".

Similar to the preservative care described by Bowers (1988), the final purpose described in the women's stories was *to maintain their parent's sense of personhood*. This purpose theme is very much linked to the purpose of maintaining normalcy in their parents' lives. Again, the adult daughters address this purpose in several ways. First, these women try to maintain as much about the parent from the past as possible. They try to maintain the parent's physical appearance, the parent's mental functioning, and the parent's sense of who they are.

In terms of physical appearance, the adult daughters described how their parents always cared about what they looked like. The adult daughters saw it as their responsibility to maintain the "smart look" that was so important to the parent in earlier times and very much a part of who the parent was. They made sure to buy clothing for their parents similar (in the same colours and styles) to what the parents would have bought for themselves. Katherine explained this part of her role to me:

> My mother was always a very smart dresser, always liked nice clothes and always dressed in a … she didn't dress in sort of little old lady clothes, she and I could have easily exchanged our clothing, she was always a very up-to-the-minute smart dresser but that type of clothing now doesn't work too well. I tend to buy her now either pants or full skirts that will cover her legs when she sits in a [wheelchair] but I still try to keep the smart look that she always had.

Related to maintaining the "smart look", family members become very distressed when they find their parents' clothing to be dirty, sloppy, or wet. Although the adult daughters understand how difficult it would be to change each resident every time they spilled something, they also know that their parents would never want to be seen in public with soiled clothing. Jennifer, for example, explained how upset she feels when she finds her father in dirty clothing:

> My dad is sloppy with his food sometimes and I wrote on the questionnaire, that is one of the things that bugs me the most of anything, they don't change their clothes often enough. During the week is one thing but it really, really bothers me when I go over there on the weekends and they have my dad sitting in the hallway or the dining room and other people are in there visiting their family and my dad has pants and a shirt on that are caked with food. That bugs me, bugs me more than anything. My brother says, so what, you know, but my attitude is that he has lost everything, he has lost his identity, he has lost his freedom, don't take away, don't take away his characteristics.

So, in many instances the family member would change the dirty clothing or toilet the parent themselves. The adult daughters also removed facial hair in order to maintain their parents' physical appearances. One daughter also described how every time she goes into the facility she has to fix her father's hair because the staff combs his hair differently than how her father always wore his hair.

For some of the women, part of maintaining as much of their parent as possible also involves trying to maintain their parent's mental functioning. Some women complained about the lack of mental stimulation that their parents received within the home. They also recognised the importance of regular mental stimulation to maintaining cognitive abilities as long as possible. Thus, these women took it upon themselves to provide stimulation in the form of mind games or other activities so they could keep their parents' minds as active as possible for as long as possible. Carrie-Ann expressed her sense of the importance of mental stimulation in slowing down the disease process:

> I think that there are more activities here in that unit than there were at the other home that she was in. I think that [the activities] are more in line with what the residents are able to handle and any sort of stimulation, to me, I think that, I don't know if it is true or not, but I have a feeling that they would go down hill faster. So, I think that any stimulation that I can do and that the staff are doing is going to help.

Some adult daughters also talked about some characteristics they remembered their parent always possessing, for example, a great sense of humour or wittiness. In visits, these women would try to bring out those aspects of their parents they remembered so well.

Very much related to maintaining normalcy, the adult daughters also described how they feel the need to give their parents a sense of who they are. They do this by talking to their parents about people in their parents' lives, both from the past and in the present, and they remind their parents about things they have done or accomplished in their lives. Sandra, a regular visitor, told me that maintaining her father's sense of self is an important part of her role. When I asked her how she did this, she explained:

> We talk about people that he knows and things and I remind him of different things and sometimes you can get him, well before, you could get him talking about them, that was important. And he was still reading the paper, he got us to get him the Globe and Mail again, you know, and he was actually reading it because he'd discuss it with my husband. I don't read it much but he'd discuss it with [my husband] and it would be fine, I mean he was following it, [my husband] would know what he was talking about.

Adult daughters also decorate their parents rooms with familiar objects from the past or with things that the parent is used to having in their home, or they know their parent would want to have in their home.

Maintaining their parent's sense of personhood also involves ensuring that their parents are treated as adults; that is, with respect, with dignity, and by allowing them as much control or independence as possible. Some adult daughters described how they consciously try hard to talk to their parents at eye level, and how they make every effort to refrain from talking down to the parent (e.g., responding to parent as one would when responding to a child). Deborah discussed this in her interview:

> ...sometimes I feel that the staff talk down to them and I try not to do that with her (mother). To me she is still, you know, a very viable adult and you know she shouldn't be talked down to like a child and I try and let her express herself and just talk to her adult to adult.

Family members also try to give their parents back a sense of control over their lives or some sense of independence. These women try to find situations where their parents can make decisions for themselves or can help with decisions the daughter is trying to make. Also, some adult daughters come in regularly to help with feeding so that the parent is allowed the opportunity to feed him or herself rather than being fed by the staff. To the adult daughters, these seemingly small gestures allow the parent to retain some control and dignity in their lives.

Maintaining the parent's dignity also involves making sure the parent is not put into undignified or inappropriate situations. One regular visitor, for example, spoke with much distress about an incident where she had gone into the facility to find her father lying on his bed wearing only a diaper. To make things worse, while the parent lay there barely clothed, his roommate was being visited by his own family members. Jennifer described this incident for me:

> We went in there in the summer time and it was hot. I don't know what happened but I guess they had [my father] sitting in his wheelchair and when [my father's roommate's wife] came in with [Leonard], father was laying on [Leonard's] bed face down and he had wet himself. So, [Leonard's] bed was wet. So, I gather that all they did was take him from [Leonard's] bed and they laid him on his bed on top of it and all he had on was a diaper. And, I flew out of that room and I nailed the first person that went by and I told them in no uncertain terms that he has to still have a bit of vanity and I did not appreciate the fact that they left him laying there in a diaper. I said that it is degrading for him. Ya, they lose a lot of dignity, they lose their personality and everything.

Other daughters spoke about how they would sometimes go to the facility to visit with their parents and find that they had been placed in their wheelchairs and positioned facing a wall, either in their own rooms or in another room within the facility. These types of incidents or behaviours were seen to be attacks against their parents' sense of dignity and they took measures to ensure that they did not happen again.

To summarise thus far, those adult daughters more involved in the facility, active monitors and regular visitors, tend to think of their role within the facility in terms of the purpose they ascribe to themselves in the care of their parents. The main components of their role are to maintain a sense of normalcy or continuity in their parents' lives, to monitor their parents' care within the facility, and to ensure that their parents' sense of personhood is preserved as much as possible. Several activities or strategies are used by these women to address the various purposes they ascribe to their role. In fact, their behaviours in the role are directly linked to their objectives for themselves.

Active Monitors and Regular Visitors: Similarities and Differences

There are several similarities between the active monitors and the regular visitors. First, active monitors and regular visitors visit their parents at the facility on a regular basis. Active monitors, however, tend to be more intensely involved in the facility, visiting their parents at least three times a week and often much more than that. Regular visitors generally visit their parents at least once a week and certainly no less than once every two weeks. Second, for the most part, the adult daughters in both of these groups believe that their parents still exist and still recognise them when they visit. For those few women who no longer see their parent in the resident they visit, they still place great importance in having a regular presence in the facility. Finally, both the active monitors and the regular visitors define their roles to some degree in terms of the three purposes described earlier. Some adult daughters think about their roles in terms of all three purposes, and others focus their concentration on one or two of the purpose areas. Nonetheless, all active monitors and regular visitors define their roles in terms of at least one of these purposes.

There are also some distinct differences between the two groups of involved family members. To begin with, active monitors and regular visitors have slightly different perceptions of who they are supporting in the facility. Active Monitors tend to define their role in terms of supporting both their parents and the staff. They perceive themselves as "being there" for their parents so the parents know they are always there for them. They also see themselves as "being there" for the staff, providing services that the staff would normally perform, and giving some relief to the staff. Regular visitors, on the other hand, tend to focus all of their energy in supporting the parent and generally do not talk about their role in terms of supporting the staff. Regular visitors tend to describe their role as being more of an extension to what the staff provide within the facility; that is, providing more of the personal and emotional aspects of care. Thus, active monitors and regular visitors also differ in terms of the amount of direct, hands-on care they provide. Active monitors are more likely to see themselves as part of the care team. All active monitors are performing some type of care the staff members are usually responsible for and may even volunteer in different capacities within the home. In contrast, most regular visitors do not perceive themselves as being involved in hands-on care, and most do not want to be involved in the physical aspects of care. Some regular visitors certainly will provide hands-on care if it is deemed necessary, but they do not talk about it terms of how they define their role. Further, although regular visitors place great importance in having a presence within the facility, many feel very divorced from the care their parents are receiving and describe themselves as not really having any role in their parents' care aside from the social role of visiting regularly. Some regular visitors also describe their role in terms of being a recreational director for their parents – planning and implementing recreational activities they know their parents will enjoy.

Active monitors and regular visitors also differ in terms of the amount of pressure they feel to be at the home, with active monitors feeling much more of a pressure to be involved in the facility than regular visitors. This pressure most often comes from the adult daughters themselves and their sense of obligation or duty to be involved in their parents' care. In some cases, however, this pressure seemed to be rooted in the adult daughters' dissatisfaction or unease with the care provided in the home. For instance, although all the adult daughters I met with were generally satisfied with the care their parents were receiving, active monitors' stories were far more likely than were regular visitors' stories to reflect areas of dissatisfaction with aspects of care (e.g., more staff needed within the home). These women often feel more of a pressure to be at the facility regularly because of their concerns with care. In contrast, regular visitors tended to describe much satisfaction with the care their parents are receiving. Knowing their parents are safe and well cared for gives the adult daughters in the regular visitors role manifestation a "peace of mind" and an enormous sense of relief from the pressures and concerns they once felt. In a few cases, the pressure to be at the home often appeared to come from the adult daughters' perceptions of what their parents expected of them. For example, a few active monitors felt that their parents expected them to be at the facility regularly and described in their stories how their parents had explicitly or implicitly made their expectations known.

Finally, the adult daughters in these two groups also differed in terms of the temporal phase they are at in their caregiving careers. Active monitors are in early phases of the caregiving career in this particular facility. Only one active monitor had a parent who had been living in the facility for several years. After talking with this particular adult daughter and with the staff, however, it became clear that this woman had only become involved in the care of her mother three months before I met with her. Three months earlier, her mother had fallen in the home and broken her hip. At that time, the adult daughter became much more involved in the care of her mother within the facility, taking on a regular and more direct role in her mother's care. Regular visitors, in contrast, tend to be in mid to later phases of their temporal caregiving careers. Nevertheless, a few of the women in this group are in early phases of their caregiving careers.

The active monitor role appears to be an initial role that some adult daughters take on at the admission of their parents into the facility. My sense from the women's stories is that once these adult daughters become more comfortable with the home and the care their parents are receiving they gradually relinquish the direct, hands-on activities and move into more of a regular visiting role. Once in the regular visiting role, if the situation remains relatively stable, they could remain in this role for the remainder of their institution-based caregiving careers.

First Profile of an Active Monitor: Carrie-Ann's Story

Carrie-Ann is in her mid-forties, is married, and has two teenage children living at home. She works part-time as a supply teacher and says that this type of position gives her the freedom to be able to be more involved in her mother's care. Carrie-Ann has an older sister, Margaret, in her mid-fifties who lives approximately one hour away. In fact, Margaret was far more involved in the care of their mother at the beginning of their mother's illness. Their mother was living next door to Margaret and her husband, and so they kept a regular eye on her. Five months earlier, Margaret and her husband thought they might move away from the area as Margaret was due to retire shortly. Carrie-Ann and Margaret both decided that it would be better for their mother to be close in proximity to at least one of them and it made the most sense to move their mother to a retirement home near Carrie-Ann. Both Carrie-Ann and Margaret described this process in their interviews:

> Like at one time, my mother lived right behind us, where we lived. And then it got to the point that she couldn't stay by herself anymore, and so it was a big decision as to where she should go. Whether it should be down there [near Carrie-Ann] or whether it should be up here. Well, we had, my husband and I retired and we spend in the summer, we spend some time up North. And we wouldn't be around quite as much. And Carrie-Ann being up here, and being younger, she's ten years younger than I am, she can come in more often. So, it was, it was a big decision because we knew that we'd be taking mom away from friends, but it was almost at the point then that I don't think it really mattered that much to her [Excerpt from Margaret's interview transcript].

So, Carrie-Ann and her sister moved their mother to a retirement home shortly after the decision was made but their mother had a hard time coping with the move. As their mother's cognitive abilities declined, the administration and staff at the retirement home found it more and more difficult to handle the resident. Carrie-Ann described the history of her mother's placement to the long-term care facility. Her depiction is very representative of the stories told by many of the adult daughters regarding the many moves that older adults often have to make before a suitable facility is found:

> So, she went into a retirement home from May through to, well she was there until about October and she was having a lot of problems coping. They couldn't handle her, they tried different medications, they couldn't seem to stabilise her. They put her into [a] hospital to see if there was something organically wrong and they really couldn't come up with a definitive conclusion apart from senile dementia. But they felt that her decline in her mental state was more rapid than it often is so they put her into [another] hospital for a period of time, in the psychiatric unit there to do some more testing. What it amounted to basically was that they worked on medication to see if they could get something that would work with her better. So, she was at that hospital from the end of October through to almost the end of November. There was no way that she could go back to the retirement home because she had been trying to leave there, it was not a secure facility. So, she had to be in hospital until they could find a nursing home bed for her and at the end of November they found a bed for her at a [Homes for the Aged in the area]. So, she went to [that facility] and she was there from the end of November through until the beginning of August of this year. At that point she had been on a waiting list because that facility was not our first choice of home for her and at that point I had to decide. A bed came up here and I had to decide whether I should move her. That was another difficult one because she, I wouldn't say that she was happy where she was but she was kind of settled, you know. She was used to the staff as much as she could be. At the time it happened my sister was away at the cottage. They don't have a phone there and I couldn't contact her and it was kind of, um, it fell on me to make the decision whether she should move or not. And, I thought it over carefully as to the benefits and the things that I didn't care for at the [prior facility] and I decided, yes, that we would move her here.

Carrie-Ann's mother had been living in the facility for approximately three months at the time of my meeting with her. At the time of her interview, Carrie-Ann was in an early temporal phase of her institution-based caregiving career.

Similar to many of the women I talked to, Carrie-Ann discussed how her role has changed over the years in the care of her mother. In fact, both Carrie-Ann and Margaret talked about how their roles have reversed. For example, Carrie-Ann reflected:

> Well, [my role] certainly has changed a great deal. When my mother was an hour and a half away from us we didn't go to see her that often. It was special events kind of thing and we would talk to her on the phone and that kind of thing. But certainly I wasn't always dropping in on her. Now my sister was, she was across the back fence so she was there to support her more and to make sure that everything was going all right. But that was more of, it was a distance thing. Now my sister, she comes about once a week to see her because she is retired now and she is a little freer than she was before she retired, to visit. So our roles have kind of reversed.

Carrie-Ann now saw herself as the primary caregiver to her mother and her sister was more of a visitor. When I met with Carrie-Ann's sister Margaret, she agreed that her role now was more to support Carrie-Ann as the primary caregiver and to visit her mother weekly.

Carrie-Ann is now intensely involved in her mother's care. She usually visits her mother five times a week and at the beginning of her interview described for me why she visits so often:

> I guess the reason I do come so often is that my mother was used to having the support of my sister being around, close by and she is cut off from everybody that she knew before. Like, she is so far away from friends that they don't come and visit her. So I feel that I can, just by coming, I can be some support… I see myself as a support I guess for my mother… It is somebody that she knows, that she is familiar with. So, if I do nothing more than that even I feel that I have done something to kind of help her, her feeling of some sort of a security, whether it is, or not. But that is part of my feelings with why I come.

Carrie-Ann needed to "be there" for her mother, to be her mother's support system. She saw her role as providing a sense of the familiar for her mother. By being at the facility and with her mother often, she felt that she could maintain a sense of normalcy in her mother's life. Her mother was used to having a daughter close by and visiting often, therefore, it was important to both Carrie-Ann and her sister that one of them "be there" for their mother regularly, if not daily.

In her description of a typical visit with her mother, Carrie-Ann also talked about the activities she does with her mother to further provide some normalcy in her mother's life:

> When I come, I talk to her about the family, I sometimes bring pictures. We have pictures in her room that have family members and I will go over them with her ... I will bring her in little treats to eat. She was always somebody who liked sweets so I will bring her in some chocolate or a donut or a donut and some coffee or something like that .... I will bring something like that in because I realise that she doesn't get them most of the time. So I do that ... She was a school teacher and she used to like to do word puzzles. The last few years she used to have books of them and so I continued doing things like that with her. It got to a point though that now she tends to jumble everything all up so I can't really see the value in doing it now. It would just be confusing for her. But, I will do, and my sister does as well, she will come in and play little word games of X and O's, different little games. I will have her play solitaire and I will watch what she is doing and she has gotten to a point where she could do that very easily before but she has gotten now so that she doesn't do things, uh, she doesn't do it in the right way or she gets confused so I will help her, help her go through the game. She enjoys doing that kind of thing.

Carrie-Ann's narrative also indicated how she places much importance in her monitoring role. Being at the facility regularly allows her the opportunity to observe the staff with other residents as well as with her mother and to gauge how her mother is cared for when she is not around. She explained her need to monitor her mother's care as follows:

> I guess I feel that I like to keep an eye on what is going on. I think you always hear horror stories of nursing homes and I feel that by coming in I know a little bit better what is going on and how the staff is treating other residents that I see and it gives me a better handle on just what they are doing, who are the ones that, if I have a problem that I see, who are the ones that I can go to that I feel I might get results from. They have been very good here. I haven't had a lot of concerns and when I have brought up a couple of issues they have been dealt with very promptly. [Member Check Insert – If I felt that she was being neglected or abused, I would complain. I find it helpful to watch the interaction with staff and other residents as well. I can see how residents are being treated by staff. I can also see how the residents react with each other.]

Along with maintaining normalcy and monitoring her mother's care, Carrie-Ann also described a final purpose of her involvement: preserving her mother's sense of self. Throughout her story, she elaborated on how important it is to her that her mother is treated as a person, an individual. Carrie-Ann, however, stressed how characteristics of the facility and staff can influence the degree to which a resident is treated as an individual. According to Carrie-Ann, it is crucial that the staff also be involved in preserving each resident's personhood. She described her thoughts on this issue:

> Well, if I was to compare this to the other home that she was in I feel that here there is more, that she is being treated as an individual more. That is important. Where she was, she was in a much larger unit and because of that I don't think that there was as much individualised care. And that is a concern for a lot of family members that you want your family member to still be looked on as a person and not this blob to be put here and put there. Mind you, I think the staff in the other home were caring, it wasn't that I would fault them at all it was just the sheer numbers of people. I think that the larger the number, the harder it is to give individualised care. So that is an issue that I have noticed.

Her mother's final move to this facility has given Carrie-Ann a little more peace of mind, nevertheless, she still feels the need to be at the facility often. Throughout her story she continually emphasised the need she feels to have a presence in the facility. Much of the caregiving literature has talked about the reversal of roles when an adult child takes on the care of a parent. The adult child becomes the protector and the parent becomes the protected. In summarising what her involvement in the facility caring for her mother means to her, Carrie-Ann described her role in a similar manner:

> Well, it means that I can support her and look after her. I guess in a way, that we have now reversed roles and often you hear that with people that as their parent gets older you feel like they are more of the child and you are the parent. I think there is some of that, that you are a support for them, you are looking after their care and making sure that they are getting the type of care that you think is appropriate for them, that they are being treated as an individual, that they are safe, that you are doing things that can make them as happy as possible, that you are giving them some stimulation and helping them to see that there is caring there for them, that they are appreciated and that you see them as a spiritual being.

Her need to be more actively involved in her mother's care may have something to do with her perception that her mother still very much exists for her, or at least continues to recognise Carrie-Ann as her daughter. She did talk, however, about how difficult she feels it will be on her when her mother no longer recognises her. In comparing her role as a daughter caring for a parent with the role of a spouse caring for a husband or wife, she expressed her concern about the future:

> I think maybe as a daughter I find it easier than, I often look at women who have husbands in here or vice versa and I think it is more difficult for spouses than it is for daughters. When I see people, the spouses and just how devastated they seem to be at times when their loved one doesn't recognise them or that they are walking around with someone else and thinking that it is their husband or wife, that would really be difficult. I realise probably the difficult thing will be when my mother doesn't recognise me at all.
> ***So she [your mother] still knows who you are?***
> Ya. That could be difficult.

Carrie-Ann's mother very much still exists for her. Thus, she places great importance in all three of the purpose themes: maintaining normalcy, monitoring her mother's care, and ensuring her mother's sense of personhood is maintained.

Carrie-Ann also emphasised in her story how her support role also extends to the staff of the facility.

> I like to feel that I help to support the staff in that I am doing some of the things that they would have to do if I wasn't here to do it, like tidying up the cupboard or finding my mother's teeth. Because they are always having to do that for her and if I come in a little more often it allows me to do, to take away some of it for them, that I am doing some of those things.

In her role, Carrie-Ann felt that she was doing some of the tasks that the staff also did. When asked if she considered herself a caregiver, she responded, "Yes, because I am doing things for her that the home here does". Those activities included "mental stimulation, caring for physical needs, and emotional support" which she felt the staff did in a more limited way. In her description of a typical visit with her mother, she also talked about some of the tasks she performs so that the staff does not have to do them:

> I generally go through her closet to check to see if things are in order, if they are hung up. They tend to be just plopped down and so I will hang them up and make sure that her closet is straightened out. I generally end up either looking for her teeth or her glasses or her shoes, it is a usual thing that she doesn't have at least one of those items and sometimes not any of them and probably 15 minutes after I am gone they are gone again too {laughter}.

Carrie-Ann also participates in the weekly sing-a-long with her mother. Although her mother never used to sing, she now enjoys the activity very much. Carrie-Ann likes to be there to hold the book for her mother so her mother can read along with the words of the songs. She feels this is another good way of providing her mother with mental stimulation. If called upon, Carrie-Ann will also take a more direct role in the program. She teaches music and told me that when the woman who runs the sing-a-long is unable to make it, she will replace the woman at the sing-a-long. The Director of Nursing Care also emphasised in her meeting with me how much they rely on family members like Carrie-Ann to provide these types of activities within the facility.

Carrie Ann further reflected on her thoughts regarding the importance of the presence of family members in the facility. She feels this is important for all residents, not just her own mother. Thus, as part of her role, she visits with other residents when she is at the facility.

> I think that because I am a family member that there is a closeness there with my mother that they can't have, that they don't have time always to talk to people and take time to soothe them. Some staff are better at that than others but there are a lot of people that I see that they don't always have family coming in that are very lonely and that when I come in I will talk to them and say hello and call them by name. So it is not just my mother that I come in and talk to, I will talk to some of these other people that I don't see family always there.

In fact, Carrie-Ann emphasised how one of the most pleasant aspects of her role is when she knows that both her mother and the staff appreciated what she was doing in the home; that is, the role that she was playing in her mother's care. In her interview she explained this for me:

> Well, I think it is when my mother does seem to appreciate, when she lights up when I come in, that she seems to appreciate things that I do or even that the staff seems to appreciate that you have done something and taken away their necessity to do it. Like sometimes when I come in she needs to be changed or that kind of thing so I will do that, if I happen to get here at the time, she looks wet, then I do that.

So, in her attempt to protect her mother and other residents, Carrie-Ann continues to visit the facility almost daily. She sees herself as an important component of the care team and in that role continues to provide support to both her mother and the staff. She often takes on tasks that are the primary responsibility of the staff and has taken an active volunteer role in one of the recreational activities in the facility. Carrie-Ann defines her role in terms of the three purpose categories. In trying to maintain some sense of normalcy in her mother's life, she visits her mother often to provide a familiar face for her mother in the facility. Carrie-Ann also sees "being there" as maintaining continuity of an aspect of her mother's life from the past – continuing to have a daughter close by on a regular basis. Maintaining normalcy for Carrie-Ann also involves maintaining her mother as part of the family unit and providing foods and activities familiar to her mother. Monitoring her mother's care is another important aspect of Carrie-Ann's role within the facility. She does this by "keeping an eye" on the staff, her mother, and other residents. She also speaks to the staff when concerns about her mother's care arise. Related to maintaining her mother's sense of self, Carrie-Ann spoke of the importance of ensuring her mother is treated as a human being, with respect and dignity. Carrie-Ann still takes comfort in the fact that her mother still recognises her and that her mother's personality is still present in the woman that she visits. Nevertheless, she anticipates how difficult it will be when her mother is no longer able to recognise her. Finally, in comparing the facility her mother now lives in with the facility her mother had previously lived in, Carrie-Ann expresses much more satisfaction with the care her mother is receiving. She particularly appreciates that her mother is being treated more as an individual. Nonetheless, Carrie-Ann's story was still filled with a sense of pressure she felt to be at the facility often. My sense is that this pressure comes mostly from Carrie-Ann herself and the feeling that her sister cared for so many years, it is now her turn to care. In addition, both Carrie-Ann and her sister Margaret spoke about how their mother was used to having one of them around often. Thus, Carrie-Ann feels that she needs to continue to do this for her mother.

Second Profile of an Active Monitor: Alice's Story

Of all the women I talked to in this project, Alice was by far the most intensely involved. Her whole life seemed to revolve around the care of her mother. This role, however, was not new in Alice's life. In her story she emphasised: "I have looked after parents for 30 years since my husband died. My whole life has involved looking after parents. My mother was always sick". Alice was very uncomfortable with her interview being taped and so we agreed to conduct the interview without the tape. I documented her story by taking in depth notes during the interview and by making note of my reflections in my research log after the interview. This profile is based on those notes.

Alice is in her 60s, is widowed, and works part-time as a property manager. Her adult daughter lives with her in the family home. Alice has one sister who lives approximately an hour away, but this sister is not nearly as involved in the care of their mother as Alice is.

Consistent with the many adult daughters with whom I spoke, Alice's role has changed significantly over the past several years. Her mother lived with her in her home for about two years. At that point, caring for her mother affected many other aspects of her life, particularly as her caregiving role became a 24-hour job. When Alice turned to the community agencies for assistance, her mother was very resistant of this help. Alice stated that her mother wanted her to be at home with her all day long and this gave her little time for herself. She reflected: " I didn't have time for myself or my friends. It was very difficult". As her mother became a little more difficult to care for, Alice moved her mother to a retirement home in the area. She continued to make her mother all her meals and bring them over to her mother daily. Her mother lived there for approximately one and a half years. Six months prior to moving to the facility her mother now lives in, Alice's mother was admitted to the hospital. When her mother was in the hospital it was still very difficult for her as she felt the need to be at the hospital twice a day to help her mother eat. Again, she felt she had no time for herself. It became more and more apparent that her mother needed more care than the retirement home could provide and the staff at the retirement home told Alice that they would not be able to take her mother back. Fortunately, Alice was able to get her mother a room at the facility involved in this project and, at the time of the interview, her mother had lived there for three months. Alice was in an early temporal phase of her institution-based caregiving career.

Having her mother admitted to the long-term care facility did not seem to lessen the sense of burden Alice was feeling. As I mentioned earlier, Alice was the most intensely involved of all the adult daughters I spoke with. She visits her mother every day and spends most of the afternoon with her mother. She also does all of her mother's laundry every evening. She described for me how caring for her mother still affects her life to some degree. She told me that she goes to the long-term care facility every day and spends the afternoon with her mother when she could be doing something else. She never goes away on vacation because she does not feel that she can be away from her mother for any length of time. "There is no way she could survive without me. If I go shopping and she phones and I'm not there she gets very frightened and starts phoning all over for me". Alice described for me how she feels that caring for her mother is a real pressure on her and yet how she feels that it is her responsibility as a daughter to do it.

During the interview it became very apparent that much of the pressure to "be there" was coming from what Alice perceived to be her mother's expectations that she be there regularly. She told me that her mother expects her to be there everyday, that her mother had been quite explicit about that. Much of this expectation was based on cultural belief systems. Alice is Polish and told me that in Poland it is expected that daughters will care for their parents. Alice's mother has asked her time and time again: "In Europe, my mother took care of my grandma, why am I not with you?" Having to place her mother in a long-term care facility brought much guilt for Alice, particularly since her mother became very angry and bitter after the move and Alice feels that her mother has not been happy living there. Alice feels that it came to a point where she had to weigh her needs with her mother's needs and feels more comfortable with her decision now: " I'm okay with that now. I got to the point where I was sick. I couldn't do it any more. I had to think of my own needs".

So, the largest part of Alice's role is just to "be there" for her mother, to provide some familiarity in an otherwise unfamiliar world. "Being there" extends beyond the facility in Alice's case. Alice's mother often phones her at home, at all hours of the day. She described for me how her mother often telephones her at home: "It is stressful. Sometimes she calls at two or three in the morning and wakes me up and then I can't get back to sleep". I saw evidence of how Alice's role permeated to her home in my meeting with her. When I arrived for our interview, Alice was on the phone with her mother and seemed quite frazzled when she got off the phone. Shortly after that, the phone rang again but Alice hung up the phone quickly. It was her mother again. Alice was also in the midst of doing her mother's laundry when I arrived. Providing normalcy in her mother's life also involves taking in special snacks for her mother each visit, providing companionship by spending time and chatting with her mother, and attending the church service with her mother.

Alice also emphasised that a large part of her role involves being a "voice" for her mother. This aspect of her role was very much related to both monitoring care and providing a sense of normalcy in her mother's life. Alice's mother is still cognitively alert and quite able to communicate with Alice but only speaks Polish. The facility has two nurses who speak Polish; in fact, that is one of the main reasons why Alice chose this particular facility. Those two nurses may not be in everyday and so she feels she needs to be at the facility daily to ensure that her mother's needs are being communicated to the staff. She told me that she worries her mother's needs may not be met if the staff do not understand what her mother is trying to say. Alice also feels that the language barrier could be contributing to her mother's sense of fear in the facility and by being there she can provide a sense of security for her mother.

Alice also places much importance in her role ensuring that her mother is well looked after and receiving proper care. She makes sure to talk to the staff when she needs something or has a concern. She also emphasised, however, that she will only talk to certain staff members about concerns. Related to this, Alice told me that she feels that the care provided in the facility is generally “not bad”. Nevertheless, her narrative was full of reflections of her strong sense of concern for her mother’s well-being. For example, she described how worried she is about her mother falling. She said that sometimes the staff members bring her mother into the middle of her room in the wheelchair and then leave her standing there and her mother is unable to move. Her concern is that one of these times her mother will try to move herself, fall, and seriously hurt herself. Also, her mother has told her that the nursing staff sometimes transports her to and from her bath naked. It appeared to me during the interview that Alice was quite worried that there may be some truth to her mother’s complaints. My sense from her narrative and her description of the home was that Alice did not seem to be as satisfied with the care being provided in the home as were other family members. Coupled with Alice’s perceptions that her mother expected her to be at the facility daily, she seemed to express in her story an intense pressure or obligation to be at the facility daily.

Unlike other active monitors, Alice never explicitly talked about her role in terms of supporting the staff as well as her mother. Her story, though, very much depicted a woman who was directly involved in many activities the staff would be doing if she were not there regularly. In fact, some of these tasks, like the laundry and the housekeeping activities she performed at the facility, were still perceived by Alice to be primarily her responsibility. Of course, having to speak for her mother made her a crucial member of the health care team. In my reflections after the interview, it occurred to me that taking a more direct, hands-on role in the care of her mother perhaps helps Alice reconcile having to admit her mother to a long-term care facility.

Alice continues to visit the home daily feeling that her mother would be incredibly anxious if she did not show up one day. Alice tends to define her role within the facility in terms of two purposes: providing some sense of normalcy in her mother's life, and monitoring her mother's care within the facility. Alice primarily provides a familiar context for her mother by "being there" for her mother both at the facility and at her home. A more crucial aspect of her role involves being a voice for her mother, being there to ensure that the staff understands her mother's needs. Monitoring care also involves communicating regularly with the staff about any concerns she might have about her mother or her mother's care. Unlike all the other active monitors who specifically spoke about their role in terms of supporting the staff as well as the parent, Alice did not explicitly talk about supporting the staff as an important component of her role. By weighing the intensity of her involvement in her mother's care, the many hands-on activities she performs that the facility often takes responsibility for, her emphasis on the importance of her being a voice for her mother, and her intense sense of pressure to be at the facility daily, I came to the conclusion that Alice and the way she perceived her role fit more with the active monitor manifestation than the regular visitor manifestation.

Summary of the Active Monitor Role Manifestation

Both of these profiles are representative of the active monitor role type. Consistent with other active monitors, both of these women spend a great deal of their time at the facility, often performing tasks and activities within the facility the staff are often responsible for. These women, at least to some degree, view themselves as an important component of the care team. Further, active monitors define their role not only in terms of supporting their parents, but also in terms of providing some support to the staff members within the facility. In supporting their parents, these women focus their energies in at least one of three purpose areas: maintaining some sense of normalcy in their parents' lives, monitoring the care their parents are receiving in the facility; and maintaining their parents' sense of self.

Active monitors also feel an intense pressure or need to be at the facility often; however, the source of that pressure can vary. For example, Carrie-Ann's need to be involved in her mother's care seemed to stem from her own sense of obligation as a loving daughter and the recognition of the importance of maintaining a valued tradition in her mother's life; that is, having a daughter close by on a regular basis. The pressure Alice feels, on the other hand, appeared to stem from her perception of her mother's expectations for her. Her mother's constant reminders of the way older adults are cared for in Poland further contribute to Alice's sense of guilt.

Also common to the active monitors manifestation is that the women in this group tend to perceive that their parents' personalities are very much still there. As will become evident in the description of the less involved family members, the thereness of the parent appears to be a major factor in the continued involvement of the adult daughters in the facility. Finally, active monitors, much like Carrie-Ann and Alice, are all in very early phases of their temporal caregiving careers in this particular facility. Perhaps as time goes by and their perceptions change, these women will feel more comfortable relinquishing some of the care they currently provide to the facility.

First Profile of a Regular Visitor: Sarah's Story

Sarah is in her 50s, is married, and has three grown children. She keeps very busy running the two businesses she owns. Sarah's sister lives about an hour away and is also very much involved in the care of her mother. In Sarah's story, there was a clear sense of a shared role between Sarah and her sister in caring for their mother. Sarah's sister also agreed to take part in the project and, when I met with her, she also described the care of her mother as a shared venture between her and her sister. In fact, Sarah talked about how important family was to her and how tight her family was.

> See we're a very close family too. There were just three kids and my mom and dad. My mother came from a very large family, my father from a very small family, and we travelled a lot so we were a family on the move all the time. So, we became very, very strong as a unit. If one member of the unit was off whack, all of us were off whack, so we were very, very close.

She discussed how together the family worked through various problems or issues that would come up regarding the care of her mother and her father when he was living. Sarah's brother lives in the United States and also has played a role, although somewhat more minor, in the care of his mother at various stages in her illness.

When I met Sarah, she had already given a great deal of thought to various aspects of her role in the care of her mother. She described the history of her caregiving role with great detail recalling the building in intensity of the role as her mother became less and less able to care for herself in her own home:

> [Mother] got to a point where she just couldn't cope with anything and took to waking up at night. So we started thinking that this must be Alzheimer's. Her physician said definitely Alzheimer's but nobody is paying attention to signals. Anyway to cut a long story short, dad died in September of '92. From September until January I would bring my mother home to stay with me. At the end of a week she would want to leave because of course she missed her own home. I have a very nice guest room but it wasn't anything to her. And, then she would get home and she would want to come back. So, my sister and I took turns because my brother had to go back to Pittsburg and get back to his business and I had to start getting back to my livelihood too. So my sister and I ended up taking turns and, you know, it is crazy when I think of the amount of energy and time that it took and it wiped out my sister. I think my sister suffered a great

> deal. I did too. So, I am not just thinking of her, but mother this whole time is not getting better. So we, I said to my sister and brother, "well look, I run my own businesses so I can withdraw from them now and again without them falling apart. Why don't I bring mom home to live with me because that is what dad wanted originally". Well then my brother said, "well let's talk to the medical people first. Let's find out maybe it would be better if you got her into a retirement apartment close to you. You can see her everyday on your way home from work". We started talking about this and thought gee this would be great. So, I went to [a retirement home] and they said all we would need is her doctor's certificate and her medical history. So, that was fine, we took mom to [the retirement home] in January 1993. She was quite happy there. Well it took her two weeks to settle in.

Sarah and her sister took turns caring for their mother in the community for about five months before their mother moved to the retirement home. Sarah's mother remained at the retirement home for about three months. During that time her mother began deteriorating and the administration at the home finally decided that they could not provide the more intense care that Sarah's mother needed. She had left the retirement home a few times on her own and the staff was becoming more and more concerned about her safety. So, in May of the same year, Sarah's mother was moved to the facility in which she now lives. She has lived in the present facility for 2 years, 6 months. Thus, at the time of the interview, Sarah was in a later temporal institution-based caregiving career phase.

One of the most vivid images in Sarah's story was her depiction of the move of her mother to the long-term care facility. She described events surrounding the move in great detail. Sarah still recalls the pain she and her family felt on that dreadful admission day:

> In short, [admission day] was tense, exhausting, and not done well. I think this is probably where my sister's and my last grain of guilt is left. It took a lot to get her to [the retirement home] and now [the retirement home] doesn't want to take responsibility for her because they have a feeling that she's going to start wandering around. So, when it came time to come here my sister and I would look at each other, we're sitting and saying now how do we manage this?

> So, we rented a van, and we said, Okay, now we've got the van this is how it's going to happen. I will go over to the retirement home and pack up. My sister will take mom out for a drive in my car. I was to pack up some of the stuff so that mom wouldn't be able to see. Then my sister was going to come. I would take mom out to my house for tea or whatever and my sister would move the first load of stuff in the van. Well it took a lot longer than we thought, so in the end, this was the circus of all time. My mother didn't have a clue she was moving. That's the biggest mistake that people make is you're thinking well she seems to not be with it today, this is a good day to move her. …Well we bring my mother and first thing she says is, "You're putting me away" ….and all of a sudden she's not going in and that's when it hit me that we did it all wrong. We took advantage, we did what the experts said. I thought, no, we're going to stay at my house for a month, we're going to think this over first but I'm not an expert. I don't know what to do. My sister's not an expert, we listened and they said just transfer her straight over there as fast as you can. That's what we did, literally. Bad news, first couple of weeks, she was just absolutely hysterical and if we took her out she wouldn't come back in.
>
> …I didn't know I could cry that much. I mean I did not know that you could have that much guilt and pain because here's this little tiny person behind a door she can't open. She hasn't got a clue where she is, she's probably thinking what did I do to deserve this. And, she can see her two daughters, who she loves on the other side of the glass saying have a nice day. Oh, [my sister] and I, we cried and my sister was so upset. Both of us were.

Sarah's guilt continued for many months after the admission of her mother to the home. She absolutely hated having her mother there, the pain she was dealing with seemed stronger than ever, and because of these feelings she felt a need to be at the home often. She described for me those first few months at the home:

> My husband said that for six months our lives were predicated on what kind of day [my mother] was having and it was true. The first six months were hell. I just hated it and I didn't like the Alzheimer's unit, not the people, it was just, no matter what they did to make it cheerful, somebody would take it down. People would plant flowers and they'd dig them up. It's not their fault but I found it so… and I used to think *I* did this, you know, back to my duty and responsibility. Then the pain when one day my mother just cried in my arms and I thought we'd take her home, that's it. So I did. I just walked out with her. They said are you going to be gone

> long? Oh I said, she'll be gone for a couple of days and I just walked out and I thought, I'm not ever taking her back there. We got in the car, we went home, and she had a wonderful dinner. We sat down, we gave her a glass of wine, she's not supposed to have wine, and she went to sleep like that. And, of course the next day she wanted to leave. Then my husband, who is a very logical person, said "So now what? What are you going to do on Monday when you have to be in Thunder Bay?" And, I brought her back on the Monday, crying all the way. It's the hardest thing that… I think people like the geriatric team who are doing a fine job also need to be able to help the non-experts by saying you don't have to make this decision within 48 hours. My sister and I just felt like they were all saying *now*!

Given her circumstances, Sarah was forced to try deal with the situation, to try and accept that her mother now lived at the facility and that there was nothing else she could have done. In her story, nonetheless, Sarah described how the move to acceptance was a very long, painful process with many changes in her role. Sarah's mother was first admitted to the Alzheimer's Unit within the facility. Sarah saw her mother deteriorate rapidly in the Alzheimer's Unit. This contributed even more to her guilt and she felt a need to be at the home often to monitor her mother's health and care. When her mother was moved out of the Alzheimer's Unit and to another floor, Sarah felt that her mother was beginning to show many improvements. Within time, Sarah was able to become much more comfortable with the facility and the care her mother was receiving in the home. She gradually was able to relax somewhat and relinquish the hands-on, direct aspects of care and to step out of the parent-type protector role and concentrate on visiting.

In her member check, Sarah emphasised that having gone through that process, she now saw her primary role as one of providing "love, care, practical support and some semblance of family". When asked how she defined her role now in the care of her mother at this facility, she stated:

> I am just participating in mom's life I think. I come and I don't do so much caregiving because I have learned that a lot of what [the facility] does is dead right. I don't have to get so much involved in that kind of thing you know. I will change her diapers but I think my role is really to be with my mother. I think my role is to visit, chat, provide her with some humor. Sometimes she makes me laugh so hard I don't have to provide anything but I think it is just being a person with their mother in a very natural way as opposed to a very.... in the beginning I think it was very artificial because the angst we were all suffering, not my brother.... But I guess my role is just to be with my mother. I enjoy her, you know, I really like, I like my mother.

Her focus now is on "being there" with and for her mother, just visiting and enjoying the visits and her mother. Sarah explained: "But I guess my role is very changed, I am just being a daughter again". Focusing more on just being a daughter again was very important to Sarah in her attempt to maintain some sense of normalcy in her mother's life.

Consistent with this perception, Sarah's visits with her mother now focus on enjoying each other's company. She described to me a typical visit with her mother:

> I usually come in and I check her out and see how she's doing. If it's nice weather, we go outside right away. My Mother loves the outdoors, she had a beautiful garden, so from May to October we're not even in here, we just go outside. Sometimes we go to a shopping mall. Most of the time this year, she didn't seem to be as strong physically, mentally as alert as she could be. So we just walked down the street to the church and walked back or sat out in the front or out on the balcony and talked about being outside and in the summer we looked at her plants that she has in her room and we fix them up. We talk, we usually talk about how she is and I always ask her how she's feeling and sometimes she'll say "the same as yesterday" or "I'm not feeling so well today". So we usually sit, there's something about when she's in that big room in her chair with the table on, she doesn't like it yet I'll drive her down to her room, take her out of her chair, we'll sit and we'll talk, we'll look at photo albums.
>
> My mother's never really been a TV person. So our visits I think are probably really typical mother daughter except when she's very sleepy and then I just sit and sometimes stroke her hand. I give her a lot of back rubs, she gets a lot of leg cramps so I give her back rubs and foot massages and one of my friends is a reflexologist and gave me some ideas on how to do a couple of things without causing problems.

> So our visits are usually chatty, sometimes depending on her mood. If I sense that she's sad or removed, like it's not what she says, [I can tell from] her behaviour. I can always tell when she's really down, so sometimes I'll just sit the whole hour and we'll hum a couple of tunes, we've danced because she loved dancing when she was young. Now she wasn't dancing like she would have but the rhythm and the sound, she just loved it, so that's sort of our visit, they're just sort of normal mother, daughter.

It became clear throughout Sarah's story that she now perceived her role in more social terms, primarily providing companionship and serving as a recreational organiser for her mother. In this capacity, she now thought of her role as an extension of what the staff were doing in the facility.

Although not to the same extent as she had once done, Sarah also felt that part of her role was still to monitor her mother's care. Her story was filled with ways that she observes her mother, the facility, and the staff as part of her monitoring role. An important aspect of monitoring her mother's care also means keeping the communication lines open between her and the staff. She described for me how she monitors her mother's care:

> ...by asking the nurses about her sugar level daily; by checking with [the physiotherapist] once or twice a month about mom's mobility; and finally, checking what she ate and how well-rested she was or wasn't...I often will ask about mom's situation because I can always tell when her sugar's up high. You get to know somebody. You know when the sugar's wild and I also know when they've given her tranquillisers and I don't like her to have too many of those... So, I'll go to the front desk and talk to the charge nurse and sometimes when [the Director of Nursing Care] is there I get to talk to her. But, they're very good about sharing information.

As part of monitoring her mother's health, Sarah and her sister sought out as much information as they could about their mother's illness. Both of them sent me books they had read in an attempt to understand the situation and come to terms with it. Furthermore, Sarah has always tried to keep records on her mother's progress as well. She explained the importance of this to me:

> I kept records too on Mom's [progress]....especially when they moved her up from the Alzheimer's Unit. I was really concerned, she deteriorated so quickly in the Alzheimer's unit yet when she started to come up here, she started to get better. [The Director of Nursing Care] recognised it and said this is different, your mother should be, if she's genuinely Alzheimer's she should be deteriorating like lots of the other women that I'd met down there, she wasn't. Now she is but this is different, it's not the same, so we're not sure. So I started keeping records of that and the only thing that I was doing it for was mainly me to see if Mom had mood swings ... all I was doing this research for ...was for me to understand first of all the family thing and this illness and then looking at what I could do, if I could see that there was a pattern with Mom so that I'd be able to be more helpful if need be.

A final component of Sarah's role in the care of her mother involves trying to maintain her mother's sense of self as much as she can:

> For me it's, I like to give her a sense of who she is in the sense of where she is now, like we talk about the past because old people are really comfortable with that but with Mom it's always been like that in our family, I mean all the tales for generations have come down, we all know them. So I guess part of that personhood for me is going back and saying to her remember the time when....and she'll say oh yes, and then she'll say, "I had a blue dress on", because she loves clothes, or "I had a pink dress on", so part of that is to make that connection.

On her member check, Sarah identified other ways she tries to maintain her mother's sense of self:

> I always ask her advice about the garden and what to do about the plants. I ask for help in picking out clothes for my daughter or grand-daughter. I used to ask her what she thought about [the facility]. Her answer: "It's not a bad place at all, but I wouldn't have picked it". I guess I was trying to help her with reality testing.

For Sarah, maintaining her mother's personhood primarily involves asking her mother's advice about things in her life. In this way, she feels she is including her mother more fully in her life but also giving her mother opportunities to help with decisions and still play the mother role. Maintaining her mother's sense of self also involves continually reminding her mother who she is and what she has done in her life.

Sarah said that there are several times when she goes to visit her mother that her mother does not recognise her. Dealing with this part of the disease process was difficult at first but Sarah has learned to cope with it and now looks for those positive aspects of her mother that she remembers so well, especially her mother's sense of humor and wittiness. Sarah explained this process to me:

> Sometimes she doesn't know me and I'll joke with her, "you don't know who I am today" and she'll say "no, what is your name anyway?" I'll say "guess" and she'll say "you're a girl (laughing)". But it's more natural now, it doesn't hurt. I could have been brought to tears the first year she didn't remember me and part of that's your own selfishness of wanting life to be the same. Damn it, you just want your mother to be the same. But, now it's just appreciating that every day that she has a smile, comfort, a talk with somebody, a telephone conversation, any of those things are important.

Her narrative reflected a perception of her mother as still very much existing for Sarah. Her descriptions of her mother emphasised a woman still able to hold a conversation when alert, still having a "funny sense of humour", still doing little motherly things for Sarah when she visits like "fixing her hair and fixing the bow on her blouse", and still being able to find and express the "irony and weirdness of everyday life". Thus, despite the fact that Sarah's mother was not able to recognise her much of the time now, Sarah still saw many glimpses of her mother in her visits with her and Sarah's mother continued to be a very important part of her life. This perception of her mother made it even more important for Sarah to be there for her mother regularly.

Finally, when asked if she now considered herself a caregiver, she replied "no" and instead used the terms "daughter" and "visitor" to describe her role. She elaborated:

> I never thought about it. I only started using that when people started mentioning it in here. Never thought of myself as a caregiver, just thought of myself as a daughter, a woman, you know I didn't think of it really, I

> just thought she needed a visitor, I mean I love her, I mean I didn't define it like that.

For Sarah, it took time -- time to deal with the pain and guilt and time to become more comfortable with the care her mother was receiving -- before she could move into a regular visitor role. In a later temporal phase in her caregiving career, her role is now very much more relaxed and focused on more social aspects, on being with her mother, and on providing the emotional or affective aspects of care. In fact, she describes her role solely in terms of supporting her mother and as being an extension to the care the staff provide. Sarah defined her role as having three purposes. Maintaining normalcy in her mother's life primarily involves "being there" for her mother, getting back to just being a daughter and in that role serving as an emotional support system for her mother, trying to continue some of the activities that her mother has always enjoyed, and ensuring that her mother remains an important part of the family unit by "facilitating activities for [her] mom that [they] could do as a family". In her role as monitor of her mother's care, Sarah keeps in touch regularly with the staff, she observes the staff and their interaction with her mother and other residents when she is at the facility, and she tries to document her mother's progress in a log that she keeps. An important aspect of Sarah's role is also to continue to give her mother a sense of who she is and to continue to respect her as a vital human being. Although she does her mother's laundry and will provide direct, hands-on care if needed, she did not emphasise these as important aspects of her role. She, however, continually stressed her focus on providing the social and emotional aspects of care. Although Sarah's mother often does not recognise her, Sarah's story was dominated with depictions of a mother who still very much exists for Sarah. As Sarah's mother remains a very important part of Sarah's life, she continues to be a very involved visitor, visiting her mother three or four times a week for an hour and a half each visit.

Second Profile of a Regular Visitor: Brenda's Story

Brenda is in her 50s, is married to a minister, and has two daughters who are in their 20s. She also works part-time as an accounts payable clerk.

Brenda's mother lived with her and her husband for approximately two years before moving into the long-term care facility. During that time, Brenda and her husband went to live in Calgary for a time and they took her mother with them. While in Calgary, Brenda started noticing some things that did not seem right with her mother. She assumed that the changes she was noticing were just the normal signs of aging. In August of 1987, Brenda's mother had a pacemaker put in and from that point on her mother seemed to decline much more rapidly. As her mother's deterioration continued, Brenda was forced to face the fact that her mother might have Alzheimer's but also had a harder and harder time coping with her mother's behaviour.

> Yes, I think that fall (short pause) I finally faced the fact that maybe she had Alzheimer's and I contacted the Alzheimer's Society in [our area] and got a book and just started reading from it and I didn't like what I read because I didn't like the prognosis, the hopelessness of it. So, I think that it was probably a good thing to do, but it was a bad thing to do because it kind of put me in, in a very bad state. So in January of the following year, I suffered some kind of I don't know whether it would be a nervous or breakdown like that. I just couldn't cope with her. She was always bothering me and I was always trying to correct her. She would say things and I'd try to (short pause) say it's not that way [Member Check Insert – Mother was always hanging over me, watching me, correcting me, asking "are you cold dearie?", wanting to look after me as if I was a young child.] and ...because I really didn't know how to cope with this (short pause), we started thinking then that because I wasn't able to cope with her, that we should start doing something about it.

Brenda's aunt (her mother's sister) was very protective of her sister and did not want to see her sister admitted to a nursing home. So, at that time, Brenda and her aunt made arrangements to share in the caregiving responsibilities of her mother.

> My mother's sister [Member Check Insert – Who is 7 years younger] who she had lived with before was very protective, they've always been very protective of each other and she didn't want to face the fact of having my mother put into a nursing home. So there was a bit of disagreement there because she felt that she had rights as a sister ...and she had known my Mom longer than I had but you know, her opinion was just as valid as mine. But what we had started to because of my situation is we said, "well then can you help look after Mom?" So what we did for most of that year is I would take my Mom up to her place and she would have her there for a few weeks or a month and then she would come back to me for....depending on holiday situations and stuff like that but basically we just took turns and then finally she came to realise just from doing that well she finally agreed that Mom would have to be put into a nursing home ...because some things happened with my Aunt. Like my Mom started a fire in their toaster oven and so I think that kind of scared them and then I think they got, my Aunt, also her husband was not very well so I think that between caring for what my Mom was doing and her husband it was just too much for my Aunt too.

About the same time, Brenda and her husband went away for a week and asked her brothers to care for her mother while they were away. Up until this point, her brothers also felt that their mother was not in need of nursing home care. Having to provide direct, hands-on, 24-hour care changed her brothers' minds. While Brenda was away, they became convinced that there was something terribly wrong with their mother and that none of them were equipped to provide the level of care that their mother needed. The decision to find suitable accommodations in a long-term care facility was made. The facility Brenda's mother now lives in was in the final stages of construction at the time and they were able to get their mother a placement relatively quickly. At the time of the interview, Brenda's mother had lived in the home for 4 years, 6 months. Brenda was in a later phase of her temporal caregiving career at the time of her interview.

Six months prior to our interview, Brenda and her husband moved to the Burlington area but she decided to keep her job and commute back and forth. Since she would be working in the area she also felt that it would be best to leave her mother in the facility she was used to. Nonetheless, she still feels the need to visit her mother regularly, which for her is once a week.

Although Brenda's role has changed dramatically over the years, she now defines her role more in terms of providing the more emotional or affective aspects of care. She described her role now more in terms of "caring about" her mother as opposed to "caring for" her mother. In her story, Brenda described how so many aspects of her mother are gone now but that she places great importance in making sure that her mother knows she is loved, and also in ensuring that her mother receives regular stimulation. Nonetheless, it became clear in the way that Brenda described her role, that her visits are also very much for herself searching for glimpses of the mother she once knew. Brenda described her role now as follows:

> Now, I don't know whether I go for her benefit or for mine. Even though she's not my mother in many many ways, she still is. The physical body is still there and there's still …I guess when I go I feel that if I can get some kind of a spark I call it of some kind, whether it's a spark of recognition of me or just a spark of something I've said or she might have said that does make sense….or if I get a smile out of her just by talking about some things and get her to respond, I feel that I've accomplished something that visit. Most of the times I can get one or the other or both. Sometimes, a few times, there's absolutely nothing, which means, she doesn't know who I am. And often she's very sleepy when I'm there but if she's sleeping you know dozing in her chair, I started bringing knitting with me and so I'll just sit and knit. And then sometimes she'll wake up and say something and I'll just say "I'm still here you know".
>
> ***So, it's just important for you to be there?***
>
> Well, I guess like the Chaplain said, even just to, I just feel that touching her and telling her that I love her, like my Mom always used to love to give massages to people. She wasn't a massage therapist but she had good hands and she would just love to massage people. I know that some of the nurses use

> to say that you know she likes to rub my back and so sometimes I might ask her to you know "Mom, massage my arm" or something and she'll have hardly any strength you know but sometimes even on her own, she'll start going like this (moving or hands and fingers back and forth) or you'll see her with her dress. She'll be doing that ...her hands just seem to automatically do that. But I'll scratch her back and massage but I think that if I can bring her some kind of touch or comfort her ..or tell her that I love her and occasionally she'll respond to that and say "I love you too" you know so even though she might not remember it five minutes later, I'll think that I helped.

Similar to other regular visitors and related to her perception of her role, Brenda described her visits much more in terms of social aspects. In terms of maintaining normalcy in her mother's life, she sees her role as being an emotional support system for her mother. Further, an important aspect of maintaining normalcy for Brenda is maintaining her mother's faith and connection to religion and the church. She emphasised touch, reading or singing to her mother, and keeping her mother up-to-date regarding family news. She described a typical visit as follows:

> Yeah, I usually, when I find her, I come in and I hunt her down and usually she's in her wheelchair...I usually kneel down in front of her, squat down in front of her so we're at eye level...and I say hello to her and give her a hug or um, give her a kiss. Sometimes you know there's, she'll say "Oh hello honey" and so she'll respond and give me a kiss or sometimes there's absolutely no response and she'll just kind of look at me as if to say "who are you" or she'll say something that has to do with just having gotten to you know, seeing each other again. Then I usually take her into her room, if the other lady's not in, if the other lady's there I try to find another spot in one of the lounges or ...one corner of the dining area and just sit with her and try to hold her hand and maintain some kind of a touch with her. I'll sometimes read the Bible to her because she was very very involved in, well she was a very active follower of Jesus and she was very involved in her church and so we would read together or I'll read to her. I try to read most of the psalms because there's a lot of verses in there that she'd be familiar with ...that she's underlined. It's her bible that I read from. So, I read some of the lines she's underlined and occasionally she'll, I'll slow down a bit, and she'll say some of the verse with me and other times I can read the same verse and there's no...no response at all. [Member Check Insert – I am finding now that she responds more to music, singing hymns or choruses, rather than the reading.] And then sometimes I'll pray with her and then I'll ask her just, you know, a few questions. "How was your lunch

> today?" or something like that. If there's family news I try to share it with her. For instance, her sister that I was mentioning to you, she died in June at our place and so I told mom about it because they were close but there was absolutely no response when I mentioned it to her. Didn't seem to twig to it at all so then um a couple of days later I did mention it again and there was a bit of response but not really a negative one for the closeness.

In fact, ensuring that her mother remained a member of the family unit was an important part of Brenda's role. In order to do this, she tries to arrange family get-togethers.

> One of the other things that I didn't mention in caring for her that I do is I like, I try to arrange family do's....for the, to get us all together with Mom, like um at Christmas time perhaps. When she was still with us, we'd try to get the family down for birthday times. And, then since she's been in the nursing home, the first while I would bring her to our family and she'd come to our house and we'd have something. On the last couple of birthdays we just had a party in the home, I set that up and ...then I did something at our house without her after because it was just too hard to bring her out again.....And I used to take her out to, when her brother's wife died, I took Mom, I took her to the funeral, things like that. So if there's family functions or activities I try to make sure she's involved.

Much of this description reflects Brenda's need to provide some sense of normalcy in her mother's life but also her role in trying to preserve her mother's sense of self as much as possible. Later in her interview when she was asked to elaborate on how she tries to maintain her mother's sense of dignity, personhood, or sense of self, Brenda again emphasised how important it is to her that her mother knows that she is not forgotten and that she is loved:

> I think by telling her I love her. I mean she's not, I mean her quality of life is almost nil. She used to wear glasses. Well, they got lost a number of times and then they got broken and then ...so you know she's not wearing them now. She can't see very well, she can't do much, so quality of life is rather, it's very low but I think that if ...if I reaffirm that I still love her ...and that I'm willing to be there and touch her, love her, hug her, um that she's worthwhile. [Member Check Insert -- I don't yell at her at all or speak down to her or use "baby talk". I try to encourage any responses I do get.]

Brenda also described her role in terms of monitoring her mother's care in the facility. If she notices something wrong with her mother she will check with the staff and if she is particularly concerned about something she will make a point of attending the care conferences for her mother. On her member check, Brenda outlined how she monitors her mother's care in the facility:

> [I] visit her, observe her appearance and clothes, watch how the staff treat her, ask questions of the staff, have care conferences, try to express appreciation to the staff, check with my daughter(s) who work(ed) there, [and] trust the staff for all the times I can't be there.

Similar to the other adult daughters' stories, Brenda's narrative depicted the many changes in her caregiving role. Her role went from being a 24-hour a day job in the community to a fairly intense yet different type of involvement when her mother was first admitted to a long-term care facility. As her mother's health, particularly mental health, deteriorated and Brenda's own situation changed so did her caregiving role within the institutional setting. Now she feels that she visits to relieve some of the guilt that she feels for having to put her mother into the facility. But, more importantly her role has shifted to being more of an emotional support person for her mother, providing the personal attention that the facility staff are not able to provide. Much like Sarah's story, Brenda's depiction of her role was focused completely on supporting her mother.

Related to the guilt Brenda had and to some extent still feels, she reflected on how the move to admit her mother to long-term care facility affected her sense of self-esteem and competence. Nonetheless, she also described how going back to work actually helped her cope with her sense of failure and her guilt:

> The fact that I did finally get to go to work in the Fall, after she had been put in was a good therapy for me because it was I think I felt like a failure because I couldn't [keep caring], because of the break-down I had and I couldn't look after my Mommy who I loved so much. And I felt like I had let her down. So I think being able to get back because I had worked in Calgary as well, part-time there as well. I think that getting back in the work force helped restore some of

> my confidence that I could still do some of those things. It helped take my mind off my problems with Mom. I could come here and work and not think about her, think about the problems. So it's been, you know, it's been really good.

Brenda actually recounted for me the process she has gone through to get to the point of acceptance she now feels. Her mother's move to the long-term care facility gave the entire family an enormous sense of peace of mind, however, there is still a process of grieving that Brenda feels she had to go through:

> I think that when Mom did go in there I think that there was a great sense of relief for all of us and the family being so supportive and my husband you know, being supportive too. But 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 they are, the person that you knew is gone.

Brenda, unlike Sarah, had many more points in her narrative where she struggled with the thereness of her mother; that is, whether or not the mother she remembered still existed for her in the woman that she visits at the facility. In many respects the personality of her mother was gone. Not unlike Sarah, however, the physical body was still there and Brenda continued to look for glimpses of her mother during her visits. Also, she emphasised that because her mother still existed, at least in body, it was important for her to continue to be involved in her mother's care and life.

For Brenda, two other important factors in helping her through this long process have been her faith and her doctor.

> You asked me like what has helped me in my role and I left out a very important… Like I'm a follower of the Lord Jesus Christ and my faith and my relationship with God is really what's pulled me through most of it. [Member Check Insert -- By faith I have accepted Jesus' offer of forgiveness and a personal relationship with God. I have committed my life to Him and because His Spirit lives within me I can talk to God in prayer just like a child does to a loving Father. When I feel overwhelmed or anxious I turn to Him. He gives peace despite the circumstances.] And my doctor too, when I went through

> that breakdown. I have a Christian doctor who gave me a medication to take. But he was very understanding and didn't seem to point the finger at me. He'd always try to reassure me, well it's part of your mid life, your menopause and all that, there's a lot of factors here. It could be a chemical thing as well. There are a lot, the change of moving, there's just a lot of things at that time in my life but I think that my Mom was the biggest factor. So, he was very helpful too.

Also being in a later temporal phase in her institution-based caregiving career, Brenda is now quite comfortable with the care her mother is provided in the home and in observing the staff and talking to the staff has come to realise her mother is seen as an important person in the home. Because of this, she can relax in her role and concentrate on providing those aspects of care that she feels she needs to provide: companionship, love and affection. Brenda defined her role in terms of her purpose in the care of her mother and her story contained aspects of all three of the purpose categories depicted in many of the stories of the involved adult daughters. A large component of maintaining her mother's sense of normalcy involves just "being there" for her mother and serving as her mother's emotional support system. Another part of this role is to ensure that her mother remains part of the family unit and also maintains her connection to religion and the church. These activities are also very much connected to trying to preserve her mother's sense of self as much as she can at this point in her mother's disease. A lesser but still important purpose described in Brenda's story involves monitoring her mother's care. Monitoring care, for Brenda, is primarily a visual thing. But, if she notices something wrong or becomes concerned with her mother's care or health, she will talk to the staff about her concerns. Essentially, Brenda's role in the facility was focused on her mother and the emotional and social aspects of care. Brenda's story also described a long process of learning to cope and coming to accept the situation. Watching her mother change and deteriorate over time and realising that she was not able to care for her mother any longer were very difficult aspects of her caregiving process. But, being able to return to work, having a supportive and understanding doctor, and clinging to her strong faith all helped Brenda reach a point where she could find some peace in knowing that her mother is well cared for. Despite the fact that much of her mother's personality is now gone, Brenda's mother still very much exists for her. So, as part of her regular routine, she continues to visit her mother weekly, dropping by the facility on her way home from work.

Summary of the Regular Visitor Role Manifestation

What became apparent in many of the regular visitors' stories was the often long and painful process that these women go through in coming to terms with their parent's illness and the situation. This process is similar to the one depicted by the accepting relinquishers, the role manifestation I will be presenting next. Unlike the accepting relinquishers, regular visitors place great importance in having a presence within the facility, visiting the facility regularly. Regular visitors still feel a need to play a role in their parents' care, often defining their role as an extension of what the staff is able to provide. Thus, in becoming more comfortable with the care within the facility and reaching a place of acceptance, regular visitors turn their focus to supporting their parent. Similar to the active monitors, they do this by finding ways to maintain normalcy and continuity in their parent's lives, monitoring the care being provided in the home, and preserving their parent's sense of self. Unlike active monitors, however, regular visitors tend to focus on the visit, providing social and recreational venues for their parent and the emotional and affective aspects of care. They tend not to define their role in terms of providing the more direct, hands-on types of care the active monitors are involved in. Physical care is generally relinquished to the staff. Finally, in most cases, regular visitors still perceive their parents to very much exist for them. Even when the cognitive impairment becomes more severe, they continue to look for and often recognise glimpses of their parents' personalities before they became ill. This factor could play a key role in whether or not, and when, a regular visitor chooses to move into a more accepting relinquisher type role.

Family Members Less Involved in the Facility: Accepting Relinquishers and Unaccepting Relinquishers

The majority of the adult daughters I spoke with tended to place importance in their involvement in the facility and to define their role in terms of how they perceive that involvement. In fact, as stated earlier in this chapter, a large majority of the women fell into the regular visitor manifestation. Nonetheless, a smaller minority of the women involved in the study did not think about their roles in terms of their active or regular involvement in the facility. These adult daughters fell into the two relinquisher manifestations: *Accepting Relinquishers* and *Unaccepting Relinquishers*. These adult daughters had once been very involved in the care of their parents but over the years had come to relinquish care to others. The women in these two manifestations emphasised for me the diversity of perceptions that one group of caregivers -- adult daughters -- can have in terms of their role in long-term care facilities. These women represented alternative ways of thinking about institution-based familial caregiving roles.

Core Similarities and Differences in the Relinquisher Manifestations

Although active monitors and regular visitors continue to place great importance on having a regular presence within the facility, Accepting Relinquishers and Unaccepting

Relinquishers no longer feel a need to be involved in the care of their institutionalised parents. The adult daughters in both of these manifestations have essentially relinquished all care of their parents to the facility, or to someone else whom they trust. This relinquishment includes both physical and emotional aspects of care. Whereas the active monitors continue to provide both physical and emotional aspects of care and regular visitors typically relinquish physical tasks to the staff to focus on emotional and social aspects of care, the daughters in the relinquisher manifestations perceive very little need (as in the case of accepting relinquishers) or feel unable (as in the case of unaccepting relinquishers) to provide either of these aspects of care. Thus, these women do not perceive any aspect of what they are doing as caregiving, and therefore do not think of themselves as caregivers. The adult daughters in the relinquisher manifestations visit the facility irregularly, accepting relinquishers visiting once a month or less and unaccepting relinquishers visiting once every three months or less.

There are two other similarities between the accepting relinquishers and unaccepting relinquishers. These common themes are both related to why these women, for the most part, choose to relinquish care to the facility or others. First, these adult daughters feel very satisfied with the care their parents are receiving in the home. They are completely confident that their parents are being cared for in the best possible manner and that they themselves would not be able to provide the quality care the facility is providing. Related to this, these adult daughters generally believe that their parents are content at being in the home, are comfortable, and are happy. Rae Anne, for example, described her perception of the facility and the staff:

> [Mother] is getting excellent care...They [the staff] have been excellent, they really have, absolutely excellent. From all of my years in nursing and I have worked in a lot of nursing homes, the last 10 years of my career as a nurse I worked in nursing homes, [this facility] is by far one of the nicest, one of the friendliest. The staff are just unbelievable. They treat the residents like family, they really do. And mother is quite comfortable with them there and she just loves the people that look after her.

Given this high satisfaction with the care provided in the facility, accepting relinquishers and unaccepting relinquishers feel no pressure to be at the facility regularly or to provide a more active approach to monitoring their parents' care.

A second similarity between the accepting relinquishers and the unaccepting relinquishers is the way in which they describe their parents. The women in both of these manifestations tend to perceive the impairment, particularly the cognitive impairment, their parents are displaying to be far more severe than what the more involved family members perceive. Most of these adult daughters talk about their parents as being gone; that is, their bodies are still very much present but the parents they once knew in terms of their personalities no longer exist. When I probed Carol about whether or not she still saw glimpses of her mother in the person she visits, she responded:

> No, I really don't. She's my mother in body...she's there, she's breathing, but she's not my mother.

Thus, most accepting relinquishers and unaccepting relinquishers feel that they no longer have meaning in their parents' lives. There is no longer any need for them to be regularly involved in their parents' care.

Related to the temporal caregiving career phase, the adult daughters in these groups tend to be in later phases of their institution-based caregiving careers. The parents of accepting relinquishers have all been living in the facility for at least four years or more.

Unaccepting relinquishers also tend to be in later phases of their careers or moving into later phases in that their parents have lived in this facility and other facilities for at least two years or more.

The major difference in the stories told to me by accepting relinquishers and unaccepting relinquishers has to do with the way that they define or talk about their roles in the facility. Accepting relinquishers now view their roles as overseers of care which can take on different forms. Typically, overseeing care involves visiting the facility once a month or less and assessing how the facility is functioning and how people are interacting within the facility. This approach is similar to the "visual thing" of monitoring care described by the more involved family members. In overseeing the care their parents are receiving, accepting relinquishers, for the most part, take a very hands-off approach. By this I mean that unlike active monitors and regular visitors, accepting relinquishers do not feel the need to have regular communication with the staff about their parents' conditions and rarely, if ever, take an active role in providing direct care. The metaphor of the guardian angel watching over from above captures how these women view their role within the facility.

Accepting relinquishers' narratives also depict a move towards taking care of self. These family members have typically gone through a long process of learning to accept the situation and their parents' condition. In their stories, they shared the history of coming to terms with their parents' illness and gradual deterioration and how they have moved into a place of acceptance. All of these family members now describe themselves as being at peace with the situation. This move towards acceptance is similar to the process many regular visitors talk about in terms of learning to cope with the situation in more realistic ways. What is different for accepting relinquishers is that they have moved even further along the acceptance continuum to turning the focus to themselves. Essentially, accepting relinquishers feel that they have dealt with the circumstances, no longer feel any guilt, and have moved on to focusing on their own lives.

Unlike the accepting relinquishers, the unaccepting relinquishers are having a very difficult time coping with the situation. Thus, they describe their role not in terms of how they define their role within the facility but primarily in terms of their *experience* in the role. Their stories are filled with descriptions of the extreme difficulty they have in dealing with the circumstances and with the deep pain these women feel. They have a very hard time watching the deterioration of their parents and also find the inability of their parents to communicate any longer very difficult. Some of these women find the facility itself very distressing, not the quality of the care or the physical structure of the facility, but the amount of deterioration and illness they are forced to face with each visit. These adult daughters also feel an intense sense of helplessness in visits – they do not know what to do when they are at the facility or may freeze when asked to perform certain tasks. In Rae Anne's story, she described how her inability to cope actually started affecting her own health. She also described her difficulty in visits:

> I don't really have a role in her [mother's] care. Oh Lord, I don't think I could at this point in time. I went to my doctor here about a year after my husband passed away and I said, look I can't handle this any more. I was getting up in the morning and I was standing in front of the toilet retching my guts out and nothing was coming out and I was in such a state of depression that I just could not cope. ...One time we were there for lunch [my sister and I] and the staff thought that I would like to feed mother her lunch and I couldn't do it. I can't give you an explanation why. I have fed people, especially during the last 10 years that I was nursing and I managed fine. But when it came to feeding my own mother her lunch something inside me just rebelled and I can't explain it. I just froze. Maybe it is

> because I have always seen her so self-sufficient. I find it very difficult to see her this way. And, knowing that any day they could phone to say she is gone, it is almost like a sword hanging over my head (family member weeping).

Because of their difficulty in coping with the visits and their parents' deterioration, unaccepting relinquishers avoid visiting as much as possible, visiting the facility maybe once every three months or less. When they do visit, they seldom visit alone. Avoiding visits or making sure other people accompany them on their visits represent ways that unaccepting relinquishers deal with their inability to cope with the situation. The only role they see themselves playing is ensuring that their parents' care is maintained at the facility.

First Profile of an Accepting Relinquisher: Dora's Story

At the time of the interview, Dora was 68 years of age. Her husband had died 12 years ago of a brain tumor and Dora has been widowed ever since. She holds a Master's degree in education, was an associate professor in the Faculty of Nursing at a prominent University in Ontario for ten years, and then served as one of the Directors of Nursing at an area hospital until her retirement in 1989. Dora had been caring for her mother in her 150 year old home in the country for about five years when she herself was diagnosed with a breast malignancy. At that point she decided that she could not manage caring for her mother and herself at the same time. Fortunately, she was able to get her mother into the facility relatively quickly following her diagnosis and her mother has been there ever since (4 years, 5 months).

Dora talked about how her role has changed over the years from being her mother's guardian, to being relatively intense, to being almost non-existent. When Dora's mother first moved in with her, she felt that she played more of a "custodian" role and gradually became a more direct caregiver.

> ***So how would you have defined your role as a caregiver [when your mother moved in with you]?***
> I was a custodian. I was certainly a custodian for the first probably three years. Mother could manage her personal hygiene, after that she couldn't. After that I was sort of more of a caregiver and that was fine.
>
> ***Was that more intense?***
> Yes, because she just forgot more and more. More and more of her training and more and more of her ability to function, she was losing.

When Dora's mother first moved into the facility, she visited her mother once a week. Gradually her visits became less frequent as she began relinquishing care to the facility. Now she visits the facility about once a month to ensure that her mother's care is adequate. When asked to describe her role in the facility now she talked about her role in terms of overseeing her mother's care:

> My role is only to see that she is given the care that, to say that we could afford sounds unkind, but it is her estate and her money and it should be spent appropriately and we think it is. Like when you do everything else you look for value for your investment and that sounds unkind and callous but I think that is where I see my role now.

When asked what types of things she would do to make sure her mother is getting value for her investment, she replied:

> Very little really. I worked all over the North American continent, and here, and I think I get a sense of how the place runs. It is a little like before I was an administrator, I was an operating room nurse and I would always say give me 10 minutes with somebody in the OR and I can tell you how they will function. It is the same sort of thing. That tells me a tremendous amount. I don't need to check for bed sores and I don't need to read the chart and I don't have any difficulty with that.

My sense from talking with Dora was that in gradually stepping away from a more active, caregiving role, she now defined her role in terms of standing back and overlooking her mother's care. She did this by visiting the facility occasionally to assess whether or not the facility was doing their job, providing her mother with quality care. It was interesting to me how she defined her role as overseer of her mother's care in terms of her job as an OR nurse. She adapted skills she had developed and perfected in her training and career to help her evaluate the care her mother was receiving in the facility.

Part of the reason Dora felt comfortable with relinquishing care to the staff had to do with the fact that she no longer felt her mother existed, at least in terms of her personality. Dora's story was filled with descriptions which reflected her perception that the mother she once knew was now gone. When I asked her about her relationship with her mother now, she stated:

> She is no longer here. She really has no personality now, you know. All of the things that were mother are gone. Before, even when she moved in with me, she would forget who we were but her sayings and her thinking were still the same. Now all of that is gone, absolutely nothing, nothing at all.

When Dora went on to describe her mother for me, she focused on the lack of mental capacity her mother now has. She explained:

> I am not sure that it is true but I think that mother is at a stage if we left her in a room and closed the door and never came back she wouldn't even roll over let alone call out. There is no ability, there is nothing that she learned from birth on that she still retains. ....To see the tissue there and to know that there is absolutely none of the personality left at all, it is hard and I am not sure that it is productive. If mother were this way and knew me and my visits produced anything I would come, even if it were difficult, I would come. .....I visit to be sure that her care is adequate because I feel that the visit does nothing for her and nothing for me. She is not at all aware of the fact that I am here.

Unlike the active monitors and regular visitors, Dora no longer sees glimpses of her mother when she visits.

Dora also felt comfortable relinquishing care because she and her siblings have been very satisfied with the care her mother is receiving in the facility. She emphasised her satisfaction in her interview: "I have been very pleased, we've been very pleased with [this facility] and so [my involvement] is really to just keep in touch...We know that she is well cared for".

Over the years, Dora has learned to accept the situation and to move on. Given the circumstances, the only positive strategy in coping with the situation for Dora was acceptance and moving on with her life. She described 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. You know we didn't have any, we worked it all through. There isn't anything that hasn't been resolved. ....What 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 it. I am not going to change the past and I think a lot of ardent caregivers have a problem with that. I know that my mother can no longer help me when I have a breast malignancy, she can't do that. I need to be able to deal with that alone, she isn't there to do that. I need to acknowledge that and move on and the fact that her heart still beats means that I would give up my house to support her in here but that isn't necessary. You know we all feel that we were great when it was time to be great and we can't, we really can't help her any more than this. This is all that she can utilise.

Dora also emphasised that knowing that her mother is well cared for but also that mentally her mother no longer exists have allowed her to move on and focus on her own health and her own life.

Finally, when I asked Dora if she considered herself a caregiver, her response was "no". She does not feel that she is providing any care and for Dora ensuring that her mother is receiving quality care or overseeing care does not constitute caregiving.

According to her, what she is doing is no different than "making sure the furnace works or that the man who is fixing the roof is doing it appropriately". Nevertheless, she did find it helpful to think about her role:

> It is useful to think it through. I was almost pleased when you called because things evolve and you don't really sit down and think, how do I think about myself as a caregiver. I really do not. I guess if someone is being well cared for and they have no mental capacity to recognise the difference between caregivers, I don't know, [to mother] I am the same as everybody else, less because she doesn't see me as much and she doesn't see me intimately.

So, in her role as overseer of her mother's care, Dora continues to visit the facility once a month. By making observations about how the facility is run and how the staff operate within the facility, she is able to evaluate the quality of her mother's care. Dora does not feel any need to have any direct or active role in her mother's care and sees the facility as being responsible for her mother's physical and emotional aspects of care. Dora is comfortable relinquishing care to the facility for two reasons: she no longer feels her mother exists and she is extremely satisfied with the care her mother is receiving at the facility. Over the past four years, Dora has gone through a long process of learning to accept her mother's condition and the situation. She now focuses her attention on her own life and health.

Second Profile of an Accepting Relinquisher: Melissa's Story

Melissa's life situation is quite different from Dora's. At the time of the interview, she was in her 40s, married, had two young children ages two and five, and was working full-time as a legal secretary/law clerk for a local law firm. Unfortunately, Melissa's interview did not tape very well, so her story here is recounted primarily from the notes taken during the interview and from Melissa's responses to the member check.

Melissa's mother was cared for in the community for several years by her mother's common-law partner and a paid helper. In 1991, Melissa got a call from the paid helper expressing her concerns about her mother's deterioration and the paid helper's increasing inability to provide adequate care. Melissa became concerned that her mother's common-law spouse was no longer able to care for her mother's needs and arranged for her mother to be taken to a hospital. At this point she became far more intensely involved in the care of her mother. A few months later, her mother was transferred to a special geriatric ward in a hospital in another city awaiting the availability of a bed in a long-term care facility. A few months later, her mother was transferred to a long-term care facility in the city where Melissa lives and 6 weeks later was transferred to the home in which her mother now lives. Her mother has lived in this facility for four years, two months. At the time of our meeting, Melissa was in a later temporal phase of her institution-based caregiving career.

Like Dora, Melissa spoke of how her role has changed dramatically over the past several years. "It is incredibly intense when you first go at it", she said. For the time before her mother moved into the home and for the first year or so in the facility, she felt overwhelmed and unsure of how she was going to cope with everything. Most of the time she felt quite anxious. In her member check she wrote: "There were court appearances, decisions about her possessions, the disappearance of certain possessions, and the other emotional family members who were acting out yet needed support and comfort". She felt so responsible for her mother's care, that she put through a legal application to get control of her mother's affairs and also sued her mother's common-law spouse in order to be able to sell the couple's home so she could provide proper institutional care for her mother. Although she felt most responsible for her mother's care, she stressed that she included her mother's common-law spouse and her brothers in a lot of the decisions that had to be made.

Melissa also described several traumatic experiences which she attributes to the caregiving experience and the stress she was feeling in her early, community-based caregiving role. For example, when she was moving her mother out of her house she was in an accident, wrecking her husband's truck. More traumatic for Melissa, however, was the extra-marital affair that her husband had in 1992. She is convinced that the affair happened because she was so immersed in the problems with her mother, her mother's care, and the care of her young children (1 and 4 years old at the time). She described her caregiving activities as very intense at that time. Her perception is that her husband was feeling neglected by her intense involvement in her mother's care and so turned elsewhere for what he needed. In her member check she expanded on what she was feeling at the time: "There was a sense of my husband being in the most advantageous position of independence that it was easy to make the decision, that in the short term he could be spared that attention".

Melissa and her husband were separated for two and a half months but she described how that episode forced her to make some changes in her life and to turn her concentration towards preserving her own immediate family. The episode in Melissa's life lead to the gradual relinquishing of care – physical care to the facility and emotional aspects of care to her mother's common-law spouse.

When asked to describe her role now, Melissa talked about her role in terms of overseeing care, and similar to Dora, adapted skills from her career to help define her role in her mother's care. Melissa works for a law firm and has been trained to deal with legal and financial matters. Thus, for Melissa, overseeing care not only involves visiting the facility to ensure that her mother is receiving quality care, but it also involves overseeing the business and financial aspects of her mother's affairs. She feels her strengths are in these areas so, for her, this role "just fell into place". She feels that her mother's common-law spouse is in a much better position to provide the emotional aspects of care her mother needs because her mother feels more connected to him and because he can be with her mother more regularly. She perceives her mother's partner to be loyal, faithful, and very much in love with her mother. She also feels her mother identifies more with her common-law husband. With that awareness, it was easy for her to completely relinquish emotional and affective aspects of care to her mother's partner. She also stated that she feels the staff also provide her mother with some of the emotional aspects of care.

As far as the physical aspects of care are concerned, Melissa has come to realise that, given her circumstances, she would not be able to provide the quality care that her mother is now receiving in the facility. She expressed much satisfaction with the care her mother is receiving from the staff at the facility. Knowing that, she emphasised that she does not have to feel guilty for not having a more direct, hands-on role in her mother's physical care.

Similar to Dora's story, Melissa also spoke of how important it is to accept the situation and find realistic ways to cope. It was a very difficult, emotional time for her in the beginning, so much so that she feels that she would not have been able to talk to me about her experience or her role three years ago. But, now she describes herself as being very much at peace with the situation. The awareness of her husband's extra-marital affair represented a significant turning point for Melissa. She could not go on the way she was. In her member check, she also described how, for her, moving into acceptance also meant finding ways to let go of the need to feel guilty. In order to come to terms with her mother's condition, Melissa has learned to focus on the positive aspects of the situation. She also reads a lot of self-help books and feels these have contributed to her acceptance of the situation. Melissa is on the board of directors for a local charitable organisation and discussed how her involvement on this board is another way she copes with the situation. Melissa did not speak about why this involvement has helped her cope, but my sense from talking with her is that her contribution on this board has given her a renewed sense of self-esteem. Her involvement with this organisation could also have helped her focus her energies in another area other than caring for her mother. Whatever the case, Melissa now feels very comfortable with the situation and said that if her mother continued on like this for another five years, she would be okay with that. She confidently expressed to me that she feels quite able to handle the situation now.

Aside from Melissa's different life situation, her story also differs from Dora's in another respect. Melissa still sees her mother in the woman that she cares for and that is very important to Melissa. "A big part of me still hangs on because she is still my mother to me". She spoke of already losing one parent and how she is not ready to lose another yet. She also said that at some level she feels that she is reaching her mother even though there is no feedback from her mother. In her member check she elaborated on why she visits her mother: "I visit because I want to. I can talk to mother about what's going on in everyone's lives as if it mattered to her. That way our relationship is still important". So, Melissa now visits her mother as well as the facility once a month to oversee her mother's care, although she did suggest that her visits are getting more difficult now that her mother is no longer mobile. At the end of the interview she described again how she has been gradually withdrawing from the situation.

When asked if she considered herself a caregiver, Melissa said that she did not feel that she is involved in her mother's care enough to be considered a caregiver:

> I wouldn't say on an emotional level I'm a caregiver. I don't think I'm present enough. I guess I've sort of allowed the employees at [the facility] to take on that role. There are some spouses that probably go in every night and take them you know a newspaper and just sit with them and whatnot, and to me that would be a caregiver. So I would have to say no, I am not a caregiver.

Similar to Dora's experience, relinquishing care to the home and her mother's common-law spouse was a gradual process for Melissa. Moving from an intense caregiver to more of an overseer of care as well as towards re-framing the situation so that she could focus more on her own life and well-being were seen as important adaptive coping strategies for Melissa. She now describes herself as being very much at peace with the situation and at a far more comfortable place in her caregiving career. Melissa is very satisfied with the care her mother is receiving and also knows that her mother's partner is taking good care of her mother, thus she does not feel a pressure to be at the facility regularly. She does, however, feel that her mother still exists and so continues to visit her mother approximately once a month. She did stress that she is comfortable with her visits and enjoys them but she does not go unless she is in the mind-set to go and feels that she really wants to go. What Melissa does do in her role she perceives as her responsibility, but similar to Dora, does not consider it to be caregiving.

Summary of the Accepting Relinquisher Role Manifestation

Accepting relinquishers continue to visit the facility occasionally but have essentially handed over the physical and emotional care of their parents to others. The women in this manifestation have, in many ways, removed themselves from the caregiving role, and prefer to think about their roles in terms of overseeing aspects of their parents' care. In this new role, they no longer define themselves as caregivers. Accepting relinquishers have reached this point in their caregiving careers only after a long, often difficult, struggle in the caregiving role. The move towards acceptance for accepting relinquishers is often precipitated by a crisis situation. In Dora's story, the crisis involved a diagnosis and subsequent battle with breast cancer. Melissa's crisis point came when she became aware of her husband's extra-marital affair and recognised that her own family was falling apart. Learning to accept the situation, particularly the deterioration they were witnessing in their parents, was an important component of their stories. Only in accepting the situation were these women able to move on from the situation and turn the focus to their own lives and their own well-being. Accepting the situation and what they can realistically provide for their parents has freed these women of the guilt and the many pressures that so often accompany the caregiving role.

First Profile of an Unaccepting Relinquisher: Carol's Story

Carol is in her 50s, is married and works part-time in her husband's office. She has two older brothers, but neither of them live in the area. Thus, Carol considers her mother's care primarily her responsibility. She defines that responsibility as ensuring that her mother is receiving adequate care.

Carol cared for her mother in the community for about two years before her mother moved into a senior's residence. Her mother lived in this residence for approximately five years and then moved to the facility in which she now lives. At the time of the interview, Carol's mother had been living in the current facility for two years and eight months. Carol was in a later temporal phase of her institution-based caregiving career.

A pattern that began to emerge in the women's stories was how incredibly intense and difficult the caregiving situation was right before the admission of the parent into the long-term care facility. This was particularly true in Carol's situation. She described the few months prior to her mother's admission into a home as a very difficult, trying time because she did not know what was going on with her mother. She explained:

> I was involved, I was very much involved just prior to her going to the home and prior to us making the final decision because at this point in time her mind was doing wonderful tricks on her and she was imagining people living in her house, imagining people breaking in. She really lost respect for other people's time ... Oh, I would say the last two months it was just terrible because of these voices that she had and I think at this point she really got the pills all mixed up and I tried, I got her one of those daily pill dispensers and she couldn't even handle that and she was so out to lunch she didn't know what time - she didn't even know the difference between day and night. She was involving the neighbours and they were phoning me. I had the whole world calling me, even the police because she had got the police involved and this nice young Waterloo policeman made the biggest mistake in his life. He gave her his phone number and then I can

> remember working one day at my husband's office and the receptionist came back and said Carol, the police are here for you … the Waterloo policeman said to me, "Would you please stop your mother calling me" and I said, "I can't!" I said, "I wish you could stop her calling me!" But I would be leaving here [my home] any hour of the night because she would call just panic stricken and then I would go over and sleep with her. So eventually I was getting exhausted because, not so much from that but my own sadness. You know, I'd wake up in the middle of the night and I'd think, oh how is she doing? What is she doing? What's going on? So I finally called my brother in Ottawa and I said, look can you send [Penny] up, my sister-in-law, and help me because I said I just can't go any longer, I'm tired.

For those few intense months before her mother was moved into a long-term care facility, Carol perceived herself to be a caregiver. In her caregiving role, her primary responsibility was to run to her mother's home every time her mother would call and to try make her mother feel more comfortable and safe. She felt that during that time she was on the run constantly.

Over the years, Carol has come to relinquish all care to the facility. She no longer considers herself a caregiver. When asked to describe her role in her mother's care now, she 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. Not that I'm not accustomed to seeing old people, I guess it's because it's *my* mother and because my mother was widowed when I was 16 we had a very, very close relationship and I haven't accepted it well, that's the bottom line. The only thing I can really care about a lot right now is that she is well looked after and in my opinion they do a tremendous job. She's always clean, she's always well groomed and I know she's fed all right and in my mind I guess that's where I'm at. They're taking good care of her and I find it terribly stressful to see her.

In her story she described how she began relinquishing care when her mother lived at the senior's residence. A turning point for Carol was when she realised that her mother no longer recognised her. She explained this to me:

> I used to see her a lot and then toward the... when I could see her going down too at [the senior's residence], 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. By 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.

It became clear as Carol continue with her story that she thought about her role more in terms of her experience in the role rather than what her role was in the facility. For her, the experience was very difficult and painful. In fact, because of her difficulty coping with the situation, she no longer felt she had a role to play in her mother's care.

Carol was finding her mother's deterioration, particularly her inability to communicate, very distressing. Thus, Carol has a very hard time visiting and described her experience and her visits with her mother now as a "nightmare". She elaborated on this:

> [The visits] are brutal. It brings tears to my eyes when I think about it that I can't talk to my mother (family member weeping). My mother doesn't even know who I am and I'm not doing very well with that ... If they called me tomorrow and said she was admitted to hospital, no problem, I'd have something I can physically do for her. You know, fine, I'll go in and I'll do it. I'll go and feed her her meals. I'll go wash her and clean her. I don't have a problem with that when she's in hospital. I have a problem with that when she's in [the nursing home] because they're [the staff] doing all those things for her so I have nothing to do. I guess that's the feeling, like I go and I just sit there and I just feel bad and my friend's gone. When I just go and sit with a lump [in my throat] and she can't finish a sentence I don't handle that part at all.

The loss of her mother's companionship, her mother's inability to communicate with her, and the feeling of helplessness in not knowing what to do during visits have all contributed to Carol's difficulty in visiting her mother now. For Carol though, the most important factor for her and her experience was her mother's mental capacity. As her mother's mind deteriorated more and more, she had more and more difficulty coping with the situation. Carol mentioned that her mother existed in body only. Her mother's personality is now gone. As she was less and less able to cope with her mother's deterioration, her visits became more and more infrequent and it became easier for her to gradually relinquish all care to the facility. Carol now visits infrequently, once a month is a lot for Carol.

Carol was having such a hard time dealing with her mother's condition, that she expressed to me that she was not even sure if she could fulfil one of her daughter's wishes. Her daughter, who seemed to be dealing with the situation better than her mother, was soon to be married. Her daughter's one wish was to have a wedding photo taken with her family, including her grandmother. Carol recounted this in her story:

> One of her [my daughter's] wishes is that my mother's still living when she gets married in April. She wants her picture taken with her grandmother (family member crying) because she was the only, there were only two grandchildren that lived here with her. Her big wish is that she [grandma] have her picture taken with the rest of us. And I said, "oh [Susan], that's going to be just awful for me". I don't want to be in the picture, and yet I do. But, I said, "I don't think I could stop the tears because grandma loved you so much and she was so close to you that for the last" … you know when she was little it was, she was just like having me over again and [Susan] spent a lot of time with her grandmother and I said, "I understand your wish, it's just going to be awful for me but I'll do my best".

Carol was clearly struggling with how to fulfil her daughter's wish knowing that she was going to have to come face-to-face with the pain she was feeling again.

Further, all of the unaccepting relinquishers talked about how they are incapable of visiting their parents alone. Carol, for example, only visits when her daughter [Susan] can go along on the visit with her. Carol emphasised how much she depends on her daughter to visit with her when she does visit her mother:

> I have to say because I don't handle it well, I always take my daughter and I said to her, "please you have to understand that I can't handle sitting and talking to my mother who can't even complete a sentence but I've got you, you and I can talk and she's with us so that relieves the stress off me". So that's ... I'm afraid that's what I do. If my daughter can't go, I don't go.

Carol now visits out of a sense of obligation. She calls it a "duty call". She primarily visits to ensure that her mother is well cared for. She also stressed that she has always been very satisfied with the care her mother is receiving at the facility and so does not have to check up on the care very often. Knowing her mother is well cared for gives Carol some comfort in relinquishing care. Carol reiterated this thought on her member check:

> I do not enjoy seeing my mother like this. It hurts but then I want to know that she is cared for well, so I visit to make sure she is well taken care of and I have always been very satisfied with her care.

Carol continues to visit her mother irregularly, primarily to ensure her mother is receiving quality care. Similar to all unaccepting relinquishers, she only visits when her daughter can visit with her. Carol's story was far more full of descriptions of her experience in the role than on her actual role in her mother's care. She found the experience incredibly difficult and painful, and felt very helpless during visits with her mother. She no longer considers herself a caregiver. She has essentially relinquished all physical and emotional aspects of care to the facility. Carol did mention that her daughter visits her mother more often than she does and so Carol may feel that her daughter is also playing a role in providing her mother with the more personal and emotional aspects of care. Two factors have helped Carol relinquish care: Carol no longer feels that her mother exists, at least in terms of her personality, and she is quite confident that her mother is well cared for at the home.

Second Profile of an Unaccepting Relinquisher: Grace's Story

Grace's story is one of the most unusual of all the women I spoke with. When I met Grace, she was in her 40s, had been separated from her husband for ten years, and was caring for two teenage boys. Before her father was admitted to the long-term care facility, he lived with her sister who took primary responsibility for her father's care. Grace would take her father to her home every other weekend but gradually her father became, more and more unrecognisable. Grace explained:

> [I was a] sort of every other weekend caregiver [when my father lived with my sister]. We hadn't even heard the word Alzheimer's you know. It takes a long time to get through your head, yes my dad is ill and he has to be put away. It's a terrible stubbornness that you don't really admit it. It's just excruciating. But the thing is when he's in my house, he was not my dad. He, like I had the hair raised on the back of my neck if he was standing behind me. It was like taking someone in, a hitchhiker off the road. This body in my house is not my father. I don't know who he is. So, it's really awful.

As her father became more and more disoriented, he also became quite violent at times and Grace and her sister became very worried about their safety and the safety of their families. In her story, she described the incident which lead to her father's admission first to a hospital and then to the facility he now lives in:

> [My father] started believing that [my sister's] house was his house and then he got to the point when he didn't recognise them [my sister's family]. One day her teenage son came home from school and I don't know if dad had in mind that he was an intruder but he punched him and threw him out of the house. So the, because the home care worker was there, [my nephew] stood outside and he opened the door to say, [Evelyn] are you okay? Dad punched him again and threw him out. So my sister was just

> frantic and they called my brother and [me] and my brother got there first and he took dad down to the hospital. He's never been able to live with himself for it. And, it was just, it was a have to situation and my sister's doctor who is dad's doctor, who is very wonderful just said, you take him *now*. You know, there was no other choice cause we were afraid to go home. He didn't know who we were.

So, Grace's father was admitted to a local hospital and remained there for over a year as he waited for a bed to become available in a long-term care facility in the area. In 1992, he was admitted to the facility he now lives in and at the time of the interview had been living in the home for 3 years, 6 months. When I met with Grace, she was in a later temporal phase of her institution-based caregiving career.

Grace was having a very hard time dealing with her father's condition and particularly the fact that he was living in a long-term care facility. She finds the atmosphere of the home very depressing and in her interview described how difficult it had become for her to visit her father there. In the beginning, she visited her father frequently, every three days. But gradually the situation began to take its toll on Grace and she sought the help of a doctor. In her story she described how her own role changed very quickly:

> [The doctor] said, "Grace you're going to kill yourself. You're going to get sick and you won't be any use to your boys or your dad. He doesn't even know ten minutes after you're gone that you were there". And, I was just drained totally. So, then I would say okay once a week [I'll visit] and then it got to be once every other week, and as time went on, it's just so painful, I mean I don't go. ... I can go six months without going. I'm ashamed to say it, but...I should go twenty times more than I do. But it's almost like, you think of going and your stomach crunches up and you got to get yourself to that day and then you get there and there's only so much time. He was downstairs in a locked up facility. There's only so much time you can spend in that environment and you just start to go nuts and you got to leave and *then* half the time he wouldn't know you were there until you were leaving and when he looked at you and got tears in his eyes, oh, it's just awful. Just awful.

Similar to Carol's narrative, Grace's story was full of her depictions of her experience in the role. The experience was difficult and very painful. Grace went on to describe her visits with her father as going to a funeral over and over again. In fact, many of the women I spoke with described their experience watching the deterioration of their parents as the long good-bye, particularly after the mind has gone but the body is still there. The father Grace once knew no longer exists for her:

> Well, this is a terrible thing to say but I think for most of us, our self conscious thoughts are, my father died three years ago. I can go and see this empty shell and I can kiss him and hug him and cry but it's like going to a funeral every three months for your father.... It's almost like a period of mourning after a death. It's intense, and then gradually you begin to cope. But the hard part about this is that every time you go back you're in mourning again, at least for 2 or 3 hours after you come home. That's what is really hard on the family. It's a never ending mourning.

Like Carol, Grace discussed how it got to the point that she could only visit with her sisters. Visiting alone just became too difficult and too painful. When I asked her if she always visited with someone else she replied:

> Oh, we got to the point you had to. The last time I went alone I had to run out because I was bursting in tears. I mean you just sit there and you rub his hair and you hold his hand, and of course if he gets a hold of your hand he could just about wrench it right off. Silence, you know there's only so much you can kind of make in a one way conversation not knowing if he can hear you or, it's just too hard. So the only way we can stand it is when the three of us can get there on the same day, which isn't often cause my one sister runs a business and we all have to travel. It is just to go and visit with each other with him in the room and that's about the best we can do for us and for him.

As I mentioned in the first line of this profile, Grace's situation was unusual from the others. She was similar to the unaccepting relinquishers in her inability to cope with the situation which had lead to her relinquishing all care to the facility. Visiting once every six months or so with her sisters was about as much as she could handle. When we began to delve into where she saw her role now in her father's care, however, she had a somewhat different response. Other relinquishers had come to accept the fact that their parents were going to spend their last days in the facility. In fact, given their difficulty in dealing with the situation, it gave them much comfort to know that at least their parents were getting good care. Grace, on the other hand, felt much guilt about her father being in the home. She had a hard time dealing with the deterioration and the fact that the father she remembered so well no longer existed. But, even more difficult for Grace was the realisation that her father could die in the facility without any loved ones around him. She described this to me:

> Why do I go? Because I feel guilty. Because he is there and from the last time I saw him I'm just filled with horror for the day the phone call comes that he's gone and I can say oh, I didn't go in the last six months. It's just a terrible circumstance. And, yet to go is more painful than not going.

Grace was beginning to think that the only way she could cope with the situation was to find a way to bring her father home. She could not deal with her visits at the home so the answer for her was to bring her father to live with her and her sons. She felt confident that she would be able to deal with her father if he was living with her, out of the environment in which she was having so much difficulty. When I asked Grace if she felt she had a role in her father's care now, she responded:

> Well this might not fit in with the research you're doing, I think my role right now is to get him here. Cause to go into an unusual place and sit there and look at him laying there as though he's in a coffin, is just too hard. But if he were here, I wouldn't really, I mean the time would not come when I would just sit and stare at him. He would be here. I could be cooking and baking and the radio would be on and singing. I could have his brothers, like his brothers and sisters are a very close family and they all get together and play Euchre every week. Well I could have them do that here. I wouldn't even have to be here but have him in his gerie chair sitting here and have tea and coffee and say bring your cookies and play your Euchre

> here. They wouldn't have to walk into a room alone and try to do something to communicate. They could just visit and laugh and play cards. ... You know my one sister said, do you think you could handle him dying there [at my house]. I said, "oh yes", cause he, I mean you're not going to stop it. It's either here or it's there. And, I can't stand to think of it being there. And no offence to them because government provides as much staff as it can, I just I have an awful feeling I'll get off the phone and think well gee was he dead for three hours before they noticed, you know? I'd rather be holding his hand (deep sigh) anyway.

Grace had analysed her situation. She felt that her difficulties, her inability to cope had to do with the fact that she did not have anything to do during her visits. She could not continue to visit him in the facility. To her is was very much like visiting her father's coffin every six months. But, she could not bear to have him die there alone. If visiting was too painful for her, then the answer for her was to bring him home.

At the time of the interview, Grace's story, particularly her focus on how painful the experience visiting was for her and how she had gradually come to relinquish care to the facility, was very much representative of the stories of other unaccepting relinquishers. How she differed, however, is that she perceived that for her there was a solution to the problem. Her role at the time of the interview was becoming one of finding a way to care for her father in her home. When I asked Grace if she considered herself a caregiver, she responded: "I look forward to being. I have not been". I spoke with Grace several months after our first interview and indeed she had been successful in getting her father home, was no longer feeling the guilt she had been feeling at the time of the interview, and was coping much better with the situation. Her experience was a reversal of what most family members go through. Instead of the intense involvement to the gradual relinquishment of care to the facility, Grace went from being an every other weekend caregiver, to completely relinquishing care to a long-term care facility, to becoming a full-time primary caregiver in her home.

Summary of the Unaccepting Reliquisher Role Manifestation

The most salient characteristic of the adult daughters in the unaccepting relinquishers group is their focus on their experience in their role rather than what they do in that role. In fact, because of their inability to cope, they do not perceive a role for themselves in the care of their parents. The do not think of themselves as caregivers. The experience they describe is extremely difficult and painful for all of the women in this group. The most important contributors to the difficulties they experience in the role are: (1) the inability to accept the situation, particularly that their parents no longer recognise them and are unable to communicate with them during visits; (2) the feelings of helplessness in not knowing what to do for their parents during visits; and (3) coping with the pain, the never-ending mourning which re-emerges every time they visit their parents in the facility. Unlike the accepting relinquishers, the women in this group have not generally been able to find a way to accept their parents' deterioration and move beyond it. Grace's story represents a very unique case in which she was able to find a way to deal with her pain and guilt by removing her father from the home and becoming his primary caregiver. This very much represented a transition in Grace's caregiving career. Up until that transition her story was very much representative of the other unaccepting relinquishers. The majority of accepting relinquishers feel that the only way for them to cope with the situation is to relinquish both physical and emotional aspects of care to the facility. Because of their difficulty with the visits, they visit irregularly and only when other family members can visit with them. Knowing their parents are receiving quality care lessens the pressure for these women to be at the facility often. When they do visit, they do so only to ensure their parents are continuing to receive good care within the facility.

Caring for the Caregivers: Indirect Supporters

My sixteenth interview in this project was with a woman who had both of her parents still living; her father in the long-term care facility and her mother who was considered the primary familial caregiver. This particular adult daughter viewed her role in the care of her father differently than any of the other women I had talked to previously. I became very intrigued by this woman's story and her description of her role and set out to interview other women who still had both parents living. Interestingly, all but one of the women in this situation described their roles very similarly. I gradually identified these adult daughters as the *Indirect Supporters.*

Adult daughters in the indirect supporters group do not view their role in terms of their parents living at the facility. Instead, these women view their role as providing support for the *other* parent, the parent living in the community who they perceive as providing the primary care to their institutionalised parent. This perception of their role was reflected in both their stories told to me during their interviews, and in their personal logs. Indirect supporters feel confident that their parents living at the facility are being well cared for both by the facility and by the other parent. They feel the person who is in most need of help and support is the other parent living outside of the facility. For example, when asked how she defined her role in the care of her father living in the facility, Mary emphasised that her role was more focused on the parent living in the community, her mother. She stated:

> The only way I can say it is as a support for my mother. I mean, my mother is a strong person but she just finds it very difficult to make decisions. I talk to my mother every single day and every single day she has got some problem, a very minor problem or whatever. So that is the biggest support with my dad is to support my mother because she is the major support for my dad and somebody has to support her.

In their stories, indirect supporters described how providing that support became their job, their responsibility. In most cases, it is a very intense job, some even described it as a burden, and yet they would never think of not doing it.

Similar to active monitors and regular visitors, these women also define their role in terms of their purpose in the situation. Two overarching purpose themes emerged from the women's stories. The first purpose theme identified by the daughters in this manifestation was to support the other parent in the care of the parent living in the facility. In assisting with the caregiving role, they help their parents make all decisions concerning their parent in the facility. They also serve as a sounding board off which the other parent can bounce ideas. Further, if the other parent makes a request of the daughter related to caring for the parent in the facility, they will ensure that the request is fulfilled (e.g., making phone calls on the mother's behalf, helping with the move to the facility, helping with the decorating of the resident's door at Christmas, providing transportation). Assisting with care occasionally involves taking over for the other parent in the facility if the other parent is ill or away. These adult daughters also monitor the other parent monitoring the parent in the facility by prompting the other parent to do things that need to be done and by encouraging the other parent to speak up when concerns are raised.

The second purpose theme related to supporting the other parent is to monitor the other parent's health and well-being. These women all discussed how a very large part of their role involves making sure the other parent is taking care of her or himself. Monitoring the other parent's physical well-being means ensuring that they do not become overwhelmed in their caregiving role and overtired. These women also recognise the emotional loss and pain their other parent is experiencing and so also serve as a shoulder or emotional support system, being there to help the other parent deal with the emotional aspects of caring. The other parent's emotional well-being often takes precedence over their own well-being. In an attempt to maintain their other parent's well-being, indirect supporters go to great lengths to provide distractions to the other parent from their caregiving role. They do this primarily by involving them in a variety of family events. Some adult daughters in this group also find ways to get their other parents involved in rewarding activities outside of the facility and the family unit, such as volunteer work in the community. Finally, indirect supporters try to serve as role models for their other parents in an attempt to help lessen their parents' involvement in the home and also ease the guilt the parents often feel if they are not at the facility often.

I should stress that even though indirect supporters describe their role in terms of caring for their other parent, it does not mean that they do not visit their parent in the facility. They all do. The dominant focus of their stories, however, is on their role as a support system for the *other* parent.

In relation to their temporal phase in the caregiving career, indirect supporters appear in all of the career phases. For this group, the most important factor seems to be the presence of another parent living in the community who is quite independent and relatively healthy. In fact, in many cases these women take on the indirect supporter role before the ill parent is admitted to a long-term care facility. It becomes their primary focus upon, or shortly after, the institutionalisation of their ill parent.

First Profile of an Indirect Supporter: Diane's Story

Diane is in her 40s, is married and has two sons (one living at home and one away at university), and works part-time as a physiotherapist specialising in arthritis. Diane's mother cared for her father in the family home up until August 1994 when her father was admitted to the long-term care facility in which he now lives. Diane's father has been living in the special care unit of the facility for one year and three months. At the time of the interview, Diane was in a mid temporal phase of her institution-based caregiving career.

When I first contacted Diane by telephone to recruit her for the project, she found it interesting that I would want to interview her for the project as she did not consider herself as playing a role in the facility. During that telephone conversation it became clear to me that Diane was trying to sort out for herself what her role was in the care of her father, and she mentioned to me that she did not see her role in terms of her father's care in the facility. Instead she viewed her role as a support to her mother. During her interview she expanded on this notion:

> After you talked to me [on the telephone] I thought yes, in reality, and I mentioned it to my husband, we see it as being caregivers to my mother not to him and we help her in the decision making and are people that she can bounce ideas off but he [my father] is looked after, she is not. So sort of the concept that she is the one right now that does not have the support and needs it. It is a really different type of caring isn't it? It is not like a

> nursing care but we see it as we are more her support system rather than his.

Similar to many of the other indirect supporters, Diane mentioned that this role of supporting her mother was really something that began long before her father was admitted to the long-term care facility. For these women, the supportive role often evolves as the ill parent becomes more and more difficult to care for by the other parent, and more and more unmanageable. Diane described the progression of the role for her:

> As [my father] continued to deteriorate, as I commented to you before, I feel that we have become far more of a caregiver to my mother and even during that period of time as he went down hill, the different stages when he would misplace something and then feel that it had been taken, so very paranoid about things. And, then he went through a stage when he didn't know who my mother was a lot of the time and he was very angry with her. I would say for two years before he went into [the facility] that we would get a call at least every second night, she would be in tears, she was exhausted. So it was helping her.

In Diane's story she talked about how difficult her father's deterioration has been on her mother, and the losses that her mother has had to endure because of her father's condition. Watching her mother's experience in the situation, especially her mother's pain, has served to reinforce for Diane where the focus of her role should be – that she and her family had to provide a support system for her mother. She expressed her perceptions of her mother's experience:

> It is horrendous for the spouse and just an aside, I work with elderly people and young people and people look at me and say you are crazy but in many ways I find that people have a much harder time dealing with the death of a spouse than they do with dealing with the death of a child. They say you are crazy and I say no, when it is a child the support system is all still in place. When it is a spouse it is a total lifestyle change. They are alone. There is nothing left. They have to redefine who and what they are and the Alzheimer's is a living death. My mother is having to deal [with that]. She knows he no longer exists in her larger life. She doesn't have the support, she doesn't have the understanding, she doesn't have anyone who really

> knows what they are doing when she even gets a hug. So she then is totally on her own for all the financial, for all the housekeeping, for all the decisions, for all the social activities, and yet society would frown on the fact, that is, if she'd go and find a boyfriend. She has got nothing. She has lost him but she hasn't. It is horrible, horrible for her.

This depiction of her mother's experience is consistent with what has been labelled quasi-widowhood (Rosenthal & Dawson, 1991). Quasi-widows often feel ambiguity surrounding their marital status, particularly once the institutionalised spouse no longer is present psychologically for the community-based spouse. Quasi-widows are left to face the rest of their lives on their own, yet because the institutionalised spouse is still physically present, new intimate relationships are not a possibility and quasi-widows remain in limbo for long periods of time. Sensitive to this reality in her mother's life, Diane sees her priority in providing support to her mother. She feels her father is getting support both from the staff at the facility and from her mother. In Diane's perception, someone has to support and care for her mother, the caregiver.

Interestingly, when I asked Diane if the staff had ever expressed their expectations regarding what she should be doing in the home, she told me that they had never explicitly talked to her about her role, but that they had indirectly suggested that her focus should be on her mother. She explained: "I did get a call from [the Director of Nursing Care] the one time saying that we are worried about your mother. So, obviously there is an expectation that I am her caregiver as well, which is interesting".

When asked what providing support for her mother involved, Diane identified several things that she does in her role. She provides "emotional support", is a "sounding board for decisions", at times she assists her mother with the care of her father, and she "assists with yard work and other chores". Primarily, Diane feels she needs to be there to talk through things with her mother, confirming or not confirming her mother's perceptions of different situations. She explained to me how she prefers to do this:

> ...The last couple of times that I have been in he has been in obviously a tremendous amount of pain so I have communicated to the nurses about that but you know, a lot of times I don't feel that is my role to interfere to what is being done there. My mother looks after that and I give her then sort of the back up. She says to me, "he is in a lot of pain what do I do?" I have seen it as well so I can say, "yes I agree with you" and "yes this is worth looking at", or "gee no I think it was just sort of...", you know?

Diane also described her role as one of providing reassurance to her mother regarding her father's care:

> [My mother monitors my father's care]. I hear a lot about it on an ongoing basis. There has been times that I have been quite sorry for the [facility] staff but they must expect that because I think some of it occurs with the frustration of the system and I find it in a lot of, my mother was trained as a nurse and she, it is the old fashioned [way] that everything gets done just so, and I think the nursing home setting sometimes drives her crazy. You know, the hygiene isn't up to her level and you have to sit back and say, "look, let's look at this objectively and realistically and what are the expectations for the staff they have, what is actually needed? This is not acute nursing care that we are talking about". So take her through it step-by-step and she sort of relaxes and backs off.

Diane also felt that part of her role was to monitor her mother's well-being. Once her father was admitted to the facility, a big part of her role in supporting her mother involved trying to find distractions or social activities for her mother to participate in. These distractions were important to maintaining her mother's health and well-being. She explained to me how she got her mother involved in volunteering to help form other support networks for her mother:

> ...trying to include her in the fun things that are companion type things. When I worked with the Arthritis Society I got her in volunteering and part of that is, the work group that I have, we have a phenomenal team. It is three therapists that work part-time and one secretary and they just loved

> her up and down. They found all the neat jobs for her to do so that she is going in and volunteering but she is getting a lot of support there.

Finding distractions also involves finding activities that she and/or other members of her family can do with her mother. For example, the night before the interview her mother had come over and together they made chocolates.

Providing support for her mother is and has always been very time consuming and demanding for Diane. She described to me the intensity of the role and how despite the fact that her father is now living in a long-term care facility, a lot of that intensity still remains:

> It has taken a tremendous amount of time and energy, tremendous amount of time. I would say basically it started, the worst of it started about two years before he went into the nursing home and it is actually better now than it was for those, gradually getting worse over those two years. As I say, it was phone calls, emergency calls, I need help [from my mother] and literally you had to drop what you were doing and go and help. The constant, it was a tremendous emotional drain. It was extremely difficult to watch my mother to go down hill emotionally, that was very difficult. We have a little cabin up north and my parents have one as well and mother would plan to go up there when we were there so even our holiday time appeared to be taken up with them. When she had had a tough day and she would phone and let's go into town or let's do this, or let's do that and what she really was doing was begging for time with us. So, yes, holiday times were interfered with, our evenings were interfered with. During this period of time as well my husband's parents had a serious car accident so we were down, back and forth from Hamilton. His mom was in intensive care for quite a period of time ... Ya, between parents and helping kids, the kids really got left in the lurch to some extent, we really felt we had absolutely no time for ourselves. You know, things that needed to be done around here, things that just a lot of time and energy was spent caring not only for my parents but my husband's parents as well. So ya, even now I look at it and there are times when my husband says, "hey, we have to go and see other family members. My parents need a little bit of time." My mother still is taking quite a chunk of time right now even, yes.

Sometimes providing support to her mother, along with all of the other roles Diane plays in her life, can become overwhelming. In fact, one of the most difficult aspects of her role she finds is realising that she has to be there and that as demanding as it is, she can never not be there for her mother:

> The most difficult thing in dealing with this, I guess, again, it is guilt sort of. There are times when I think I don't want to do this today. I don't want to be here for her today. I want out of here and I think just constantly realising that that is not how it is going to work is probably the most difficult part of it. The reality is that I want to be there for her but I am selfish enough to say and sometimes I don't feel like doing it.

Although the focus of her role is on her mother, when asked if she felt there was anything that was important for her to do in the care of her *father*, she did emphasise the importance of seeing her father. She responded:

> I feel that I should see him. I believe in touch and hug and as the mental function decreases I think those things still have meaning. Maybe that is my need not his because I believe that he gets quite a bit of it from the staff and yet he is my father and I want to have that, a remnant of communication of some sort .... I look at it now and I, you know, I love him. He is my father and you can't take that away and I want him to know that there is family around that does love him and care for him.

Diane tried to visit her father every month or six weeks. But, similar to the women in the relinquisher groups, she described how difficult the visits were now that there was not much that her father was capable of doing in the visits:

> I find it a very, I work with people, I don't mind elderly people, I mean it doesn't upset me but I find it an interesting process. You cannot visit and unless there is something that you can do for him it is very, very difficult. And really, my mother sort of takes on that role and I find what she does very interesting as well because she has taken on the nursing role and by going in to feed him supper she has a purpose in being there because to visit it just doesn't work.

Primarily, though, Diane's role in the facility and in the care of her father centred on her mother and on developing and maintaining a supportive network around her mother. Her purposes in her role were to help her mother in the care of her father and to monitor her mother's health and find ways to maintain her mother's well-being. She still feels that it is important for her to visit her father but she also knows that her father is being well cared for by her mother and the staff. Therefore, there is no need for her to be involved in that area. I found out later that Diane's "indirect supporting" role continued even after her father died. When Diane sent her member check back to me, she wrote a note on the top of her transcript informing me that her father had just died. She wrote: "The support for my mother continues but I see signs that she is starting to heal". Although not surprising to me, Diane continued to focus on her mother even after her father's death. What I found interesting, however, was that there was no mention of Diane and how she was doing. Her note reflected how she often described her experience and role in the long-term care facility; that is, with her mother and her mother's needs as the focal point. There was no mention in the note about how *Diane* was healing.

Second Profile of an Indirect Supporter: Leandra's Story

Leandra is 49 years old. She is married and has two children, a teenage son and a married daughter. She also works full-time as a teacher-librarian. When I first talked to Leandra on the telephone to recruit her for the study, it was very clear that she was feeling strained by all of the different "hats" that she was being forced to wear at this time in her life. She also talked about how her father's disease process had affected the family as well. She was feeling so much strain that she only agreed to talk with me if I could meet her at school during her lunch break. Anxious to talk to her about her experience, I agreed.

Several years ago, Leandra's father had been diagnosed with early onset Alzheimer's disease. Her mother cared for her father in the family home until she decided to sell the home and buy a condominium. Her mother continued to care for her father in the condominium but Leandra became more and more aware of the fact that her mother was not coping well with the situation. Leandra began looking into nursing home placement and in March of 1994 her father was admitted to the facility in which he now lives. When I met Leandra, she was just moving into a later temporal phase of her institution-based caregiving career.

Although Leandra had once perceived her role in terms of caring for both of her parents, her priority had turned exclusively to her mother as her father's mental capacity deteriorated. Leandra explained this in her story:

> So I don't feel that my care is needed with my dad anymore, maybe initially, it might have been because of his awareness right at the beginning but he has, he's really taken dives as far as his ability to talk and to recognise and to recall anything any more. They're not all like that up there at [the facility]. [The focus has been] just shifting to mom really because there's no point in it for dad.

When I spoke with Leandra on the phone originally, in fact, she told me that she no longer had a role in caring for her father and that she did not want a role in the facility. It was not that she did not care about her father, she loved him dearly; however, her perception was that her mother was much more in need of her support than her father was. Leandra described her perception of the situation:

> I used to go up maybe once a week or something like that to check in on him, usually with mom or sometimes we'd go up after church, but if I thought it would make a difference I'd go. If it were just a physical ailment, not that cancer is anything less but if the person's mental state was stable, you'd go all the time, you know, but when it isn't. That's what I said to mom, he has no idea that you or I or anybody else is there. He's happy, he's cared for, you know, he's healthy, the nurses are wonderful, you know, what point is there? Doesn't that sound awful?

Leandra's father was being well cared for, and in her mind her father no longer existed. Thus, she did not perceive a need for her to be involved at the facility or a role for herself in her father's care.

Leandra's concern was now with her mother and her mother's well-being. Taking care of her mother had become a family affair for Leandra's family:

> [Caring for my mother], it's the big role. I mean I think we've all taken on Nana, you know. My daughter too and [her husband] are really good at inviting her over even if we're not there. She'll phone up and have mom come over to see the Christmas tree or this or that, so everybody is in on the care because I think they see that as the greater need. It is the greater need, there's no doubt about that.

Leandra had just recently seen the need escalate as her mother was hospitalised and there was a concern that she might have a stroke. She described her concerns regarding her mother's physical and mental health to me:

> I think that mom was sort of laboring under the illusion that if she didn't go up and visit him every day or quite a few times a week that the nurses would think that she was awful or that some other person would look and say oh, isn't that awful you haven't been up to see your husband very much this week. And, I think it's just been recently that she's finally gotten over that and realised that if she doesn't get on with her life… I don't know though, how do you get rid of those feelings for your spouse or your father, it's hard but she's going to have a heart attack, I'm sure, and I'm going to lose her before I lose my dad. I mean we almost lost her last week. That's when she went in for the shot and I'm thinking, if this happened I'd have such a hard time, you know. However, I think she did some stocktaking then and I mean we've been telling her this all along, mom, you just can't go up there, you're driving yourself nuts. Sometimes I would phone her or my husband would phone her and she'd be in her pajamas you know at five and I thought, oh she's going to slip into some huge depression and you know, we're not going to be able to yank her back.

So, Leandra defined her role primarily in terms of monitoring and maintaining her mother's well-being. She felt that the only way to address the problems her mother was having was to try and wean her mother off her regular visits to the home and to encourage her mother to get on with her life. The first thing she needed to do was to be a role model for her mother:

> I don't have any problems with that [guilt] at all. In many ways, I've felt that, and I've talked about this with my husband, I feel we need to model that for mom because she needs to see that. It doesn't mean that I don't care, it just means that I have to get on with my life and getting on with my life involves like my two children and [my son] especially. He's just started high school. Getting on with her life means something else, but it's the same, getting on with that, we all have to do it.

Like Diane, monitoring and maintaining her mother's well-being meant she had to encourage her mother to get more involved in other activities.

Related to this, Leandra also felt that she needed to help her mother develop a social network or activities outside of her caregiving role. She explained this idea to me:

> That's what I said to mom, you have to focus your energy on the important things here, and the important thing is establishing a social life for her and some outlets for her where she can develop. I mean she's not an old woman and she still has lots of opportunities to learn some new things and so on and that's what she needs to do now and just get outside of that framework of going up to the nursing home and outside of that guilt of not seeing dad today, or I've only seen him once this week.

She was most concerned about her mother on the weekends as her mother found the weekends very difficult and very lonely. Leandra tries to encourage her mother to go out more and to travel more:

> So, we encourage her, she could go away to lots of places more than she does. [Member Check Insert -- Money holds her back from going places]. I just say to her just go and spend the money, like why are you, don't even think twice about it, just if somebody invites you to go, go. So anyway, I think she sees that a lot more now than she saw it before but weekends are bad for her ... But I think any single person, weekends are always bad. You know, I'm sure if I lost my husband, weekends would be bad for me too.

Much of Leandra's role now involved organizing her mother's time, particularly on the weekends. She feels a need to touch base with her mother on a regular basis, but also puts much effort into ensuring that her mother is included in all family activities, particularly on weekends:

> I would say it's constantly thinking, more the thought processes of okay, what's mom going to do this weekend if I go away to this conference, for example, next weekend. What will my mom do? Should I phone my brother to say why don't you and [your wife] come up or, so in many respects it's like organisation more than anything else. It's not necessarily work, it's just organising to make sure that on Thanksgiving weekend, or whatever we've decided to do, that mom could come along, that kind of thing. Or consciously thinking okay, I haven't talked to her for a couple of days, I'd better make a phone call. She will not phone me because she thinks I'm too busy and she would be interrupting and so on, she's some hang-ups about that so she never phones me. So I always feel I'd better phone her because what if something has happened and she didn't want to phone me and bother me because she's so worried about bothering people and being a nuisance or whatever.

Organizing her mother's life, along with all of the other responsibilities Leandra had in her life, was incredibly overwhelming at times for Leandra. In her story, she described the role strain she was feeling in trying to balance all of her roles and how overwhelming the pressures could be at times:

> I have to be here every day at my job, I have a teenage son, I just got a daughter who was married, I'm going through menopause, I'm thinking, oh, let's see what else we can throw in this. I'm 49 and I just figured I'm just getting hammered here with absolutely everything all at once but I mean you have to take it a day at a time (family member has been crying). I haven't cried about this for so long...We've just gone from one crisis to another, mostly with mom, just trying to get her organised, you know, as far as, and she's still got a whole house full of his clothes. Like she needs to get rid of them but she has to do that when she's ready to do that. And, she has a hard time on the weekends, so she's over at our house all the time. I have very little leisure time. It's not that I, it's not that I don't want to be with her but it just, it seems, and then I keep thinking, oh my kids. When Andrea was still at university, I remember her saying, we had supper one Friday night, the four of us and the kids saying, we never do anything

> just the four of us anymore and I'm thinking, oh well I never really thought about that because I'd always involve my mom or in some way get her involved in everything. There's nothing wrong with that, it's just that my kids were saying, where's the time for us, you know and that's the pinch I'm feeling now is that same thing.

The strains were becoming so intense that she finally felt that she needed to play the family manager role and get her brother involved in some of the weekend organization. She arranged for her brother to take over occasionally so she could have some time with her family and for herself:

> My brother lived here for a length of time but he's in Brantford now and he, I know it's not, he cares for my mom a lot, I mean he was the baby in the family. She spent a lot of time with him and he can do no wrong kind of thing but he doesn't want to see dad, you know, and I don't blame him, it's not great. But I said to him for my sake, you have to see mom, I mean it can't be *me* all the time, I have to have some time off. So they've started to, he and [his wife] come up Friday night and have a sleep-over at her house which is fun and my mother really enjoys it. She's extremely humorous and she loves a good time, you know, she's a wonderful person to be around.

Unlike Diane who never considered herself a caregiver, Leandra felt that given the intensity of the care that her mother needed, she was very much a caregiver. Again, she was not a caregiver for her father in the long-term care facility. According to her, he was receiving good care by the staff at the facility so there was no need for her to play a role in his care. No, Leandra perceived herself to be the primary caregiver for her mother. When asked if she considered herself a caregiver, she responded:

> Oh definitely, big time caregiver. That's what I said, sometimes I think, I don't want to be IT anymore. But, it's the sandwich generation too though I think that a lot of staff members here probably are in the same position, round about the same age, going through menopause, dealing with teenage kids, dealing with aging parents, dealing with a career, it's just that whole 40 to 50 kind of thing and I'm sure that it continues on so and it's nothing that you can't cope with, you just need to know that you're not in it by yourself.

One final thing that was reiterated in Leandra's story several times was the impact that the disease process has had on the family. Different family members had different perceptions of the situation, of her father's condition, and of what needed to be done, particularly when it was time to look for nursing home placement for her father. These differences in perceptions had caused great family conflict and, much to Leandra's distress, had had severe consequences on her relationship with her sister. Often fighting back tears, Leandra recounted the struggles the family had experienced:

> …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 (family member is crying through most of this and having a hard time talking) over stuff like this and I'm sad about that relationship and it's all because of this rotten disease, you know. I feel so stupid crying. … Well, I think it's difficult for her [my sister] when she's at a distance. In many ways, you know, 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, you know, 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, you know, like I just got that impression from her that she didn't... and even this summer, my daughter got married this summer, and she went up to see him, I knew that it would be awful because we knew how badly he had slipped, you know. 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. I mean [the Doctor's] not going to lie about something like this or [the Director of Nursing Care], so you know, she just....she wouldn't even talk about it, you know, it really wasn't worth taking her on to try and convince her because she wasn't going to be convinced so that was really unfortunate.
>
> ....and we had...let's see when was that...I think it was two years ago March, he went into the nursing home, was it, yeah, this coming up March, she came home. She was home for this length of time too and that was like a horror show, you know, that day that we had to take him in and I got the call at school here, it was awful. My mom, I thought it was going to break her heart, you know.... [Paul], my husband went and the doctor and my brother took him over and he didn't want to go. I think he knew, I think he had a little bit of awareness yet as to what was happening, you know, which made it even worse

> but [my sister] and I had a major argument then and it was awful. I never fought with my sister, you know and it was just because everybody's nerves were shot and you know, it was just a bad scene. We've been a lucky family, we don't have a lot, haven't had a lot of really terrible things that have happened in our family so this was kind of the first major thing that we had to deal with, that was, you know, of a serious nature, so and that was awful and I don't feel that we're back with the right relationship again. I feel alone (she is upset) because of that.

Leandra talked about how she felt that she really needed to try resolve the situation with her sister in the near future.

So, the focus of Leandra's role was in caring for her mother. For Leandra, this primarily involved monitoring her mother's physical and psychological well-being. A major part of her role was to find ways to help her mother re-establish her own life. Her mother's physical and psychological well-being depended on this. She described her role as an organisational role, helping to develop a social network for her mother, encouraging her to go out and travel more, and arranging her and her brother's weekends so her mother would not have to be alone. She continues to visit her father, but not on a regular basis. Leandra's father no longer exists for her. According to Leandra, her father gets nothing out of her visits and is well cared for by the institution. Her priorities now have to be with her other parent, her mother.

Summary of the Indirect Supporter Role Manifestation

The women in the indirect supporter manifestation represent a unique group of caregivers rarely, if ever discussed in the literature; that is, those women caring for the caregivers. These adult daughters feel confident that their parent living in the facility is being well cared for both by the facility and by their other parent. Also, for several indirect supporters, the personalities of their institutionalised parents no longer exist. Thus, the person in most need of their care and support is the other well parent living in the community. These women go to great lengths to assist their other parent in the care of their ill parent. Much of their role, however, is focused on monitoring their other parent's health and well-being, ensuring that the other parent always has a strong support system to rely on when needed. Although they are involved in a different type of caregiving, their stories depict similar pressures, burdens, and emotional distress often associated with the more traditional caregiving role.

Chapter Summary

Within this chapter I have identified and described the core features of each of the five caregiving role manifestations that emerged in the women's stories. I have also tried to illustrated these role types by providing exemplary and differing portraits of the women in each caregiving role, trying to maintain as much of the whole experience for each of the women as possible. The profiles thus reflect the similarities and yet uniqueness of each woman's experience in her role. From listening to the women's stories, the importance of the caregiving career and idea of process as a salient feature of the caregiving role became clear. In my final chapter (Chapter Seven), I bring both the process and role manifestations together to develop a substantive grounded theory which helps explain the various caregiving career paths in the long-term care facility context. Before I present the substantive grounded theory, two other important aspects of caregiving roles also emerged from the women's stories -- the demands of the caregiving role and the resourcefulness of the women in dealing with these demands. These two aspects are presented and discussed in the next chapter, Chapter Six.

CHAPTER SIX
CARGIVING DEMANDS AND CAREGIVER RESOURCEFULNESS

THE DEMANDS AND RESOURCES OF THE CAREGIVING ROLE

As I was working on a grounded theory of caregiving career paths present in long-term care facilities, I became aware of two other aspects of the caregiving experience in the women's narratives. Their stories were full of descriptions of the demands and stresses of the caregiving role. Interspersed with these descriptions were many portrayals of how these women draw on their strengths and creatively find ways to cope with these demands. The demands and resources presented and discussed next represent those pressures and capabilities that the women expressed in their stories. The patterns and themes related to demands and resources are illustrated in Figure 5.

Institution-Based Caregiving Demands

According to Patterson (1988, p. 79), the demands of a role include both the "stressors (an event producing change) and the strains (ongoing tension from unresolved stressors or from tension associated with role performance)". The adult daughters described several demands of the caregiving role, especially the emotional, behavioural, and environmental demands.

Figure 5

The Demands and Resources Associated with the Institution-Based Caregiving Context

DEMANDS

Emotional Demands

- watching deterioration of a loved one
- dealing with ambiguous loss
- emotional difficulties with visits
- guilt
- sense of helplessness
- sense of failure
- dealing with family crises

Behavioural Demands

- time stresses
- balancing multiple roles

Environmental Demands

- perception of facility and care
- loss of privacy

RESOURCES/COPING TECHNIQUES

Personal Resources

- gratification/pride in doing for others
- reciprocity of care
- faith/spirituality

Family Support Resources

- emotional support from family
- instrumental support from family

Facility Resources

- staff instrumental support
- facility support group
- quality care/caring staff

Community Resources

- community support groups
- reading materials in community
- friendship networks
- church groups
- work

Coping Techniques

- re-prioritising activities
- increasing resources
- re-framing the situation
- avoidance

Emotional Demands

One of the most difficult stressors echoed over and over again in the women's stories was watching the deterioration of the parent. Gretta described the emotional pain she felt in her role:

> I am still upset every time I leave [the facility]. I know she is receiving excellent care, but seeing her gradual deterioration is so difficult. This is not an ending anyone would wish for anyone, let alone your cherished mother, confidant, and friend.

This emotional demand becomes even more difficult when the adult daughters have to deal with the psychological loss of the parent. The following quote from Evelyn's story depicts the pain of this process:

> ***What are the most difficult aspects of caring for your mother?***
> 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.

One of the most commonly identified emotional stressors associated with caregiving reported in the literature is the concern and stress regarding a loved one's deterioration (Stephens et al., 1988; Williamson & Schulz, 1993). Cicirelli (1987) labelled the distress about the anticipated decline and death of an aging parent and the associated concerns regarding the caregiver's abilities to meet anticipated needs as "filial anxiety". As suggested by the adult daughters in this study, watching the deterioration in other residents surrounding the parent can contribute to filial anxiety. Witnessing the deterioration of a loved one may be particularly important to the caregiver's well-being. In fact, researchers have found that patient-related characteristics such as the severity of the illness may be more important predictors of caregiver well-being and depression in caregivers than others such as nursing home problems (Kinney, Stephens, Ogrocki, & Bridges, 1989; Stephens et al., 1988).

Related to watching the deterioration of a loved one, the family members also talked about the ambiguity they experienced regarding whether their parents still exist for them or not and the emotional struggle of dealing with that ambiguity. Jane described this process as the most difficult aspect of her role:

> I think the most difficult is that fact that you know she has past that level where we can communicate with her satisfactorily. In view of the person she was especially who was tremendously in charge of, believe me, of everything and just a very self-sufficient woman and very able to cope and everything. She just was well informed, a good conversationalist, just all of those nice things. And, the fact that she has lost all of that makes it very sad for us and very difficult for us because when you sit there and she looks like, somewhat like the person she always was and yet you know she is not, her mind has just left, the body is there the mind is not. We don't know how much is there but in lots of ways a lot is gone because she just does not respond. If you had dealt with people who have had strokes and their mind is intact but they are not able to communicate you still know they are hearing everything and the expression and what have you and you see mother does not have that response so I know that there is a lot that is just completely gone.

This phenomenon of struggling with whether a loved one is still alive or not has come to be known as the concept of ambiguous loss or boundary ambiguity (see Boss, 1977, 1980a, 1980b, 1987, 1988, 1991; Boss & Greenberg, 1984; Boss, Greenberg, & Pearce-McCall, 1990; Fravel & Boss, 1992). In the case of Alzheimer's disease, the loved one is physically present but gradually becomes psychologically absent as the level of cognitive impairment increases. Boss, Caron, and Horbal (1988) argued that ambiguous loss is the greatest stressor associated with caregiving and that this stressor causes the most distress for caregivers and the family. They explained how boundary ambiguity develops and gradually wears down the caregiver:

> The degree of ambiguity increases as the patient becomes unable to interact emotionally with the caregiver and the family. The patient becomes psychologically absent while physically present, and this incongruence between physical and psychological presence creates high boundary ambiguity in the

> family system and keeps the caregiver and family in a highly stressful state. The patient *is there, but not there*, in the sense that he or she no longer relates to the family in the old, familiar ways. The family, and especially the caregiver, is held in limbo. No resolution is possible when a family loss is ambiguous (p. 124, italics in the original).

Doka and Aber (1989) suggested that ambiguity can become even more problematic when the care receiver is institutionalised and the person is removed from the day-to-day life of the caregiver. The psychological death of a loved one can lead to a grief reaction as well as profound feelings of hopelessness, guilt and ambivalence as well as a tendency to view caregiving tasks as useless (Doka & Aber, 1989). Similar to a phrase used by Kapust (1982), some of the women in this study described the process of watching their parents die little by little, with the gradual loss of the essence of the person as an "ongoing funeral".

The family member's perception of the situation seems to be critical in dealing with ambiguous loss. Each caregiver defines for her or himself the reality of the situation in an attempt to cope with the changes they witness in their parent. In the case of the women involved in this project, some adult daughters, particularly accepting relinquishers, have found ways to come to terms with the loss of their parents and have been able to move on and focus on their own well-being. Other adult daughters, particularly unaccepting relinquishers, have not been able to deal with the ambiguous loss problem. They describe feelings of helplessness, guilt and uselessness in their role and, thus, avoid contact with their parents. Indirect supporters, in many ways, cope with ambiguous loss by turning their focus to the "other" parents who are still very much present in their lives. Active monitors have yet to deal with boundary ambiguity and regular visitors, to varying degrees, are just facing the psychological loss of their parents.

The concept of anticipatory grief (Lindemann, 1944; Rando, 1986) may help explain the experience of the caregivers in dealing with the decline of their loved ones and the process that many of these women have gone through. Anticipatory grief is "the progressions through phases of grief prior to the death of a loved one" (Walker, Pomeroy, McNeil, & Franklin, 1994, p. 23). Rando (1986) expanded this definition:

> The phenomenon encompassing the process of mourning, coping interaction, planning, and psychosocial reorganisation that are stimulated and begun in part in response to the awareness of the impending loss of a loved one and the recognition of associated losses in the past, present, and future...anticipatory grief mandates a delicate balance among the mutually conflicting demands of simultaneously holding onto, letting go of, and drawing closer to the dying patient (p. 24).

The accepting relinquishers seem to have reached a place of acceptance of the psychological loss of their parent and have likely moved into the final phases of anticipatory grief. They have in many ways let go of their parents by relinquishing all aspects of care to the facility. Researchers have suggested that in the final stage of anticipatory grief – acceptance – some 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). Acceptance also seems to involve a phase where caregivers are more at peace with the situation and realistically accept their limitations in the care of their loved ones (Teusink & Mahler, 1984). As caregivers reach acceptance, both the intensity and the number of grief behaviours seem to decrease (Ponder & Pomeroy, 1996). Although accepting relinquishers have come to this place of acceptance they continue to hold onto the situation to a degree by overseeing the care their parents are receiving.

Unaccepting relinquishers, on the other hand, describe more difficulties in dealing with the psychological loss of their parents and, therefore, may be in earlier phases of anticipatory grief. Walker and her associates (1994) pointed out that "resolution of the grief process is made more difficult by the ambiguity of a psychosocial death" (p. 29). The differences in the course and experience in the process of anticipatory grief are also likely related to differences in coping styles and resources available throughout the process as well as a number of other factors. Rando (1986) emphasised that anticipatory grief is influenced by psychological (e.g., the nature and meaning of the person and the relationship to be lost, the personal characteristics of the griever, the characteristics that relate to the illness and the type of death that is anticipated), social (e.g., the patient's knowledge and response to the illness and anticipated death, the general socioeconomic and environmental factors of the griever), and physiological (the griever's physical and mental health, energy, nutrition) variables.

Although watching the deterioration of their loved one and ambiguous loss seem to be the most difficult of the emotional demands on the caregiver, the women also talked about other emotional stresses. Some of the adult daughters described the emotional difficulties associated with the visits. Jessica recalled her visits to her mother:

> 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. I just, I find it very difficult and I think that that affects [other] things to some extent.

For many women, leaving the facility is extremely painful, particularly when they are aware that their parents are distressed by them leaving. Lesley, for example, gave an account of her difficulty with leaving the facility:

> I would say the last two weeks, especially yesterday again, when I say I'm leaving now, she breaks out in tears again so she doesn't want me to go. I don't think I'll do that the next time, I don't know if I should or not but I'm crying all the way going home. It's hard enough for me without (short pause). I think I would say I'll get you a coffee or I'll pick up a paper, I don't think I'll, it's very hard for me.

The difficulties with visits described by these women are consistent with much literature which describes the frustrating, painful, and difficult nature of visits for family members in long-term care facilities (Dupuis, 1993; Edelson & Lyons, 1985; Greene, 1982; York & Calsyn, 1977).

Another emotional stressor identified by the women is the feeling of guilt they carry with them, often throughout their entire institution-based caregiving careers. Other researchers (e.g., Aneshensel et al., 1995; Pratt, Wright, & Schmall, 1987; Riddick et al., 1992) have documented the feelings of guilt and, related to that, the sense of inadequacy experienced by institution-based familial caregivers. Some women talked about the guilt they feel in having to place a relative into a long-term care facility. In her story, Evelyn emphasised the guilt she was feeling:

> My mother always said when she was younger and did not appear to have as many symptoms of Alzheimer's as she does now, she always said don't ever let me end up in a place like that. And, that is rolling around in my head every time I come here, every time I leave here and I usually cry all the way I am coming here and I cry all the way home because of that. If my mom didn't have Alzheimer's, she would not be here. If she was in her right mind she would not be here. So, it is a very, very difficult thing when you know they wouldn't be here.

For some of these women, guilt also stems from a sense of not being at the facility enough. Candace described the guilt she feels because she does not visit her mother often enough and because she feels the staff think she should be there more regularly:

> I think [the staff] expect me to be in there more often…I am sure they do because I used to say the same thing myself when I used to be with my mom all the time, because I was there so much I would see that other people didn't get company or they didn't get it very often and I would think it was mean. Now, I am learning too and I am sitting maybe where some of these family members had been sitting where they just can't seem to go the same. But I feel the burden myself that I should be there more but sometimes I think that the staff when they see me come in, I kind of wonder if they are thinking it is about time she showed up. That is probably my own guilt playing into that.

Some of the adult daughters described the feelings of guilt as one of the most difficult aspects of their role. Diane, for example, confessed: "I think when you talk about caring for my father, I think the hardest part is the guilt for not seeing him as frequently as I feel I should. That is probably the most difficult thing".

A sense of helplessness in not knowing what to do for the parent, particularly to stop the disease process or helplessness felt during visits, was another emotional stressor for family members. Again, this finding is consistent with other research which reports the frustration family members feel in their inability to help (Dupuis, 1993) and the need they feel to do more for their loved ones (Pratt, Wright, & Schmall, 1987; Hansen et al., 1988). Barbara described her sense of helplessness in watching her mother's deterioration:

> I think just seeing her slowly deteriorate and not being able to do a damn thing about it. I can't reverse it. I can't. I mean, I shouldn't say because I am trying to still show her love because I do love her but I can't stop the process and so that's distressing. You know there's nothing you can do to change that.

Jamie desperately wanted to find ways to improve her mother's quality of life in some way but felt helpless in that role:

> ***What are the most difficult or distressing aspects of caring for your mother right now?***
> 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, being more fulfilled, but I don't know what it is. Things like taking her out don't seem to be it. Things like fussing over her clothes don't seem to be it because she looks like a bag lady most of the time. Not knowing, or believing that there probably is, if I only knew something to give meaning to her life.

Related to the sense of helplessness that the adult daughters often experience, another emotional stressor echoed in the women's stories was the sense of failure felt particularly when they are forced to give up caring for their parents in the community. Evelyn recalled how she felt when she had to admit her mother to the facility:

> When I first put mom in here as I think any daughter would feel, I felt like I had failed, that um, you know, why can't I look after her at home and why isn't there a solution to her wandering? You feel like a failure, like there must be another solution.

A final emotional demand that some of the women talked about in their stories was the emotional strain of dealing with family crises related to the caregiving role and the care of their parents. Strains are often put on family relationships when individual family members have different perceptions of the parent's illness or when difficulties arise in negotiating the care that is needed. Leandra's profile in Chapter Five depicts the distress she was feeling as a result of the conflict between her and her sister related to whether or not her father was in need of institutional care and whether or not he was receiving adequate care. Deborah also talked about how her relationship continues to be strained with her sister:

> It was a lot of bad feelings when mom was still at home because we are equals as far as I am concerned but the brunt of it fell on my shoulders and I couldn't do it alone so I guess I accused her [my sister] of not doing enough and there is still a bit of friction there. We are trying to work things out but I don't call her very often. I don't know what is really going on in her life and I don't want to know how little she visits because I know it is very little.

Smith, Smith, and Toseland (1991) found that sibling conflict is common among community-based family caregivers. A few of the women in this study also described conflicts with other family members such as husbands or aunts related to the care their parents were receiving.

Behavioural Demands

The tasks associated with caring for an aging parent can take up an inordinate amount of the caregiver's time to the point of being exhausting. In many cases, this does not necessarily end when the care receiver is institutionalised. Consistent with other research (Aneshensel et al., 1995; Bitzan & Kruzich, 1990; Hook et al, 1982; Moss & Kurland, 1979; York & Calsyn, 1977), the majority of the adult daughters visited their parents weekly or more. Further, active monitors spend great amounts of time during the week at the facility providing both physical and emotional aspects of care and often volunteering in different capacities in the home. Their role often does not end when they leave the facility. Many active monitors continue performing caregiving tasks in their own homes, doing laundry or mending clothing, keeping family members informed of the parent's condition, and continuing to play a supportive role for the parent over the telephone. Indirect supporters, although not spending a lot of time at the facility, spend comparable amounts of their time trying to organise the "other" parent's life, being a support system for this parent, and ensuring that the parent remains healthy.

As illustrated in the profiles of both Leandra and Diane, balancing multiple roles (e.g., mother, wife, employee, caregiver and so forth) at the same time can make the behavioural demands of the role overwhelming. Sometimes just trying to arrange visits can be difficult. Shelley, for example, explained how difficult arranging her visits can be:

> Scheduling in the visits can be a nightmare some weekends. I can feel like, to spend and hour with mom, there's the drive there, the drive back and the shuffling of events to make sure it works. Sometimes I feel really stressed out doing that but that's my own life.

Several of the adult daughters talked about the stress of feeling sandwiched in the middle, having to meet everyone's needs. Marian described the "balancing act" she felt she had to perform in her role:

> Sometimes it's difficult, you're balancing with her [my mother], like I say in a squeezed generation. I've got my parents and I've got my grandkids and my own children and my husband and you're trying to balance all these age groups and trying to do what you can and as much as you can for each one of them

> and it's a balancing act. You're dealing with such extremes in ages, 89 and 90 year olds down to 4 year olds, it's a challenge....Sometimes you think you can't spread yourself any thinner but you manage to get through it all.

Thus, it seems that Brody's (1981) concept of "women in the middle" is applicable to institution-based caregivers as well as those caring for relatives in the community. Despite the growing evidence that the "women in the middle" experience may not be normative (Rosenthal et al., 1996; Rosenthal et al., 1989; Spitze & Logan, 1990), it clearly is a reality for many adult daughters trying to juggle competing roles and demands and can make the experience in caregiving more problematic. Trying to balance multiple demands can be a serious issue as feeling pulled in multiple directions was found to be one of the predictors of depression among children caring for institutionalised parents (Brody, et al., 1990). Aneshensel et al. (1995) did not find role overload to be a common problem among familial caregivers in nursing homes. Nevertheless, they did find that for those who do experience role overload and are unable to find relief, the strain can have widespread consequences on the caregiver affecting their work, finances, socioemotional support, and emotional well-being.

Environmental Demands

Two environmental stressors were also mentioned in the stories of the adult daughters. Some women talked about the importance of their perception of the facility and their degree of satisfaction with the care their parents are receiving in the home. Unease with the facility or the care being provided can be an added source of stress for family members. Most of the adult daughters came to the realisation of the importance of this aspect to their role by past experiences in environments in which they were very unsatisfied. Carrie-Anne reflected back on her discomfort with the facility her mother was in previously:

> When she [mother] was in the other facility I was more concerned with her safety than I am now and so I looked at it in a little different light than I do now because I feel that she is a little safer in the environment that she is in now. Over the time that she went from facility to facility, I was very concerned about safety because she had several falls. She is at times loud and so people would push her, that kind of thing. It doesn't seem to be as bad now. I had those concerns, not that I could do a lot about it but I had the concerns about her.

Similarly, Janet and her husband James recounted their dissatisfaction with a previous facility Janet's mother had lived in:

> James - We weren't very happy with [the first facility].
> Janet - It is disgusting. It is the most disgusting and to me that place brings people who are, like when she went in she was pretty good I mean, you know, considering the disease but by the time she left, what four months like June until January...
> James - The atmosphere there increased her Alzheimer's.
> Janet - It was horrible, it was really horrible.
> James - We think.
> Janet - No, I don't think, I know...You have no idea how I wanted to get her out of [that facility]. I was even depressed when I would come home, I must say some of the staff were excellent, excellent but that wasn't sufficient.
> James - They could only do so much.
> Janet- There wasn't sufficient staff and it is pathetic. It is pathetic that people have to be as I say in holding tanks until they [can] get somewhere else. But some people chose to stay there
> ***So it made your role much more difficult?***
> I just wanted to keep her. I didn't want to bring her back home [to the facility]. I didn't want to bring her back. We had a few bad experiences there.

Although few women were experiencing this issue in the facility their parents were now in, it became clear that when family members are concerned about the quality of the care or the safety of their parents, they can experience great distress and concern in their role.

A second environmental stressor mentioned by some of the family members was the loss of privacy in the facility. Having to visit their parents in view of staff, residents, and other family members was often difficult and seemed abnormal for the women. Diane, for example, talked about her discomfort with her visits being on display:

> I still find [visits] stressful....There is almost a sense that your interaction with your father is on display, it is public with him being in the home...You know they do monitor what is going on and they don't ever judge but the feeling that if you give him a kiss or you give him a hug or something, this is a public display of affection which doesn't feel comfortable.

Some of the women suggested that there was a need in the facility for a "place where they can visit privately" (from Mable's transcript) with their loved ones. This recommendation by some of the family members is interesting given that the facility had turned over one of the family visitation rooms to an ongoing research project. Hopefully the administration's plans to provide more family visitation space in their renovations to the facility will address this problem.

To summarise thus far, the stories told to me by the women involved in the study reflected several demands and stresses associated with the institution-based caregiving career. Perhaps the most distressing for these women were the emotional demands of the role, particularly those associated with watching their parents slowly deteriorate and with dealing with ambiguous loss. These women also experienced behaviour and environmental demands at different points in their caregiving careers as well. It is important to stress, however, that the demands of the caregiving role and the needs of individual family members change over time depending on the changing circumstances in the role. Thus, certain stressors may be more salient at certain points during the caregiving career than others. Further, it became clear from the women's descriptions that family members usually experience a combination of simultaneous demands to deal with in their roles.

Resources and Coping Techniques Utilised in the Caregiving Role

Despite the difficulties and demands associated with the institution-based caregiving role, many of the adult daughters also described the experience as "rewarding" and talked about how they had "become stronger" in having to take on the role. Although much of the early caregiving research focused on the negative impact of caregiving, recent studies have demonstrated that caregivers often have positive as well as negative experiences in their caregiving roles (Farran et al., 1991; George & Gwyther, 1986; Hasselkus, 1988; Javanjee, 1994; Lawton, Moss, Kleban, Glicksman, & Rovin, 1991; Motenko, 1989; Noonan, Tennstedt, & Rebelsky, 1996). The narratives also reflected the strengths and resilience of these women in relation to the many ways they find to cope with the situation. Family members identified several resources and coping behaviours they drew on in order to cope at various points in their caregiving careers. Patterson (1988, p. 97) defined resources as "traits, characteristics or competencies of individual family members, the family system, or the community which can be used to manage demands". Resources, thus, refer to what is available to caregivers to assist them in coping with the demands of their roles, as opposed to what caregivers do (Pearlin & Schooler, 1978). The women in this study relied primarily on four types of resources throughout the caregiving process: personal, family system, facility, and community resources.

Personal Resources

An important personal resource for these women simply involved drawing on the sense of satisfaction, peace of mind, or even pleasure family members felt in knowing that they had helped their parents in some small way. Others talked with great pride about their resourcefulness in the role – how they were able to manage difficult situations. Sarah, for example, spoke with much pride about her ability to help not only her own mother but the other residents and staff too:

> Sunday it was a rainy miserable day and I went to visit mom at [the facility]. It was a horrible day and lethargic, even the staff were like that. So I said, "oh my goodness, this is awful". So I went over to the piano and I can't play without reading the music of course. I haven't got my glasses on, so I'm ad-libbing it. One of the girls and I started humming, one of the girls started singing, another of the girls started doing this (snapping her fingers). One of the girls from Jamaica started doing "banana boat come", well the patients started to sing....My point here [is] that on a rainy dull Sunday, both the staff and residents were made to feel better when they sang.

Marian also discussed how she tries to concentrate on the good times and gets much pleasure out of doing little things for her mother:

> ...you do little things for her that you know she gets pleasure out of, like she loves ice cream. When she comes here, I'll ask her what she'd like and I say would you like some ice cream or would you rather have something to drink and she'll say, "oh I'll have some ice cream" and she sits there like a little girl eating this ice cream. So you sort of feel well gee, that's made her happy or just taking in a little flowers or something to her. She was one that always loved flowers, so she does appreciate that. There's a lot of little things that you feel good about doing for her, they're not big things or that much but it can bring a smile to her face and you feel good about that. That's probably why a person does the things they do because it brings some happiness to a person and that makes you feel good.

These women seemed to draw on the sense of comfort and even the pride they felt in having done something special for their loved ones or others. Caregivers in other studies (Noonan et al., 1996; Farran et al, 1991) have also described the gratification and satisfaction associated with caregiving and the confidence and pride they feel in being able to help in the care of their loved ones. These aspects of the role are often described as rewarding for the caregiver and may help buffer some of the negative experiences in the role.

Many of the women also talked about the reciprocity of care, how the parents had once taken such good care of them and now it was their turn to return the care. Eva, for example, described to me the relief she felt in being able to reciprocate the love and care that her mother had always shown her:

> I like doing it. She did for me and so now I'm doing for her, make her happy…To me, it just, it brings out the goodness in you I think, the good feeling. When I leave here then I figure I've done my part.

Similarly, when Candace was asked if there were any positive aspects of caring for her mother, she replied: "I think I am giving her back some of all the years she gave me". A sense of family responsibility and reciprocity emerged as an important meaning theme associated with the rewards of caregiving in the study conducted by Noonan and her colleagues (1996). Norris and Tindale (1994) described this type of exchange as "global reciprocity". They argued that reciprocity is more often long term across the life span rather than situational and that it is very much related to the history of the relationship and attachment. In most cases, the attachment to their parents for the women in this study was very strong and now that their parents needed care it was a good opportunity for them to give back to the parents some of what they perceived their parents had given to them. As Evelyn explained: "It is returning to a loving caring person what she gave to me all my life."

Another personal resource mentioned by a few of the women was a strong faith in God. In Barbara's profile in Chapter Five, she elaborated on how her faith had helped her cope with the demands of caregiving and her feelings of being a failure. Other researchers have also suggested an important link between spirituality and coping with the demands of caregiving. Farran et al. (1991) and Jivanjee (1994, p. 40 and p. 41) proposed that spiritual support can be a central resource for some caregivers "giving them strength to cope with the demands of caregiving" and helping them "find meaning in their suffering and to grow".

Family Support Resources

Research on caregiving has begun to recognise the contributions of others and the notion of the family care system in the care of older relatives (Cicerelli, 1992; Keith, 1995; Matthews, 1987; Matthews & Rosner, 1988). Several researchers have found that family support, both in terms of emotional support and direct assistance with the care of a loved one, is an important resource in adaptation to chronic illness (Patterson, 1985; Sargent & Baker, 1983). In the caregiving literature, Jivanjee (1994) found that emotional support from a person the caregiver is close to helped caregivers cope with the demands of caregiving. Further, Pratt et al. (1985) reported that assistance provided by other family members was associated with lower levels of caregiver burden. Pushkar Gold et al. (1995) confirmed this finding suggesting that social support can play a key role in reducing the negative outcomes associated with caregiving. These researchers also concluded that a larger support system was related to increased positive outcomes or experiences in the caregiving role.

Nonetheless, Thompson, Fulterman, Gallagher-Thompson, Rose, and Lovett (1993) did not find a relationship between caregiver burden and instrumental or emotional support. In their study of community-based caregivers, they found that engaging in social interaction for fun and recreation was the most important contributor to diminished caregiver burden. In a community setting where the physical demands of caregiving and the risk of isolation can be so much greater, social integration rather than social support may be more important in coping with caregiving demands. In the institutional setting, family members are at a somewhat less risk of becoming isolated. Thus, the support from other family members, particularly in dealing with the emotional demands, may be a more important resource for some in this context.

The adult daughters I spoke with talked about how their family members offered both emotional and instrumental support which, in turn, helped them in their caregiving roles. Amanda described the difficulty she was having struggling with ambiguous loss and how talking to her sister often helps her cope:

> ...once I didn't want to come because I had had such a terrible visit with her [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 <u>negative</u>, <u>negative</u> thoughts that I hadn't even thought before. Like have we all been pretending that this woman is even alive, you know. Like has it all gone and vanished. And then my sister and I call each other and you know we talk about what we've seen and whatever. And um, that usually helps. Like Sylvia will call and she'll have a crying jag or I'll call her.

Many of the women gained strength and comfort in their roles from their husbands. Janet, for instance, had her husband at the interview with her "for emotional support" and during the interview described how he sometimes helps her in her role, perhaps more so by easing her sense of guilt:

> If I couldn't have her [my mother] out, say something came up and I would say I don't know if I can do this this week, I don't know if I have enough time. George would say you shouldn't feel that you have to do this and he is very logical and sometimes I wouldn't be as logical about it. Then he would make me feel better, it was okay. It was more or less him putting a stamp on it saying it is okay Janet if you are not there right this week, you don't have to go.

Other adult daughters relied on other family members such as children and aunts for emotional support.

The adult daughters also talked about how family members came together to share in the caregiving responsibilities to ease the pressures felt by one family member. Helen explained how she and her sister try to negotiate the visits to her father:

> My one sister and I are close, the one that lives not far from here, and we phone almost daily and we also check who has gone and she says I am tired tonight or I have my exercise class and I say don't worry I was there this morning and I am going again tomorrow or she will say the same. I used to go in Saturdays after my market day and it is always hectic and I am always quite tired but I just felt that I am on my way might as well stop in and get my visit in, but the last three weeks I haven't and she has gone instead. So we help each other out, make sure we are capable...We do stay in touch a lot and just comment on who is going when.

Diane commented on the support she gets from her husband:

> My husband is an incredible person and I get phenomenal support from him and he is just as involved. There are times when my mother has called him at work and he says you sound upset and he says come and we will go and have a coffee. He has given, given as well and when I hit these times he will say, come on Diane, it is family, we can do it. That is the message and support me in it as well but not only is he sort of saying you can do it, we can do it and he certainly takes his share, I mean he gives and gives and gives.

Some of the women described how their children lend a hand in helping with the care. Janet recalled how one of her sons had come through for her and her mother at Christmas:

> Our boys were very good, if we were gone, especially the youngest was very, very close to my dad and mom and he was our fill in caregiver and would come out [to the facility]. He was the one, was it last Christmas, I wasn't going to bring [mother] out because the minute I would get her there she would want to leave and then with me being, let's say the one doing everything that day, you wouldn't want to take her but you would feel you have to. But, he [my youngest son] said, "bring her and I will look after her all that day", and he did...He got pictures out that she had given him years ago when she sold the apartment. He kept her busy trying to remember things and this went on for most of the day until supper time, until right after supper and then she was ready to go home.

Being able to rely on other family members to help when the adult daughters are away or when they are feeling overwhelmed helps these women better manage their role.

Facility Resources

Some of the family members also commented on resources within the facility which helped them cope with various aspects of their caregiving role. For example, some of the adult daughters described different ways that the staff provides support to them which helps at various times in their role. Barbara elaborated on the support the Director of Nursing Care had given her on her daughter's wedding day:

> I really appreciate [the Director of Nursing Care]. Our daughter got married a couple of years ago and we had debated what to do about mom, and then whether our daughter would just go to the nursing home to see mom. We didn't think that we could have mom at the reception because it would be too difficult for her to eat and it would just be embarrassing for her as well as it wouldn't mean that much to her. And, so when we were still debating about it, I don't know, [the Director of Nursing Care] came and we didn't even ask about this, but she offered to bring my mom to the wedding. So she took it upon herself to transport mom from the nursing home and brought her to the wedding ceremony and kept her there just for a few pictures and then she took her back. Mom didn't come to the reception but you know, I just really appreciate [her] for doing that and I never seemed like I could thank her appropriately for doing that. Like I really still feel indebted to her.

Candace talked about the support she received from a woman who had worked at [the facility] when her mother was admitted. Having a contact at one of the most difficult turning points in her caregiving career, helped Candace cope with the admission process and made the transfer much easier for her:

> Within the first few months that my mom was in [the facility] they had a lady... she was doing this service for [the facility] on the side and she came in and she introduced us to [the facility] through the people. She would tell us, who [the Director of Nursing Care] was, her title, what her duties were, and she would go down the list of all the different people who were there and if we had a certain problem, who to go to and who not to go to and if we saw something that we didn't like, you know, things like this. That was excellent. That was the first time in all the years that my mom had been in a home that I felt comfortable and I knew what was going on and what to do if I needed to have something done for my mom. It was just wonderful. I can't even remember the woman's name but she was really nice...It also put [us] in touch with people

> that were coming in at the same time and a lot of us had much the same concerns and it was really nice that you didn't feel so alone because you were meeting other people that were in the same circumstances with you, had the same concerns and the same feelings of frustration and anger and everything else...I can't praise it high enough, it was excellent. I think every home should have it.

Some authors (Riddick et al., 1992; Pratt, Schmall, Wright, & Hare, 1987) have stressed that positive adaptation of family caregivers requires health care providers who are trained to be sensitive and understanding to family members' needs and who are able to provide both support and information. The little things that the staff did to provide support to the family members were very important to these women in helping to ease the demands of the role.

One other program that is provided by the facility to help family members cope with the emotional aspects of caring is a monthly support group. Some of the women commented on how they felt this support group was important in helping them adapt to the changing circumstances. Deborah discussed this in her interview:

> I really enjoy the support group that they have set up....I used to feel so isolated and alone in my feelings. I struggled with what has happened to my family. The support group meetings have made me realise I am not the only one facing challenges. It's nice to hear how others cope.

Evelyn also described how the support group provided her with the opportunity to hear what other family members have been through and how they cope:

> We had meetings here...where other family members can just talk about their situation, just how you overcome it and how you justify everything in your mind is part of the battle of putting a loved one in here. It is something that, well, I just never thought I would be doing it but once you are faced with it you just, your mind in some cases can't handle it. You are trying to sort it out, talk it out, and sometimes it is better to hear what other people have gone through and it makes it easier.

Other studies have documented the value of social support programs to institution-based caregivers (Monahan, 1995; Pratt, Schmall, Wrigtht, & Hare, 1987). Recognising that family members continue to experience stresses after the institutionalisation of a loved one, practitioners have also stressed the need for support groups in these settings. Several benefits of institution-based support groups have been identified. Support groups, or other therapeutic programs which bring family members together, help caregivers deal with the difficult transition to the facility (Greenfield, 1984); provide a forum for discussing feelings, concerns, and difficulties with others in the same situation (Dupuis & Pedlar, 1995; Greenfield, 1984; Schmall, 1984); provide opportunities for family members to learn about the disease process and to share information and solutions to problems (Coen Buckwalter & Richards Hall, 1987; Schmall, 1984); and serve as another source of social support (Dupuis & Pedlar, 1995). The caregivers in Jivanjee's (1994) study, for example, found the support group helpful in that it provided a venue for them to share their experiences with others in similar situations. They were also able to learn new skills and how others deal with various problems. Further, Monahan (1995) found a significant correlation between support group and workshop participation and burden levels in caregivers of residents with dementia. Attendance at support groups was significantly related to lower levels of burden.

Another facility-based resource which the family members mentioned was the quality of care their parents were receiving. Knowing their parents were well cared for gave these women a sense of peace. The family members particularly appreciated how caring the staff were and the willingness of the staff to provide affection and emotional aspects of care as well as the physical care. Diane described her comfort in knowing the staff members are so caring:

> You know my sense is that the staff are kind and caring and they are not, they are not upset with giving a hug or giving a touch or and I think that a lot of institutions in this day and age are very frightened of that and yet my father needs it. He responds to it and when he is given that sort of hands on care it unburdens me. There have been times when I have really wondered, my mother gives him hugs and kisses and stuff but the staff will as well and I don't think he knows where it is coming from a lot of the time. But, I would hope that gives him a warm secure feeling.

Similarly, when Helen was asked if there were factors within the facility that help her in her role, she emphasised how important it is to have a caring staff. She stated:

> [The staff] are supportive and they appreciate it when you come by and I think it is important for them to hear comments from you, not just compliments but just that...they like to hear if something is amiss too. Staff cares and that's important....I feel comfortable and I have peace of mind. Now if it was an agitated staff, you could probably feel the vibes in the air I think and I would be very nervous having dad here and it would probably upset my life and I would stew about it or loose sleep over it.

Knowing their parents are well cared for and safe seems to give the women a sense of relief they can draw on when trying to reconcile having to admit their parents to a long-term care facility. Jamie talked about the comfort she feels in knowing her mother is well cared for:

> There's a certain peace in knowing that mother is safe. She has food to eat, a warm place to be, people who will respond instantly if she's in distress, people who will know if she's in distress. That is a source of great relief to me.

Mary also described a sense of relief in knowing her father was receiving quality care:

> You are leaving someone you love. It is I am sure what parents go through leaving their kids at Day Care. It has got to be the same kind of idea but if you can leave them and feel that they are in good hands.....It makes a big difference to know that he is some place, I guess a warm, dry, safe [place] where they are going to make sure that all his needs are taken care of and you can do everything and feel quite comfortable doing it.

Interestingly, the definitions of quality of care for many of these women were consistent with the perceptions of the caregivers in the studies conducted by Bowers (1988) and Duncan and Morgan (1994). In these studies, family caregivers felt that quality care involved both technical tasks as well as the more emotional and personal aspects of care. Thus, staff members should provide both to residents. These researchers also found that familial caregivers are much more comfortable and satisfied in their roles within long-term care facilities and that fewer conflicts arise when family members know that the staff are not merely performing the technical care but openly demonstrate a "caring about" approach with their loved ones as well.

Community Resources

Family members also relied on various community-based resources such as community support groups, reading materials obtained from the community, friendship networks, the church, and work to help them with various aspects of their role. For example, some of the women talked about their involvement in community support groups provided by the Alzheimer's society or their work as an important adaptive strategy. Evelyn explained her involvement in a community Alzheimer's support group:

> ...I do go to the meetings and try to understand about other people, what they go through and what the symptoms are and realise that there really isn't any two the same, and that some progress further than others...I don't have a lot of time to really spend with the [community] Alzheimer's group but I felt it important that I understand what was happening to my mother and if I could help anyone else too.

Shelley had the opportunity to participate in a support group offered at her place of employment. She described to me how her involvement has helped her cope:

> There's an employee's support group through [my work] that's offered as part of our group package. So I have, I have been using that and one of the people that helped me as a result of this support thing was someone who had been aware of Alzheimer's. So I had a session or two with her and that really helped me deal with the mother piece of it. I think it was the letting go piece, I was losing my mom, I had maybe lost my mom...this support really helped me. I'm

> sort of winding it down now but its been really beneficial for the last almost a year.

Other family members did not feel it was important to be involved in a support group but felt they needed to learn as much about the disease process or the caregiving process as possible. In their search for understanding, these women chose to use the reading materials available at community agencies or at the library. Carrie-Anne stated: "I have done a lot of reading on Alzheimer's and related disorders myself, so that is another thing that there is available. There is more literature than there was before". Similarly, Sarah did not participate in the support groups but felt that she was able to relate to many of the books that were written on Alzheimer's. She described two such books to me during her interview:

> When I read that book, Living in the Labyrinth, I mean, well here she was going through it and writing about it and that was really, and then Scar Tissue, I found that one, I related to that one very much and as did my sister because we were on the outside and we really related to that. That we found one of the best books ever written.

Others did not feel the need to be involved in a support group because they already had supportive friendship networks developed and relied on them as emotional supports at various times in their role. Amanda commented on her friendship network:

> ...I have a lot of friends. Like over the years, I have two girlfriends I can count on any time to help me if I ever needed it. And then we got a group of gals. Years ago at [University], we took a creative divorce course. So about 13 of us, every Wednesday night we'd go to [this bar] for drinks after [class]. And we would sit and we would laugh. And pretty soon we would have the entire group that was there that night, in with us talking....So it's great. I have a great support system in that way.

Similarly, when Mary was asked if she felt there were any services or supports that might help her in her role she emphasised the importance of her friendship network:

> I don't because I have terrific friends and so that is my support group is my friends. I have a girlfriend who, actually her father has just been diagnosed with

> Alzheimer's disease as well. So I have this great support group of friends and our parents are all aging and our parents are all going through different things and we have each other. I have a terrific husband as well who is very supportive. So I have my support groups, I don't need outside support groups....But my support is through my friends and that is all I need.

Indirect supporters also used community resources such as volunteer organisations to help develop these same type of support systems and friendship networks for their "other" parents.

Some of the adult daughters also talked about the support they received from other community sources such as the church and their work. Grace explained how her church group was a great source of support for her:

> ...But it's just this year that I've gotten in with this wonderful church and they have fellowship and they really believe that being Christian is spending all kinds of time together with a church group not just you know 11:00 till 12:30 Sunday mornings. And it's wonderful. And again, I've talked with them about this and I've talked with the minister about it...So yah, they helped me a lot.

Work also served as a resource for the adult daughters, almost providing an escape from the role. Barbara, in her profile presented in Chapter Five, described the importance of work in helping her regain some of her self-confidence after admitting her mother to the facility. Amanda also talked about work as being therapeutic in her life:

> The work turns it off. I mean, to me, work, all my life work has been therapy. If I didn't work I think I would have, they would have put me in a box years ago. Oh yeah, I think work is a tremendous therapy for people.

Recent research supports the idea that combining work and elder care responsibilities can have positive benefits as well as negative impacts on caregivers (Brody, Kleban, Johnsen, Hoffman, & Schoonover, 1987; Enright & Friss, 1987; Neal, Chapman, Ingersoll-Dayton, & Emlen, 1993; Scharlach, 1994; Scharlach, Lowe, & Schneider, 1991; Skaff & Pearlin, 1992). Work can be a place of respite or a haven from caregiving, can provide opportunities to demonstrate personal competencies and to re-establish or maintain feelings of self-efficacy, and can serve as a source of social support for caregivers (Baruch & Barnett, 1986; Brody, 1985, 1990; Goldstein, Regnery, & Wellin, 1981; Poulshock & Deimling, 1984; Scharlach, 1994; Scharlach et al., 1991; Skaff & Pearlin, 1992). Employed, community-based caregivers have also shown significantly lower levels of stress than their unemployed counterparts (Giele, Mutschler, & Orodenker, 1987).

The discrepancy between those who gain positive benefits from work and those who experience role overload (Brody's women in the middle) leads to the question, why do some caregivers benefit from employment while others experience increased stress? For example, Skaff and Pearlin (1992) found that a number of roles such as being married, having children, and being employed provides protection against the loss of self in caregiving. They suggest that the more roles a person has the more opportunities she or he has to evaluate and reaffirm positive or valued aspects of the self. They further proposed that because the employment role and identity may be the one farthest removed from family roles, employment may provide the greatest protection against the engulfment of self in the caregiving role. Similarly, Scharlach (1994) found support for the role compensation perspective (Burke, 1986; Champoux, 1978; Near, Rice, & Hunt, 1980; Zedeck & Mosier, 1990). From this perspective, opportunities in one role, such as the work role, can compensate for deficits felt in other roles, such as the caregiving role. Work, for instance, may provide caregivers with the opportunity to demonstrate competence and enhance feelings of self-efficacy which may have been threatened or diminished in the caregiving role (Scharlach, 1994).

A closer review of the literature, however, revealed that the research which examines the relationship between multiple roles and the experience in the caregiving role have generally failed to consider the quality of the experience within various roles. It seems likely that caregivers who perceive the work role as stressful and/or unrewarding may not receive the same positive outcomes of involvement in work as others do who have positive experiences in the employment role. Further, if caregivers perceive several roles (e.g., parent, wife, employment) to be unsatisfying and stressful, it seems reasonable that they may be more likely to experience the consequences of role overload, to be more negatively impacted by caregiving, and to not find the employment role to be therapeutic in any way.

Coping Techniques

As well as drawing on the personal resources and those aspects of the role that were rewarding, the family support available, and the support provided in the institution and the community, the adult daughters also utilised several coping techniques to help adapt to the changing circumstances of the role. Patterson (1988) defined coping behaviour as:

> A specific effort by an individual or a family which is directed at maintaining or restoring the balance between demands and resources. As such, coping may function to (a) reduce the number or intensity of demands, (b) increase or maintain the family's resources, (c) alter the meaning of a situation to make it more manageable, and/or (d) manage the tension associated with unresolved strain (p. 100).

Coping responses represent the concrete efforts of people to actively deal with the difficulties they encounter in their various roles (Pearlin & Schooler, 1978). Three different types of coping strategies have been identified in the literature: problem-focused (active responses aimed at managing or altering the problem causing the stress), emotion-focused (efforts directed at managing or regulating the caregiver's emotional response to various demands), and cognitive or appraisal-focused (efforts which involve altering or re-framing the meaning of the stressor or situation) (Folkman & Lazarus, 1980; Lazarus & Folkman, 1984; Wright, Lund, Caserta, & Pratt, 1991). The women involved in this project used a range and combination of these strategies to cope with the demands of the role.

First, some family members talked about the problem-focused strategy of re-prioritising activities as an important coping strategy. In re-evaluating their priorities, adult daughters gradually reduced their involvement in the home over time in order to deal with both the behavioural and emotional demands of the situation. Pauline described for me how she gradually relinquished some care tasks in order to cope better in her role caring for her mother:

> I came more often. Like I did, I took all her wash home to do and ya I came usually two or three times a week but if she was sick I came every day which wasn't easy but I did it, you know, because I wanted to be here. But, now I just...the doctor's tried to tell me you have to start looking after yourself.
> ***When did you start cutting down your visits?***
> Probably after the first year but then it depended on how I was feeling.
> ***What do you think changed it for you?***
> I don't know really. I guess maybe just because my own condition was getting worse and I just couldn't do it. And, I just felt like running the wash home all the time, it just didn't make sense. I mean, sure, I mean the stuff down here is not as good as doing it at home but with the running, the running constant, you know, you just get to a point where you have to say no. You just can't do it and it really isn't necessary when they have a laundry service here.

Similarly, Candace emphasised how she needed to cut down her visits and involvement in the home and how that has been a positive step in her adaptation to the role:

> I have needed [the time off] because I was going so regularly and I have needed to get rid of some of the stress...I feel better. I feel healthier because I am not going as much. I don't feel the stress and I don't feel the need to be there. I felt, there was a stress and a burden to always be there and available and make sure that things were going okay. And now I feel better. When I go to see my mom now I can sort of enjoy the visits because I don't feel that there is a need to be there and to make sure she is okay. I know she is okay, that she is being taken care of. So, emotionally I feel better.

Another problem-focused technique utilised by some family members involves taking actions to increase their resources. When they feel overburdened or overwhelmed in their roles, some of the adult daughters take efforts to expand the family support available by encouraging other family members to become more involved in sharing the caregiving responsibilities. Leandra, in her profile, described a point in her caregiving career that she had to call on her brother and sister-in-law to take over the care occasionally so she could have some "off" time. In addition, as caregivers reach phases in their caregiving careers where they feel they need to take advantage of some of the other resources available (e.g., support groups, community groups), they add these new resources to their repertoires.

The women in this study, however, tended to rely more on cognitive-focused strategies. The cognitive-focused strategies described in the women's stories included reframing specific situations, re-defining the situation as a whole, looking for the positive in the situation, and shifting the focus to taking things one day at a time. A coping technique common in the women's narratives was the strategy of re-framing specific situations or the situation as a whole. For example, the women talked about how they tried to change their perceptions of specific situations so they could view the circumstances in more positive and realistic ways. This was viewed as a necessary strategy in order to adapt well to the facility and the changes witnessed in their loved ones. When her mother was first admitted, for instance, Dora struggled during each visit with trying to find her mother's clothing and other belongings. She spent much of her time searching out items that had disappeared from her mother's room. Realising that her efforts were futile, she gradually came to re-frame the situation in such a way that everything in the facility was seen to be "universal", and "interchangeable", everything belonged to everyone. With this new perception of the situation, it no longer was necessary for her to continue to find her mother's belongings. This new perspective on the situation helped her deal with that particular stressor.

Other family members talked about the importance of re-defining the situation as a whole in more realistic ways and learning to accept the situation, another cognitive-focused strategy. This becomes particularly important when family members are coping with ambiguous loss. Mable explained the difficulty she had dealing with the psychological loss of her mother. She copes with the situation now by continuously reassuring herself that she is doing all she can do for her mother at this point in the disease process:

> It is so difficult you know. It is just like you are coming in and you are talking to a body but it is not really my mother. Mother died five years ago, this is just a body and 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.

Marian talked about a similar process that she goes through to remind herself that she is doing all she can do:

> To know that she's comfortable and that you're trying to do what you can to make whatever years she has left, you know as enjoyable as you can and you try to do what you can for her....I see how she cared for her own mother and think maybe I should be doing this and feeling a little guilty about that but really, the situation is different with my mom than what it was with her mom so I guess I sort of try to rationalise that all out and say well I just probably couldn't do that, to have her in my own home with my set up of stairs and everything. It wouldn't work out so you try to, well okay I'm doing what I can do and you do as much as you can.

The adult daughters also emphasised the importance of using the cognitive-focused strategy of trying to look for the positive in the situation. For example, Sarah stressed in her profile in Chapter Five the importance of appreciating even the little things such as her mother smiling, or knowing her mother is comfortable. Marian also commented that an important coping strategy for her was to remember back to the good times and to hang on to the memories of her mother she had from before her mother became ill: "You remember and reflect back over the years of all the good things she did and that's what you kind of want to be able to remember with her".

The women's stories also reflected a philosophy of taking one day at a time. They recognised that the demands were going to change and their roles were going to alter and thus concentrating on the present. Leandra commended: "I think I've come to grips with living for the day and the best of today". Similarly, Marian emphasised that she was able to cope by dealing with each day and each problem one at a time:

> One doesn't know what's ahead. My mother always was one to say you cross the bridges when you get there. So I try to go along with that, cross every bridge as they come.

The techniques of re-prioritising activities and re-framing the situation have been identified by caregivers in other studies as important coping strategies. The caregivers in Jivanjee's (1994) study, for example, emphasised re-prioritising activities, staying calm, keeping a positive attitude, taking one day at a time, and accepting the situation as coping behaviours they used to help deal with the demands of caregiving.

Finally, a few family members employed more emotion-focused coping strategies in their attempts to cope with the situation. For example, unaccepting relinquishers turn to using avoidance techniques and almost completely cut themselves off from the institution and their parents. Avoidant-evasive coping strategies can be ineffective and more harmful than beneficial in dealing with the emotional demands of caregiving (Pruchno & Resch, 1989). In fact, the coping literature suggests that problem-focused coping and positive reappraisal and re-framing techniques may be far more effective in decreasing caregiver stress and increasing life satisfaction and well-being than emotion-focused strategies such as those involving avoidance (Felton, Revenson, & Hinrichsen, 1984; Pratt et al., 1985; Stephens, Norris, Kinney, Ritchie,

& Grotz, 1988; Wright, Lund, Pratt, & Caserta, 1987). Nonetheless, unaccepting relinquishers believe that avoidance of the situation is the only way to cope given the pain and difficulties they are experiencing in visits. For them, separating themselves from the situation is more adaptive than remaining involved and going through a continual grieving process.

It became clear in listening to the stories of the adult daughters involved in this study that the women developed and drew on various personal, family support, facility, and community resources as well as several coping techniques to help cope with the demands of their caregiving roles. They drew on various combinations of these capabilities and resources in an attempt to manage and balance out the distresses and pressures they were experiencing in caring for their parents. Given that the most common and most distressing demands for the women were those related to emotional responses to the illness and the circumstances, it is interesting to note that the women identified cognitive-focused strategies the most. Researchers have come to recognise that the costs and demands of caregiving are intrinsically inter-connected to the rewards and positive aspects of caregiving and to the resourcefulness of the caregiver. In addition, several researchers (Auerbach, 1989; Felton et al., 1984; Rohde, Lewinsohn, Tilson, & Seeley, 1990; Vitaliano, DeWolfe, Maiuro, Russo, & Katon, 1990; Williamson & Schulz, 1993) have emphasised the importance of considering the "fit" between specific coping strategies and the demands of a specific stressor. They suggest that some coping strategies may be effective in alleviating the pressures from some stressors but other strategies may be required for other stressors. For example, Williamson and Schulz (1993) found that direct action strategies such as relaxation may be effective in dealing with the practical aspects of care but may not be as helpful in coping with the emotional responses associated with losing a loved one. Further, direct action to try eliminate problems or stressors that cannot be reversed, such as memory deficits or deterioration in communication associated with dementia can be futile, exhausting, and lead to higher levels of depressed affect (Williamson & Schulz, 1993). The research seems to suggest that the use of cognitive-focused strategies (e.g., reframing/reappraising the situation, acceptance of situations that cannot be changed) used by the women may be the most effective in dealing with the emotional demands described in the women's stories (Williamson & Schulz, 1993). For those stressors that were amenable to change, such as the behavioural demands of the role, the women tended to use more active, problem-solving techniques (e.g., reducing their involvement, taking actions to increase their resources). Thus, as many of the women in this study had done, it seems important to develop a wide repertoire of resources and coping techniques to draw on in order to adapt to the demands of the caregiving role.

Nonetheless, the women in this study still appeared to experience the caregiving role differently. It is because of the diverse mix of demands experienced by various caregivers and the wide range of resources employed to help adapt to various situations at different points in the caregiving career that the institution-based caregiving role is experienced differently by family members. Perlin, Mullan, Semple, & Skaff (1990) considered the link between the demands and resources associated with caregiving in their conceptualisation of caregiving stress. They described caregiver stress as:

> a mix of circumstances, experiences, responses, resources that vary considerably among caregivers and that consequently vary in their impact on caregiver's health and behaviour. The mix is not stable; a change in one of the components, can result in the change of the others (p. 391).

This conceptualisation of stress as well as the strong presence of the demands and resources in the women's stories emphasises the importance of including both in a dialectic model of caregiving roles. Guided by McCubbin and Patterson's (1983a, 1983b; McCubbin et al., 1982; Patterson, 1988) Family Adjustment and Adaptation Response Model (FAAR), I incorporate both of these aspects (i.e., demands of caregiving and resourcefulness of caregivers) in a substantive grounded theory of institution-based caregiving career paths. This theory is presented in the next and final chapter of this dissertation.

CHAPTER SEVEN
A DIALECTIC MODEL OF INSTITUTION-BASED CAREGIVING CAREER PATHS

THE ALTERNATIVE CAREGIVER CAREER PATH MODEL

The stories told to me by the women involved in this study reflected anything but a uniform, stable, single caregiving role in the long-term care context. On the contrary the adult daughters' descriptions portray the dialectic nature of the caregiving role. The women describe different, conflicting perceptions of their roles in the care of their parents. In their recounts of the history of the caregiving role, they talk about how their roles have changed, often many times, over their caregiving careers. Further, their stories trace not one caregiving career path, but several possible alternative paths that adult daughters may take in caring for a relative in a long-term care facility. All of these are elements of the dialectic. In this chapter, I describe these elements further and bring them together in the development of the *Alternative Caregiver Career Path Model.*

Alternative Role Perceptions

Consistent with other research, the majority of the women in this study continued to have frequent contact with their loved ones after placement to the long-term care facility (Aneshensel et al., 1995; Bitzan & Kruzich, 1990; Hook et al., 1982; Moss & Kurland, 1979; Ross, 1991; York & Calsyn, 1977; Zarit & Whitlach, 1992). Most visited weekly or every second week, while others visited daily. Nonetheless, there was a small group of women who chose to have less frequent contact with their parents, visiting perhaps monthly or less. Further, as reflected in Chapter Five, the findings from this study demonstrate that adult daughters of long-term care residents do not necessarily perceive their institution-based caregiving roles in the same way. Adult daughters choose to play a variety of alternative roles based on the meaning of the situation for the individual family member. Five caregiving role manifestations emerged in the adult daughter's stories: active monitor, regular visitor, accepting relinquisher, unaccepting relinquisher, and indirect supporter. For the adult daughters involved in the study, this meant a role which could be focused on supporting both the staff and the parent, just the institutionalised parent, primarily the other parent living in the community, or focused on restoring one's own life. The focus of the role and the purpose ascribed to that role, in turn, influence the adult daughters' role behaviours; that is, their involvement in the facility and what they choose to do in the role.

Even within these role manifestations, the women individually created unique roles for themselves based on their own situations and experiences in the role at any one time. Thus, it is important to think about the key features which helped to define the manifestations in Chapter Five (e.g., involvement in the facility, role definitions/purposes, focus of support, pressure to be at facility, and so forth) along continuums of more or less importance. It is the mixture of key factors important to *individual caregivers* and the individual family member's place on a number of continuums that contribute to the uniqueness and individuality found in family member roles in long-term care facilities. In addition, how individual family members perceive various stresses, pressures, and crises and the combination of resources and coping strategies utilised by caregivers further contribute to the individuality of caregiving roles.

This approach to the caregiving role is not consistent with Litwak's (1977, 1985) task-based approach to caregiving. Within Litwak's framework, family members play only one static role within the institution over their caregiving careers; a resource role performing non-technical tasks. A number of the women in this study took responsibility as part of the care team for both technical and non-technical tasks. They preferred to think of themselves as "workers" (Glaser & Strauss, 1965), a "resource" to the facility in the total care system (Coen Buckwalter & Richards Hall, 1987; Hanson, et al., 1988; Linsk et al., 1988; Safford, 1980). Others preferred to play little, if any, role in their parents' care. Further, the women emphasised how important it was to them that the staff be able to provide emotional and social aspects of care as well as physical care. A division of labour was not acceptable to many of the adult daughters.

The stories told to me by the women were much more consistent with the role perception or meaning approach (Bowers, 1988; Duncan & Morgan, 1994). For these women, the meaning of the situation and their perceptions of the purpose of their involvement were most important in defining the filial role within the long-term care facility. The women who were more actively involved in the facility (active monitors and regular visitors) defined their roles in terms of three purposes: maintaining normalcy, monitoring their parent's care, and preserving the parent's sense of self.

These purpose themes are consistent with the patterns and themes found in other studies. For example, preservative care was the primary focus of the caregiving role for the family members involved in the Bower's (1988) study. The caregivers preserved their relative's sense of self by maintaining family connectedness, maintaining the relative's dignity, maintaining the relative's hopes, and helping the relative maintain control of the environment. Related to preserving a sense of self, the family members in the Duncan and Morgan (1994) study focused primarily on monitoring care. In their roles, they monitored staff behaviour, tried to find ways to get the staff to relate to their resident as a person, maintained ongoing relationships with staff members, and served as a role model for staff. The women in my study placed importance in monitoring care and preservative care, however, the most commonly identified theme in the women's narratives was maintaining normalcy. The stronger presence of maintaining normalcy in this study compared to the other studies is likely due to the differences in samples and the focus of the various research projects. The Bower's study included primarily residents who were physically frail. Preserving a sense of self is realistic in the absence of cognitive impairment. The Duncan and Morgan study included a sample of residents in relatively advanced stages of dementia which may explain the greater importance placed on monitoring care rather than a complete focus on preserving the resident's sense of self. Nonetheless, the focus of the Duncan and Morgan study was on the family member-staff relationship and the questions asked in the focus groups (i.e., What kinds of things make your caregiving either easier or harder for you? How does the kind of caregiving that people do at home differ from the kind of caregiving that people do when their resident is in a formal care facility such as a nursing home?) may not have been able to capture a purpose of maintaining normlacy. Ross (1991), however, found that the wives in her study placed the most importance in their caregiving role on visiting which could be similar to the adult daughters notions' of "just being there" and "visiting regularly", a crucial component of maintaining consistency and normalcy. The wives in the Ross study also described the provision of love, support, and companionship as important aspects of their roles. All of these aspects of care were connected to maintaining normalcy for the adult daughters in this study.

The adult daughters who were less involved in the facility seemed to define their roles differently than the more active women. Similarly though, they defined their roles in relation to how they perceived the situation and their purpose within that specific situation. Given the severity of cognitive impairment in their parents, accepting relinquishers did not feel that it was necessary to maintain normalcy, monitor care, or preserve their parents' sense of self. However, they did feel that they had a role in what they described as overseeing care to ensure their parents continued to receive quality care. That is, they defined their purpose in the role in terms of assessing how the facility operates and how people interact in the facility. The indirect supporters, for the most part, believed that their "other" parents were looking after their institutionalised parents' needs. Their purpose themes, therefore, focused on the "other" well parent in terms of assisting this parent with the caregiving role and monitoring the health and well-being of this parent. Although all of the women describe difficulties experienced in the caregiving role, the unaccepting relinquishers were the only group of women who tended to define their role in terms of their experience in the role as opposed to their purpose in the care of their parents. These women were struggling with several difficult emotions and issues related to the decline of their loved ones and their stories focus on these aspects of the role and how they try to deal with their emotional reactions.

Thus, the adult daughters brought a wide range of individual circumstances and meanings to the caregiving context and based on their individual situations and interpretations developed unique caregiving roles for themselves. Although some researchers (Rosenthal & Dawson, 1992; Ross, 1991) have described the various phases or patterns that caregivers may go through in their institution-based caregiving roles, few, if any, have recognised the various alternative roles caregivers may play in long-term care facilities at any one time.

Given the presence of a number of conflicting role perspectives in this study, an important question is: What factors help explain the differences in these perspectives? Although temporal phase in the caregiving career seems to be connected to some of the role manifestations, a closer examination of this factor suggests that it is not time itself that is related to caregiving role development but processes connected to time, such as the disease process. In fact, in this study, the most critical factor to role perceptions seemed to be the progression of the parent's disease. As the deterioration in a loved one progressed, the adult daughters were more likely to be faced with ambiguous loss, which, in turn, seemed to re-shape how the adult daughters thought about their continued role in the care of their parents. In fact, the adult daughters seemed to connect changes in their role with changes in their parents associated with the progression of the disease. Gretta, for example, stated: "It's [my role] changed as the disease progressed".

The literature focused on the relationship between the patient's impairment and caregiver functioning suggests that the relationship is a complex one (Gubrium, 1988). Gwyther and George (1986) concluded that the care receiver's level of impairment was relatively unimportant in determining caregiver functioning in the role. Other studies have also found a lack of a direct connection between impairment or patient symptoms and caregiver functioning (Boss, Caron, Horbal, & Mortimer, 1990; Deimling & Bass, 1986; Deimling & Poulshock, 1985; Fitting et al., 1986; Morzcz, 1985; Poulshock & Deimling, 1984; Zarit, Reever, & Bach-Peterson, 1980; Zarit, Todd, & Zarit, 1986). These studies, however, have focused primarily on community-based caregivers and on caregiver outcomes (e.g., caregiver burden; perceived strain) rather than on how the care receiver impairment influences caregiving role definitions or involvement.

Other literature suggests that the number of visits to insitutionalised relatives is not related to the amount of impairment in the care receiver (Greene & Monahan, 1982; Moss & Kurland, 1979; York & Calsyn, 1977). Nonetheless, the level of cognitive impairment was found to be negatively correlated to enjoyment in the visits (Moss & Kurland, 1979; York & Calsyn, 1977) and may shorten the length of visits (Moss & Kurland, 1979). Further, Dempsey and Pruchno (1993) found that neither parent's mental status nor length of stay in the facility were related to the family members involvement in technical or non-technical tasks.

One limitation of many of these studies is that they tend to define impairment in objective terms, for example, measuring the number of problems. Deimling and his associates (Deimling & Bass, 1986; Poulshock & Deimling, 1984), however, suggested that the caregiver's interpretation and appraisal of the impairment may be more important to caregiving functioning than perhaps objective impairment. Consistent with this notion, Puskar Gold et al. (1995) found that the caregiver's appraisal of patient symptomatology had the greatest impact on the extent of burden experienced in the caregiving role. It seems reasonable, then, that if the caregiver's perceptions of the patient's impairment affects their experiences in the role, these same perceptions may also play a role in determining how a caregiver will define their role in the care of their loved ones. In this study, the adult daughters' perceptions of the degree of cognitive impairment, and particularly the perception of the parents' psychological presence, was most important to the family member's experience and to their perceptions of what their role should be in the care of their parents.

The disease process, or the meaning of the disease process, only partly explains the differences in the role manifestations which emerged in the women's narratives. The majority of the adult daughters (active monitors, regular visitors, indirect supporters) described their involvement in caregiving as an obligation, their responsibility or duty as a family member. This sense of obligation is consistent with other research which has found a strong moral obligation and the sense of filial responsibility as motivating factors in providing care to an elderly parent, particularly in providing emotional support. (Blieszner & Mancini, 1987; Brody, 1981, 1985; Brody, Johnsen, & Fulcomer, 1984; Brody, Johnsen, Fulcomer, & Lang, 1983; Cicirelli, 1983; Hamon & Blieszner, 1990; Quinn, 1983; Walker, Pratt, Shin & Jones, 1989; Wolfson, Handfield-Jones, Cranley Glass, McClaran, & Keyserlingk, 1993). Wolfson et al. (1993) concluded that this obligation may stem partially from life-long attachments and affections between parents and their children. Finley, Roberts, and Banahan (1988) found that affection, at least toward a mother, showed a strong positive correlation with filial obligation. This did not appear to be the case for fathers. These authors, therefore, maintained that context is crucial in understanding relationship obligation and that obligation may vary according to the relationship with the parent or parent-in-law. Related to this, a family member's sense of obligation to provide care may, in part, be related to their perceived needs of the elderly parent and whether or not they feel those needs are being met by others (Adams, 1968). Perceived need certainly seemed to play an important factor in many of the women's stories in this study. Feminist theorists (e.g., Baines, Evans, & Neysmith, 1991; Dalley, 1988; Gilligan, 1982;

Lerrabee, 1993) argue that women are socialised into an ethic of care; that is, women are culturally conditioned to feel a sense of obligation to care for others.

Related to the importance of context, Pyke and Bengston (1996) identified two very different caregiving systems: individualist and collectivist. According to these authors, collectivist families focus on kinship ties and thus family roles tend to take precedence over other roles and obligations. Collectivists feel that many of their needs (e.g., sense of continuity, belongingness, and identity) are met by the family unit. They are more likely than individualists to describe their relationships with their parents in positive terms and to identify attachment to parents as a motive of caring. Collectivists show unlimited commitment to caregiving which, in these circumstances, can often become overwhelming.

Individualists, on the other hand, demonstrate a focus on such values as independence, self-reliance, autonomy, self-fulfilment and personal achievement. Individualists place a greater emphasis on self-sufficiency than on obligations to family members. Thus, they tend to be less committed and involved in caring for older family members and tend to rely more on formal supports. They do not abandon their parents but define their roles differently, primarily in terms of managing the parents' finances and caregiving arrangements and maintaining social contact. The primary motive to provide care seems to be obligation for individualists. They are also more likely to characterise their relationships with parents as negative than collectivists (Pyke & Bengston, 1996). These authors emphasised that the general orientation of the family and the meaning it attaches to care are directly related to the nature of the care provided by adult children. Certainly, these orientations may further help explain why some people are able to relinquish all care, as in the case of accepting relinquishers, while others continue to remain involved.

Attachment theorists have suggested that attachment may be a stronger motivator of help provided to older parents than obligation (Cicirelli, 1983). Others, however, have argued that caregiving is probably motivated by a combination of feelings of obligation and affection or attachment (Cicirelli, 1991; Walker et al., 1989). Ainsworth (1989) described attachment as a special case of the affectional bond which provided a sense of security and comfort related to the attached person. Bowlby (1979, p. 129) maintained that attachment was present throughout the life course, "[characterising] human beings from the cradle to the grave". He further suggested that once an attachment relationship was developed between child and parent, the adult child feels a need to protect the attachment figure, the parent, from loss or harm (Bowlby, 1979, 1980). Thus, in the presence of a life-threatening and life-changing illness such as Alzheimer's disease or other diseases/disorders causing dementia, "the adult child will attempt to provide help and care to maintain the survival of the parent and preserve the concomitant emotional bond" (Cicirelli, 1991, p. 34).

Early evidence (Blieszner & Shifflett, 1989) suggests that this attachment bond can remain relatively strong as long as the attachment figure is able to reciprocate, even in a small way, an adult child's need for emotional closeness and security. In an in depth study of five adult children caring for a parent with Alzheimer's disease, the adult child's affection for the parent declined over time in four out of the five cases. A closer examination into this fifth case revealed that this parent was the only one of the five who was still demonstrating emotional closeness towards her daughter. Over the course of care, she hugged her daughter and continued to tell her daughter that she loved her. This parent was able to continue to meet some of the adult daughter's needs for emotional security. Given the findings of this study, Cicirelli (1991) proposed "that if parents become too frail to offer psychological or emotional security to the child the basis for maintaining attachment is gone" (p. 17). Thus, the need to remain as actively involved in care likely diminishes.

Taking these factors into consideration -- the disease process and particularly the caregiver's perception of the impairment and the psychological presence of the parent, the presence of ambiguous loss and the ability of the caregiver to deal with ambiguous loss, the adult child's feelings of attachment as well as their cultural conditioning regarding a sense of obligation to care, the perceptions of the adult child concerning the parent's ability to continue to provide a sense of emotional security, and the family orientation and the meanings attached to care -- it is likely that a combination of all of the these factors plays a role in shaping the caregiver's unique perceptions of her or his role in the care of an institutionalised parent. Further, as any of these factors change, the role itself will change.

Two other factors seemed to play a role in the development of role manifestations in this study. First, the women described how their satisfaction with their parents' care was closely connected to their role definitions and their experience in the role. Those who felt more comfortable with the care being provided and who felt that the staff were providing both emotional and social as well as physical aspects of care were more likely to relinquish aspects of care to the facility than those who had some concerns with the care their parents were receiving. Further, some of the women who were now satisfied with care described facilities their parents had lived in previously and their dissatisfaction and unease with the quality of care in these other institutions. This dissatisfaction changed the nature of their experience and their roles in these contexts. Satisfaction with the unit, the care, and the staff were found to be closely linked to the career trajectories followed by caregivers in the Ross (1991) study. Those wives "embracing new realities" were significantly more likely to report satisfaction in all three areas than those "holding on to the past". Satisfaction with care has also shown negative correlations with the caregivers' sense of burden (Riddick et al., 1992). Thus, it seems reasonable that satisfaction with care, along with the other factors mentioned above, is closely related to how family members define their roles in long-term care facilities, how those roles get played out, how they experience their roles, and the ability of family members to relinquish aspects of care over time.

Second, a critical factor in the indirect supporter role manifestation was the presence of the "other" well parent. The presence of this parent significantly altered the way these women thought about their caregiving role. The focus of these caregivers on the other parent can be explained by their sense of where the need for care is, by their satisfaction in the care the facility and their other parents are providing, and by attachment theory. As the disease progresses, the institutionalised parent may lose the capacity to meet the adult child's emotional needs. This child may turn to the other parent because the well parent can continue to fulfil that need. Further, with the loss of attachment to the institutionalised parent, these adult daughters may feel a diminished need to protect this parent. Watching the consequences of the caregiving on the well parent, however, may exacerbate the adult daughters' needs to protect this parent.

To summarise thus far, one aspect of the dialectic nature of the caregiving roles revealed in this study is the differing and conflicting role perceptions that the adult daughters have regarding their role in the care of their institutionalised parents. Not one role exists for adult daughterss in long-term care facilities, but a variety of role manifestations seem to be present. Along with the various differences in each of the women's situations in the caregiving role, a number of factors help explain some of the differences in the role perceptions. These factors include the process of the disease and the presence of ambiguous loss and the ability of the women to cope with the decline of a loved one, differences in the sense of obligation or attachment felt by the adult daughters, perhaps the family orientation and the meaning attached to the caring for older adult relatives, the level of satisfaction with care, and the presence of the "other" parent in the caregiving network. Different role perceptions lead to various differing ways that the roles get played out.

Changeability of the Caregiving Role

Another pattern that was echoed over and over again in the women's stories and related to the dialectic nature of the caregiving role was the *changeability* of the role. The women emphasised how their roles have changed several times over the temporal caregiving career. Thus, consistent with the conceptual framework of the caregiving career, it became clear that adult daughters do not play one role throughout their caregiving careers but that the role is continually being altered and shifted as the women adapt to the role and the changing circumstances within or outside of the role. The role continues to shift, adjust, and develop in the institution-based caregiving context. Sarah, for example, recounted how her perception of her role changed many times over the years she cared for her mother. In her story, she described how she went from being a daughter and friend helping her mother when needed, to playing more of a parent-type, protector role, to moving into more of a social, visitor role where she perceived her role to be at the time of her interview. She recalled for me the many changes she went through in her caregiving role:

> …my role with my mother was always one of, a helper. Historically I was always her helper and even as a small child we would joke and say that I was bred for responsibility and duty … The role changed when my sister came to me one day and said that there [was] something really going on at home. This was when dad was starting to get sick and mom...so I started staying at their house whenever I could. So my role for a while became one of observer where I didn't actually do anything… My role for about six months was just watching, observing what was going on. I observed some real changes in my mom's health so I started becoming more supportive of my mother and my father. My role then after becoming an observer was my father said to me you are going to have to do something for us. That is the day I became, I guess, the caregiver but my wonderful sister was doing all kinds of marvelous things anyway and she used to ride her bicycle over there on the weekends and take stew and so on. So [my sister] and I, I guess by the time my father had passed away, September 3rd, we had both become part-time caregivers. My primary role, because she works for a large corporation was to look after all the ins and outs and itty bitty details, simply because she didn't have the capability. When you have your own business you can do things as you like but when you are reporting to other people you can't. So that is when the role changed.

Sarah's role not only changed in the community-based setting but also continued changing when her mother was admitted to the retirement home and then the long-term care facility. Sarah went on to describe the changes in her role in the institution-based setting:

> Now when I first brought her to [the retirement home] I wasn't looking after her so much as a parent as I was still her daughter. So there was a great deal of respect for mother's wishes which sometimes were not, when I look back now some of her wishes were illogical. Once she moved here, then I dived in and I think, you could probably check with [the Director of Nursing Care], I probably became the biggest pain this nursing home has ever had. I was constantly asking questions, constantly bugging them, constantly concerned about everything because now I became the parent. As soon as she moved to [this facility], I stopped being the respectful daughter and became the parent, very not controlling but authoritarian, not with mom but with other people. So when she went upstairs my role became the facilitator. I started facilitating activities for mom that we could do as a family…it took me a year to accept that things have changed this much, to accept that this place was doing a good job and to accept that my role was going to have to change yet again.

> It took me to the following Spring to actually be calm enough to actually enjoy our visits and not be value judging the care and her progress.

When Sarah's mother was first admitted to the long-term care facility, she "dived" into the role much like the active monitors approach their role. Active monitors become or remain intensely involved in the care of their parents even after the parent is admitted to a long-term care facility. Once Sarah became more comfortable with the care the staff members were providing, realised that she could not continue the intensity of her involvement, and began accepting the situation, she was able to relinquish some of the care to the staff and focus on the social and emotional aspects of care and just being a daughter again. Sarah, though, remained a regular visitor because her mother very much continued to exist for her. As the institutionalised parents begin to lose a psychological presence in the adult daughters' lives, however, these women may take the relinquishment one step further and transfer all emotional and physical care to the facility or others.

Alternative Institution-Based Caregiving Career Paths

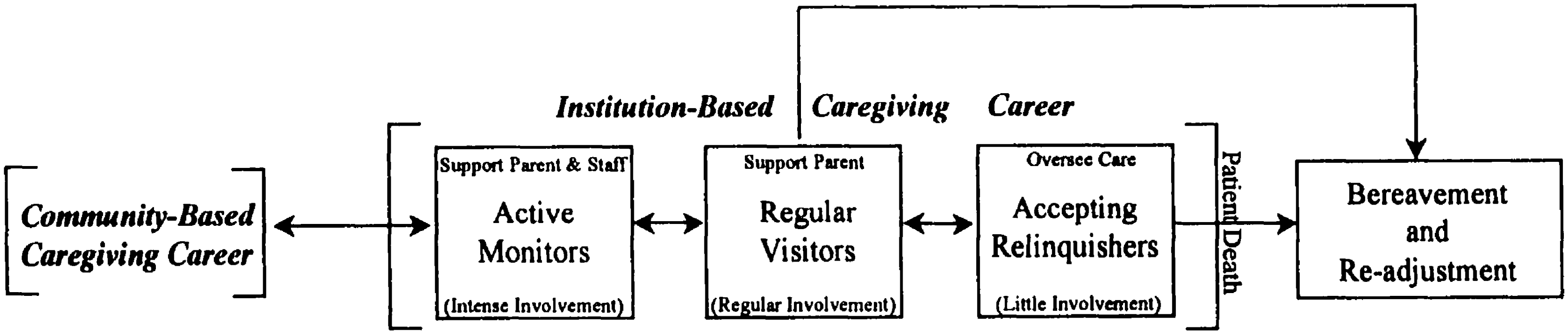
All of the women talked about how their roles have changed over the years. Guided by the alternative role manifestations that came together from the women's narratives and the notion of the changeability of the role also predominant in the women's stories, I began to develop a grounded theory or model of the possible alternative institution-based caregiving career paths. Within this model there are alternative roles family members may play and several career paths that family members could travel over their institution-based caregiving careers. At least three dominant paths emerged in the adult daughters' stories. I refer to these paths as the *Growth through Acceptance Path*, the *Coping through Protection of Self Path*, and the *Focus* *on "Other" Path*. These alternative caregiver career paths are described below and are illustrated in Figures 6A, 6B, and 6C. Again, I must stress that although the role manifestations are depicted in the visual representations as discrete, mutually exclusive roles or phases in the caregiving career, they, in many cases, overlap one another.

The Growth through Acceptance Path

In the Growth through Acceptance Path, adult daughters are intensely involved in the long-term care setting when the parent is first admitted to the long-term care facility (active monitors). Once adult daughters adjust to the new facility and become more comfortable in the care their parents are receiving, they gradually turn the focus of their role to the parent and concentrate on providing the emotional and social aspects of care (regular visitors). As time goes by and the parents begin to deteriorate more and more, the adult daughters may not perceive the parents as being psychologically present any longer. If theses family members are able to come to a place of acceptance of the situation, which can often be a long adaptation period, they may then move into an accepting relinquisher role and focus their priorities to re-establishing their own lives and well-being.

I called this path the Growth through Acceptance Path because many of the women in the regular visitor role manifestation and all of the women in the accepting relinquisher role manifestation tended to talk about the changes in their roles as being a positive step forward for themselves, a maturing of the role and themselves in the role. As reflected in her profile, Dora, for instance, talked about how unhealthy it would have been for her to continue to be intensely involved in the care of her mother. At the stage her mother was in the disease process, Dora did not feel her involvement was beneficial to her mother nor was it particularly healthy for

Figure 6A: Growth Through Acceptance Path



her. For Dora, the move to acceptance of the situation and moving on to focusing on her own life was perceived as a positive coping strategy, a moving forward in the role. The Growth through Acceptance Path, therefore, represents a process in which family caregivers are able to continually re-define their roles in order to positively adapt and cope with the circumstances that arise and grow in the role. Learning to accept the situation is a continual process, however, and one does not necessarily have to become an accepting relinquisher in order to grow in the role. For instance, Sarah talked about her move from an active monitor to a regular visitor as a positive adjustment for her. At the time of the interview she was far more comfortable in her role than she had been when she was intensely involved in what she described as her "protector" role. Thus, many adult daughters may not reach an accepting relinquisher role. Sarah called me several months after our interview to tell me that her mother had died. Sarah had developed and grown in her role but had ended her institution-based caregiving career as a regular visitor.

Personal growth in caregiving has emerged as an important meaning theme in studies of community-based caregiving samples (Noonan et al., 1996). Further, several researchers (Carver, Scheier, & Pozo, 1992; Pruchno & Kleban, 1993; Pruchno & Resch, 1989; Williamson & Schulz, 1993) have begun to recognise the importance of acceptance as a positive and healthy way of coping with the stresses of caregiving. This strategy could be particularly adaptive in the later stages of Alzheimer's disease when caregivers are forced to deal with those stressors that are not malleable. It has also been found that caregivers who remain intensely involved in care long after the placement of a loved one to a long-term care facility are at risk of poor emotional outcomes (Aheshensel et al., 1995). Carve et al. (1992) suggested that coming to a place of acceptance may represent "an effort to move forward rather than become mired in present unhappiness" (p. 180). Realistic appraisals of the situation and a move towards acceptance and growth allows caregivers to better accommodate the needs of their care receivers as well as their own needs (Pruchno & Resch, 1989).

The Growth through Acceptance Path has both differences and similarities to the stages identified by Rosenthal and Dawson (1992) in their study of wives caring for husbands in an institutional setting. The first stage of the Rosenthal and Dawson Model, the ambivalence/uncertainty stage, did not seem to emerge as a separate phase in this study. In the ambivalence/uncertainty stage, the caregiver is focused on intrapersonal concerns such as depression, isolation, guilt, resentment, and anger. Although many of the women described some of these concerns in their stories (e.g., sadness, guilt), these feelings did not manifest themselves in any one role and in many cases appeared to continue over the caregiving career. For the women in this study, the unaccepting relinquishers, who were in later temporal phases of their caregiving careers, seemed to focus the most on intrapersonal concerns such as the ones described by Rosenthal and Dawson.

In reflecting on why this stage did not appear in my study, it seemed likely that the reasons were due to the different experiences in the caregiving role for wives compared to adult daughters. Wives often provide care in the community for much longer periods of time and are much more likely to reside with the care recipient than are daughters (Diemling, Bass, Townsend, & Noelker, 1989; Noelker, 1990). Further, spouses have been identified as the highest risk group for burden and distress among all caregivers (Cantor, 1983; George & Gwyther, 1986; Motenko, 1989; Parmelee, 1983; Quayhagen & Quayhagen, 1989). Grau, Teresi, and Chandler (1993, p.133) found that among sons, daughters, spouses, and other relatives of nursing home residents, "spouses were the group most involved in and affected by caregiving". Specifically, spouses reported significantly higher levels of demoralisation (i.e., nonspecific psychological distress related to anxiety, self-esteem, helplessness/hoplessness, and sadness) than any other group. In addition, spouses demonstrated significantly higher levels of guilt or worry and significantly poorer physical health than both daughters and sons. Taking all of these factors into consideration, wives may be feeling more burden and burnout at the time of admission than other caregivers and thus may experience a period focused on intrapersonal concerns like the stage described by Rosenthal and Dawson.

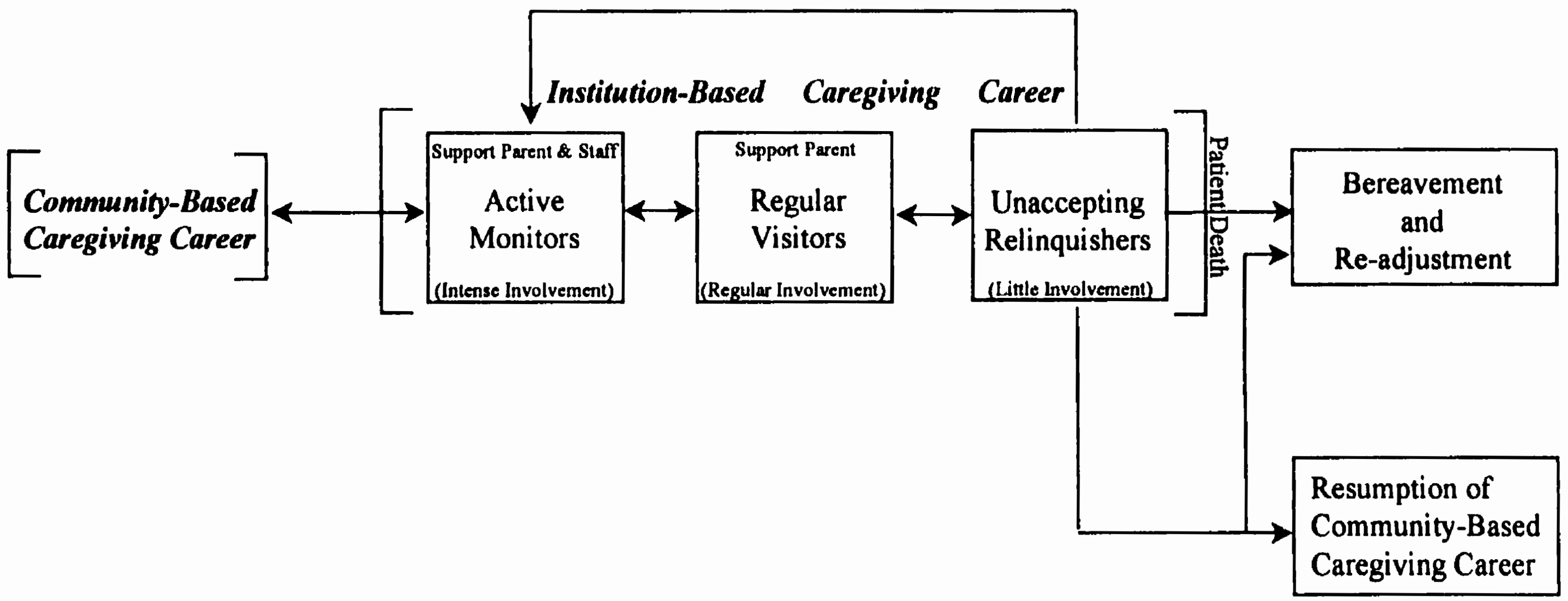
The other stages in the Rosenthal and Dawson (1992) model, however, have some similarities to the role manifestations in the Growth through Acceptance Path. Their second stage, assisting/action, is similar to the active monitor role in terms of the intense involvement of the caregivers at this phase in their caregiving careers and the tendency of the women to take on some tasks that are usually perceived as the staff's responsibility. Further, the relinquishing/augmenting stage has similarities to the regular visitor role in that women at this point in their caregiving careers become more comfortable with the care provided in the home and are able to relinquish some of their care tasks in an attempt to develop more realistic or feasible roles for themselves in the facility. The regular visitor role also resembles in some ways the pattern of caregiving Ross (1991) conceptualised as "embracing new realities". The wives "embracing new realities" in the Ross study continued to visit regularly but relinquished aspects of care to the facility. In doing so, the wives appeared to be coping better psychologically in their role. Finally, the adult daughters in the accepting relinquisher role manifestation seemed to show characteristics not unlike those demonstrated by the wives in the fourth stage of the Rosenthal and Dawson model. In the resolution/adaptation stage, the wives focus on balancing their own needs with their husbands' needs, and begin to accept the changes in their husbands and in their relationships with their husbands. Rosenthal and Dawson described this process as follows: "She has accepted the loss of the person who was her full-time spouse, and learned to live with the situation of 'quasi-widow', a woman alone whose husband still lives" (Rosenthal & Dawson, 1992, p. 412). The accepting relinquishers have also come to accept that their parents are essentially gone and have realised and come to terms with the fact that the daughter-mother relationship has changed dramatically, if it exists at all.

The Growth through Acceptance Path, thus, has adult daughters playing various roles throughout the institution-based caregiving career as they learn to cope more realistically with the situation and accept the changes they are witnessing in their parents. Throughout this process the family members and their caregiving roles continue to develop and grow, each caregiver defining for themselves how they will shape their roles. Some will gradually relinquish some caregiving tasks and turn their priorities to other purposes within the institution. Others may get to a point where they feel very little need to continue to play an active role within the institution.

The Coping through Protection of Self Path

Some active monitors or regular visitors may not be able to adjust to the deterioration of their parents. If the situation is, or becomes, too painful and difficult for individual caregivers, they may choose to take the Coping through Protection of Self Path. This is particularly true for those women who have difficulty dealing with ambiguous loss. In this path, the women may be intensely involved in the care of their parents when the parents are first moved into the facility (active monitors). If the deterioration of the parent is slow, they may relinquish some of the physical aspects of care and play a regular visitor role for a time.

Figure 6B: Coping Through Protection of Self Path



Nevertheless, as watching the deterioration of their parents becomes more and more painful and they become less and less able to cope with the situation, adult daughters may turn to avoidance of the situation as a coping strategy in an attempt to protect themselves from the situation (unaccepting relinquishers). Grace, as presented in her profile in Chapter Five, described the gradual process she went through in trying to adapt to the deterioration of her father and the circumstances within the facility. When her father was first admitted to the home, she was very much involved in his care, visiting the home every three days. In an attempt to cope better with the situation she cut her visits down to once a week and then once every two weeks. As the situation became more and more painful and difficult, the only way she could find to cope was to avoid the home as much as possible, visiting maybe once every six months and only if others would visit with her. She emphasised in her story that, for her, visiting was more painful than not visiting.

I called this caregiving path The Coping through Protection of Self Path because all of the unaccepting relinquishers' stories described the process of moving towards the realisation that they were not coping well in the role and thus on finding ways to protect themselves from the pain they experience in the role. Certainly, utilisation of avoidance techniques, especially the avoidance of visits to the facility, was one way in which these women attempted to protect themselves. Another protection strategy employed by these women was ensuring that someone else was always available to accompany them on visits when they did choose to go the facility.

Although perceived by these women as the only way for them to cope, avoidance over the long term may not be a particularly effective coping strategy. The research consistently finds that the use of avoidance techniques is associated with negative outcomes such as higher levels of burden, lower levels of overall life satisfaction, greater depression, and negative affect

(Felton et al., 1984; Stephens et al., 1988; Wright et al., 1987). Further, by not facing the emotional difficulties associated with their caregiving role, they are unable to completely meet their own needs, not to mention their parents' needs.

Those women who choose the Coping through Protection of Self Path may end their caregiving careers in this role. Others may continue to find other ways to cope and, as in Grace's situation, make further adjustments or changes to the situation and their role in order to cope more positively. As you will recall from her profile, Grace was unable to cope with the facility so decided the only coping strategy for her was to take her father home to live with her and resume her community-based caregiving role. A situation may also arise where adult daughters who have relinquished all care resume their involvement in the long-term care facility. Carol, for instance, talked about feeling helpless in her visits with her mother. In her narrative she emphasised that if her mother was hospitalised at any point in the future and needed to be bathed or fed, she would be able to do that; she would have something to do in her visits. Thus, a crisis such as the hospitalisation of a parent could be the catalyst for some unaccepting relinquishers becoming more actively involved again in the care of their parents.

Other researchers have found that family members may not adapt positively to their institution-based caregiving roles. Ross (1991), for example, found that the process of adjustment was problematic for a substantial number of wives in her study. The women who had more difficulty coping with the situation, however, were those caring for husbands with physical impairments. The difficulty these wives experienced in coping with their role was linked partially to their continued intense involvement in the care of their husbands and their inability to relinquish care to the staff. The findings of this study suggest that women caring for residents with cognitive impairment may also have difficulty adapting to the deterioration of a loved one over time and that the difficulties experienced in this situation may be more linked to struggling with ambiguous loss. Witnessing the psychological loss of a loved one can result in family members gradually removing themselves from the caregiving situation rather than staying intensely involved. Therefore, there seems to be varied reasons for the difficulties experienced in the caregiving role for different adult daughters, and thus different outcomes and responses. Given the problems some family members have adjusting to the institution-based caregiving role, Riddick and her colleagues (1992) stressed that strategies developed by the facilities to help caregivers adjust and cope may need to continue indefinitely. They recognised:

> Issues relating to the resident's inevitable decline, as well as the caregivers' expectations, concern, guilt, and sense of lack of control may need to be addressed with caregivers over the duration of the resident's stay in the nursing home (p. 73).

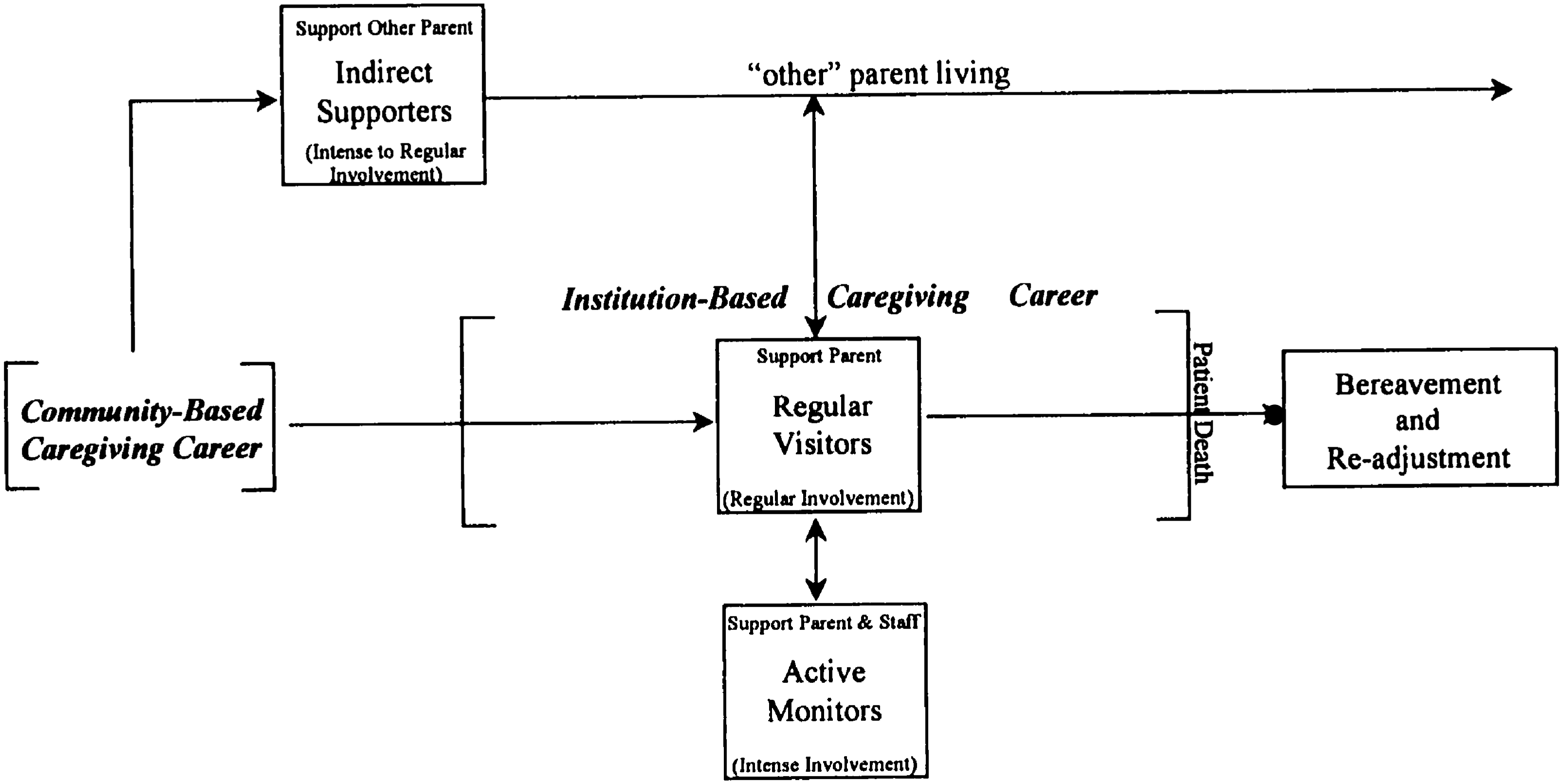
The Coping through Protection of Self Path, then, sees adult daughters go through a process of gradually relinquishing care completely to the facility. This process of backing away from the facility is very much related to the difficulties adult daughters experience in trying to cope with the deterioration of their loved ones and ambiguous loss. Unlike those in the Growth Through Acceptance Path, these family members are unable to come to terms with the situation and the experience gradually becomes unbearable. The focus turns to finding ways to protect the self from the emotional distress of the situation. Protection of self becomes a viable coping strategy for these women. Again, though, the process through this career path is unique for each caregiver. Depending on the circumstances, individual caregivers may relinquish care and begin backing away from the facility fairly quickly. Others may cope relatively well for a long period of time choosing to remain involved to varying degrees until their loved ones become unrecognisable. Further, adult daughters use very different strategies in their attempts to protect themselves from the situation. Finally, many adult daughters who choose this path will end their institution-based caregiving careers here. Changing circumstances or meanings of the situation may prompt others to resume their involvement in care either in the facility or perhaps even in the community.

The Focus on "Other" Path

Another path reflected in the stories of the women involved in this study was the Focus on "Other" Path. Those women who had both of their parents still living, the indirect supporters, seemed to take this caregiving career path. Much like the more traditional caregiving roles where the focus is on the frail or ill parent, the Focus on "Other" Path begins before the ill parent is admitted to a long-term care facility. These women perceive that their ill parent is being well cared for by the other well parent. Their role, therefore, becomes one which is focused on supporting the well parent (indirect supporters). These women do not talk in their stories about playing an active monitor role. According to the adult daughters, the "other" parent tends to play this role. Nonetheless, their role supporting the "other" parent can be as intense as the active monitor role in terms of involvement in the caregiving role. The focus of the support, however, is targeted at the other parent and not on the institutionalised parent.

When their ill parents are institutionalised, although their primary focus is on the well parent, these women seem to simultaneously play a regular visitor role. They visit their parents in the long-term care facility with a focus on providing more of the emotional and social aspects of care. Diane's caregiving role as reflected in her profile, for example, was focused on

Figure 6C: Focus on "Other" Path



her mother. But at the same time, she continued to place importance in having a presence in her father's life, in continuing to let him know that he was loved and not forgotten. Although she did not visit the home as regularly as other regular visitors she described her visits with her father much like the regular visitors did. As the institutionalised parents begin to deteriorate more and more, the focus of indirect supporters seems to shift completely to the "other" parent. Leandra, for example, had come to a point in her caregiving career where her father no longer was psychologically present in her life. She no longer felt that her presence in the long-term care facility made a difference to her father. According to Leandra, her father was happy, healthy, and well cared for by her mother and the staff at the facility. Although she had once visited her father weekly, once her father no longer existed for her, the role shifted completely to supporting her mother and monitoring her mother's health and well-being.

This focus on the well parent can continue throughout the caregiving career, even after the institutionalised parent dies. One adult daughter involved in the study, however, had both parents living but described in her story how she had gradually become the primary caregiver as her community-based parent, her father, became more and more frail himself. This particular woman's father was living in a retirement complex but was in his 90s and no longer able to provide the regular, intense care he once had. As her father became less and less able to care for his wife, this daughter gradually took on the primary familial caregiving role. At the time of her interview, she described her role in the care of her mother much like the regular visitors described their roles. Thus, it seems likely that if the community-based parent becomes unable to continue as the primary caregiver in the facility, an indirect supporters role may change once again to a focus on the institutionalised parent and an active monitor or regular visitor role.

Recently, researchers (Birkel & Jones, 1989; Finch & Mason, 1993; Horowitz, 1992; Keith, 1995; Matthews & Rosner, 1988) have begun to recognise how our traditional approach to research on elder care has failed to take into account the importance of the family caregiving network and the sharing of the care of older adult family members. Keith (1995), for example, found three types of caregiving systems used by siblings: the primary caregiver, the partnership, and the team. Related to the different types of caregiving systems, Matthews and Rosner (1988) described five styles of participation used by siblings in the parent-care system. The adult daughters I spoke with often described the involvement of other family members and emphasised the "we" involved in the care of their parents. The indirect supporter role manifestation and Focus on "Other" Path further extends the notion of the parent-care system. In this approach to caregiving, adult daughters see their role as supporting the primary caregiver, their well mothers or fathers, in the care of their institutionalised parents. They are essentially caring for the caregiver. This style of caregiving is similar to what Matthews and Rosner labeled "routine" caregiving where "regular assistance to the elderly parent [is] incorporated into the adult child's ongoing activities" (p. 188). The focus, though, is not on the institutionalised parent but on the well parent. At the same time, these women also provide a "backup" style of caregiving (Matthews & Rosner, 1988). When these women are called upon by their well parents to help in the care of their institutionalised parents, they do what is instructed of them. In this approach to caregiving we see parents and adult children coming together to care for other ill family members and each other.

The Focus on "Other" Path is a caregiver career path rarely, if ever, discussed in the literature on institution-based caregiving. Adult children who find themselves along this path have both parents living. Similar to the other caregiving career paths, this path begins in the community. The focus of the adult child's role in the community is on both the ill and the well parents. When the ill parent is admitted to a long-term care facility, these women often continue to play two simultaneous roles: one focused on supporting the "other" well parent (indirect supporters), and one focused on providing the emotional and more personal aspects of care to the institutionalised parent (regular visitors). As the condition of the ill parent deteriorates, so does the involvement of the adult daughters in the facility and gradually the focus of the role turns completely to assisting the well parent and monitoring this parent's health and well-being (i.e., focus on an indirect supporter role). This focus on the well-being of the "other" parent continues even after the ill parent dies. Throughout the ill parent's stay in the long-term care facility, the well parent is typically the primary familial caregiver to the institutionalised parent. If the well parent suddenly becomes ill or unable to continue as the primary familial caregiver, however, the adult daughters will often take on this role and shift their role to an active monitor or regular visitor role. Thus, this path also gets played out and is experienced quite uniquely by each caregiver depending on a mixture of factors such as the availability and ability of the well parent to continue to provide primary care within the facility, the ill parent's condition and the progress of the disease process, and changing circumstances and priorities which arise at different points along the caregiving career path.

Although the data collected in this study were not longitudinal, the women's descriptions of their history in the role seemed to suggest several different roles and paths adult daughters may travel over their institution-based caregiving careers. The Growth through Acceptance Path, Coping through Protection of Self Path, and the Focus on "Other" Path were three possible caregiving career paths which emerged in the stories of the women involved in this project. An integration of all the possible alternative caregiving career paths is presented in

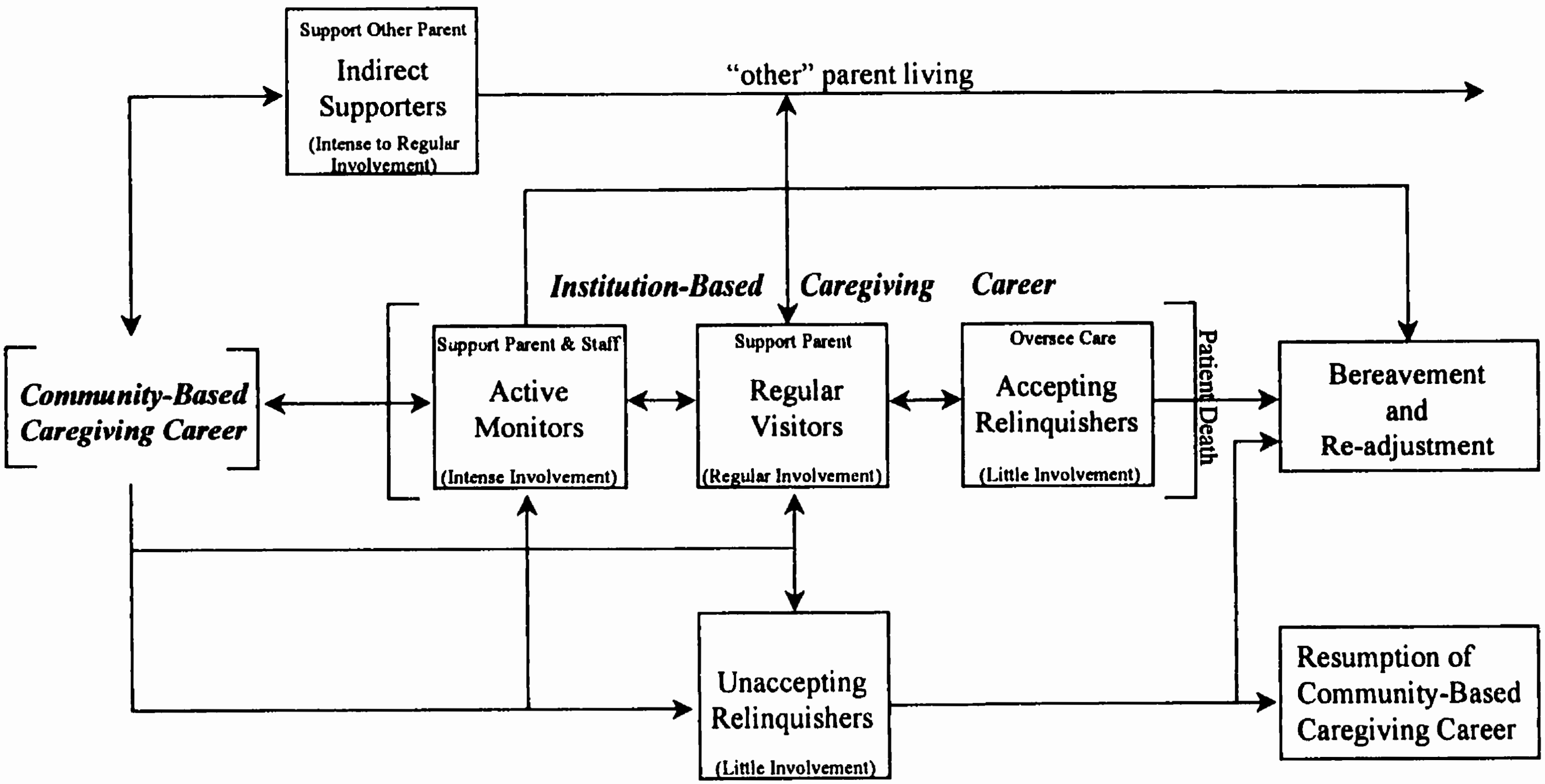
Figure 7. Each of these paths incorporates combinations of the five role manifestations presented in Chapter Five. The recollections by the women of their histories in the caregiving role suggest a fairly direct association between the various caregiving role manifestations, their experience in the role at the time, and the caregiving career paths the women choose to take. This conceptualisation of institution-based caregiving roles further augments Aneshensel et al.'s (1995) three-stage conceptualisation of the caregiving career in which institutional care represents one phase in the caregiving career. In fact, the caregiver may go through several roles, phases, and turning points throughout her institution-based caregiving career. It also expands most other conceptualisations of institution-based caregiving roles (e.g., Rosenthal & Dawson, 1992, Ross, 1991) by recognising the presence of several possible caregiving career paths.

The Dialectic Nature of Caregiving Roles and Career Paths

Threads of commonalties in the adult daughters' role meanings and behaviours surfaced in their stories. Nonetheless, it also became clear that each woman's caregiving career path was unique depending on each person's individual circumstances, how those circumstances were interpreted, and how each woman was able to cope with the situation. The career paths seemed to function along a dynamic, ever-changing process in which the adult daughters were continually interpreting the situation and trying to adapt to changing circumstances in their roles and new crises that arose. Rubinstein (1989) emphasised how the meanings associated with caregiving change over time:

> Meanings may change over time as experiences change or are matched to previous personal experiences. They are emergent from the situation, in dialog with the past and with cultural values and ideas (p. 135).

Figure 7
An Integrated Model of Alternative Institution-Based Caregiving Career Paths



As the meanings of the role change, so does the role itself. Further, the adult daughters described how they were continually trying to balance their own needs with the needs of their parents as well as balance the pressures and demands of the role with their own capabilities and resources. Diane emphasised how her role has gone from being fairly stable to hectic and changeable:

> It changes with the circumstances. There have been times when it has been, not just work but it has been hell. Like it has been really, really hard emotionally, physically draining work. And then there have been other times where we have had laughter and we have had fun and we have been able to care and share and laugh at what is happening and what life does to you....I think you try to adapt and change. You try to meet your own needs and their needs and to be able to, pie in the sky I wish. It is not realistic so I will just keep working with it and try to adapt and change as needed...It fluctuates. I have never done the physical caring for him [my father] but there was a period when he really was going down hill very quickly when there was a lot of caring (emphasis on caring) needed. Then once he was in [this facility] there was a lot of emotional support required for my mother and at this point things are far more stable. So it's up and down, it varies.

The women themselves conceptualised their caregiving roles as a process, a journey. They talked about how they were anticipating the road ahead in their role and recognised that different types of resources to meet the changing circumstances may be needed in the future. Shelley, for example, stated:

> There's still, 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. But this apparently is one I really don't know what's ahead until I'm living it... 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.

As I was reflecting on this process of continually learning to adapt to the situation, I came across the Family Adjustment and Adaptation Response Model (FAAR) developed by McCubbin and Patterson (1983a, 1983b; McCubbin et al., 1982; Patterson, 1988). This model was developed to help explain how families as a unit adjust to having a child with chronic illness. As I read through the literature on the FAAR model, it seemed to reflect and explain the dialectic nature of the caregiving role and the dynamic process that the adult daughters in my study seemed to be going through in their attempts to adjust to chronic illness in their aged parents. I drew on this model to further develop my grounded theory on institution-based caregiving career paths.

The Family Adjustment and Adaptation Response Model

According to Patterson (1988) family members dealing with chronic illness, or the entire family system, go through a continual, cyclical adjustment-crisis-adaptation process. Throughout this process, family members are continually trying to maintain balanced functioning by developing and using their resources and coping behaviours (capabilities) to meet the stresses, strains and pressures (demands) of the situation. Patterson emphasised that an important component of the model is the meanings family members ascribe to the situation, not only in terms of how they are thinking about what is happening to them but also in terms of their perceptions of their ability to cope. Because family members will have different perceptions of both the demands of the situation and their capabilities to cope, each person's experience and responses to the situation will also be varied.

The FAAR model includes two primary phases, an adjustment phase and an adaptation phase, which are linked by crises situations (Patterson, 1988). The adaptation and adjustment phases are conceptualised along a continuum ranging from good to poor representing how well the family member is fairing in each phase. According to Patterson, "[t]he adjustment phase is intended to denote relatively stable periods during which families resist major change and attempt to meet demands with existing capabilities" (p. 76). During this phase, if the family member is coping relatively well with the situation and is able to balance the perceived demands with the resources she or he has available, then the role can remain relatively stable for a time and adjustment in the role can be relatively good. If the situation changes or a crisis situation arises, however, the demands of the role or situation may become too overwhelming given the family member's resources and ability to cope. At this point the family member then goes through a process of re-defining the situation and making changes in an attempt to restore equilibrium – adapting to the new circumstances. Patterson described the adaptation phase as follows:

> During the adaptation phase families attempt to restore homeostasis by (a) acquiring new resources and coping behaviours, (b) reducing the demands they must deal with, and/or (c) changing the way they view their situation (p. 76).

Dealing with chronic illness, such as in the case of Alzheimer's disease, is a continuous process with family members going through several cycles of adjustment-crisis-adaptation. If a family member's overall adjustment is quite poor, they may be more vulnerable to crisis situations. Nevertheless, Patterson (1988) emphasised that a crisis situation is not necessarily always negative. A crisis situation can allow the family member an opportunity to re-think or re-frame the situation in more realistic terms, to grow as a person, to become more resilient, and to move towards recovery and better coping capabilities.

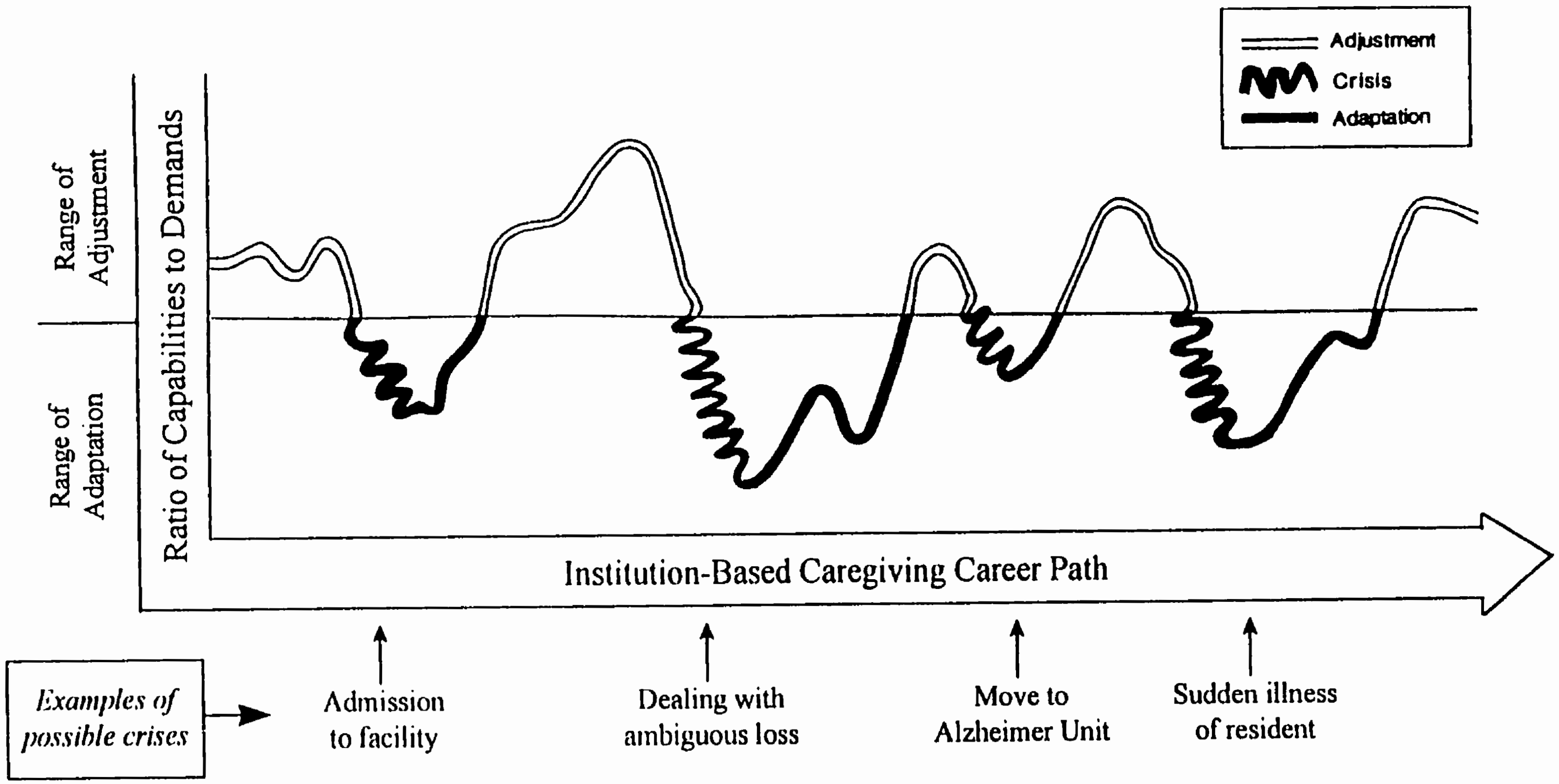
This conceptualisation of crises is consistent with Riegel's (1975, 1976) dialectical psychology of human development. Riegel recognised the "interpenetration" and "mutual dependency" of stability and crisis, equilibrium and disequilibrium. In fact, he argued that crisis situations are at the very heart of growth, movement forward, and development. He emphasised: "[C]rises should never be exclusively negatively evaluated. Many crises represent constructive confrontations leading to new development" (Riegel, 1976, p. 693). When crisis situations emerge, individuals actively work towards overcoming the crisis and re-establishing balance and stability in their lives and many individuals are able to use existing capabilities and resources or find new creative strategies to restore balance. It is important to recognise that some people may not be able to cope as well or as quickly to crises situations or changing circumstances as others. In these circumstances, the adaptation process may continue for any length of time and may be unstable as individuals struggle with balancing their resources with the demands of the situation. But even stable periods such as those in the adjustment phase are only temporary. In his dialectical theory of human development, Riegel points out that periods of stability are always temporary, they are a "transitory condition in the stream of ceaseless changes" (Riegel, 1976, p. 690). Thus, the paths individuals follow are filled with stability and balance, conflicts and crises in a continuous flux of change.

Integration of the FAAR Model to the Alternative Caregiving Career Path Model

In thinking about the women's stories, the FAAR model (McCubbin and Patterson, 1983a, 1983b; McCubbin et al., 1982; Patterson, 1988), and aspects of Riegel's (1975, 1976) dialectic theory of human development in terms of the institution-based caregiving career paths, it became clear to me that the adult daughters in my study seemed to be in a continual process of weighing the demands and stresses of the role with their own capabilities and their ability to cope with those demands – those aspects presented in Chapter Six. They were also continually weighing their parents' needs with their own needs. When the adult daughters were better able to balance the demands of the role with their capabilities and resources and their own needs with what they perceived to be their parents' needs, they seemed to cope better in their role and the role remained fairly stable for a time. When the situation changed or a crisis situation arose, an imbalance in the demands of the role and the capabilities of adult daughters to cope was created and thus forced caregivers to re-define the situation and alter their role yet again. As depicted in some of the adult daughters' profiles, the initial move to a long-term care facility can be a major crisis point for adult daughters. Several researchers have recognised how stressful the placement decision and actual placement are on family members. They argue that the process of nursing home placement should be viewed as a family crisis (Greenfield, 1984; Numerof, 1983 Schneewind, 1990; Zarit & Whitlach, 1992). Other crisis situations mentioned in the women's stories include a sudden illness and hospitalisation of the parent, illness of the caregiver, periods when parents are displaying difficult behaviours such as aggression, dealing with ambiguous loss, a move from the nursing home to the Alzheimer's Unit within the facility, and various family crises such as an extra-marital affair.

Thus, although the career paths in Figure 5 are depicted as linear and stable, the caregiving career path presented in Figure 8 represents a closer portrayal of the dialectic, cyclical, and dynamic nature of institution-based caregiving roles and caregiving career paths in this model. Again, what I am suggesting is that over the temporal caregiving career, adult daughters journey through many cycles of adjustment/crisis/adaptation (Patterson, 1988). During periods when adult daughters are able to match or balance their resources with the demands of the role, the role remains more stable than unstable and the experience in the role is likely to be more positive. The spiral points in the diagram represent crises points which force caregivers into adaptation phases. In the adaptation phase, adult daughters have to draw on new resources or coping strategies in order to adapt to the demands of the changing circumstances. The adaptation phase can be quite stressful for family members while they

Figure 8
The Dialectic Nature of Caregiving Career Paths
(Adapted from Patterson, 1988)



wrestle with the new pressures and work towards re-defining the role in more realistic ways. If able to achieve a renewed balance in capabilities and demands, the adult daughters can again find themselves in a more stable adjustment phase. If unable to find ways to cope, adult daughters may continue to adapt for long periods of time. Adult daughters continue to struggle to balance the demands of the role with their capabilities during the adjustment phase, however, depending on their ability to cope, their experiences in the role may be far more positive than in the adaptation phase and the role may shift only slightly. This cyclical process continues throughout the caregiving career no matter what phase or role manifestation the caregiver is at in the caregiving career (e.g., active monitor, regular visitor) and may even continue while the caregiver adjusts to the death of their loved one. Further, crises situations can lead caregivers to return to a previous role manifestation or take on a new role for themselves. Depending on the situation, for example, a crisis situation could lead regular visitors back to an active monitor role or could result in the development of a new role definition such as an accepting relinquisher role.

Contributions of a Dialectic Model of Institution-Based Caregiver Career Paths

This conceptualisation of institution-based caregiving roles and career paths advances our understanding of adult daughter roles in long-term care facilities in several ways. First, depending on the circumstances of the situation and the caregivers' interpretations of the situation, as well as a number of other factors, adult daughters will define their roles within the institutional setting differently. Thus, there is not just one familial caregiving role within the long-term care facility rather adult daughters will play out their roles very differently depending on the meaning of the role for individual caregivers. Some possible role manifestations found in this study include the active monitor, regular visitor, accepting relinquisher, unaccepting relinquisher, and indirect supporter roles.

Second, supporting the work of Bowers (1988) and Duncan and Morgan (1994), it appears that adult daughters think about their roles more in terms of the purpose they ascribe to their roles than in terms of the tasks they perform. Another important aspect of caregiver roles which emerged out of the women's stories was the target of the family member's attention and support. Some women in this study perceived that their role involved supporting both the staff and their parents. Other adult daughters concentrated their support on their institutionalised parents. Another group of women felt it was more important to support their "other" well parents living in the community because their ill parents were receiving support from a number of other sources. Finally, a small group of women felt there was very little need for them to continue to support the parent in the institution or the staff and for various reasons had turned the focus of their attention to restoring their own lives or protecting themselves. It is thus important not only to consider the family member's perception of their purpose in the role but where their efforts are being targeted.

Third, and consistent with the findings of Aneshenel and her colleagues (1995), the caregiving role appears to be anything but stable but instead is quite dynamic, in a continuous state of flux. Thus, institution-based caregiving roles are continually reorganised and altered as adult daughters face changes in the situation, new challenges, new demands, and various crisis situations. The women's stories seemed to depict a dialectic, a continual tug-of-war between the needs of the caregiver and the needs of the care receiver, between the demands of the role and the capabilities of adult daughters to cope with those demands, between periods of stability and crisis situations. Drawing on the FAAR model (McCubbin and Patterson, 1983a, 1983b;

McCubbin et al., 1982; Patterson, 1988), I further conceptualised the caregiving career paths as cyclical adjustment-crisis-adaptation processes which continue over the caregiving career.

Although Aneshenel et al. (1995) recognised the dynamic nature of caregiving roles, this conceptualisation expands that notion by emphasising the changing nature of roles even within phases of the role. For example, in the Aneshenel et al. model, the transition to institutionalisation is seen as the major crisis point and the period of institutional care is primarily viewed as one phase in the caregiving career. The themes in the women's stories in this study stress that the caregiving role continues to shift throughout the institution-based caregiving career and thus family members' roles may go through several phases and turning points during the institutional care period.

This model of family member roles in long-term care facilities differs from other conceptualisations in another significant way. The adult daughters' stories portrayed not one or two caregiving career paths but several alternative paths family members may take during the time of providing care to a loved one in an institutional setting. In fact, because there are several role manifestations caregivers may play at any one time, and because each caregiver appears to respond in differing ways to the changing circumstances and challenges of the caregiving role, family members' institution-based caregiving careers may take very different turns and follow very different paths. Three dominant institution-based caregiving career paths emerged in this study: the Growth Through Acceptance Path, the Coping Through Protection of Self Path, and the Focus on "Other" Path. Yet, even within these separate career paths, the individual family member career paths were unique. Within any one institution-based career path, a family member's career may include all of the phases and turning points or just some of them. Further, the separate phases or turning points may be experienced in differing sequence and some may even be repeated.

One factor echoed over and over again in the women's stories appeared to be linked to the changeability of the caregiving role and the caregiving career paths the women chose to take. Changes in the role seemed to be integrally connected to the progression of the disease and the deterioration of the care receiver over time. As the care receiver's functional status, particularly his or her cognitive status, changes over time, the demands of the role and needs of both the care receiver and the family member also shift, forcing family members to re-define their roles yet again. A particularly difficult challenge for the adult daughters involves coping with ambiguous loss. This study focused only on caregivers of persons with cognitive impairment, therefore, it is difficult to know if the disease process is also linked to the changeability and progression of roles in situations where caregivers are caring for a person with physical or sensory impairments. Nonetheless, in instances where caregivers are caring for loved ones with dementia, this factor seems to be crucial in understanding the roles of adult daughters in long-term care facilities.

Finally, this study provides support for a conceptualisation of caregiving which encompasses both the demands, pressures and stresses of caregiving as well as the rewards and gratification associated with the caregiving role. The adult daughters described several difficult and demanding aspects of their roles caring for their parents. Their stories also included motifs of personal growth, resourcefulness, commitment, satisfaction, and even pride in being able to do what they were doing. Many of the women were able to re-frame the situation in positive ways and drew on these positive aspects to help them cope with their roles. Noonan and her colleagues (1996) suggested that there were two dynamics or processes involved in caregiver meaning: *searching* for meaning (or continually trying to make sense of the caregiving situation and role) and *finding* meaning (or experiencing the caregiving context as meaningful). The caregiving role for the adult daughters in this study seemed to incorporate these two aspects of meaning. Further, integrally linked to the demands of the role are the resources and capabilities family members bring together in their struggles to continually adapt. The stories told to me throughout this project suggest that family members draw on varied resources and coping techniques throughout their caregiving careers as they actively attempt to cope with the changing circumstances within the caregiving role.

In identifying some criteria for judging a grounded theory study, Strauss and Corbin (1990) suggested that a strong grounded theory should expand beyond the single setting or phenomenon and that the possible range of applications of the theory should be identified. This dialectic model of institution-based caregiving career paths is applicable to understanding family member roles in other contexts where care is needed. This model, for example, may help explain the roles of family members in hospital settings, particularly in the care of relatives in chronic care over long periods of time. This model also may be useful in understanding the roles of family members in residential settings, such as the role of parents in the care of their children with intellectual or physical disabilities living in residential group homes.

In reflecting on the basic components of the model, especially the idea of multiple roles, various career paths, the adaptation-crises-adjustment process over time, and the demands of various roles as well as the resources available to address those demands, it occurred to me that this model may be a useful tool in understanding roles other than caregiving-type roles. For instance, in thinking about the components of the model at a more abstract level, it seemed to me that the model could be transferable to understanding the student role. Although there is often perceived to be *one* student role for *all* students regardless of individual circumstances, my observations in the student role suggest that students think about their roles differently and so create unique "manifestations" of the student role based on their own perceptions, experiences in the role, and contexts. The role manifestations will be different than those played out by caregivers but there will be a range of perceptions of roles rather than one role. Students may also journey down a number of diverse student career paths depending on changing circumstances over the student academic career. The student who devotes his or her time to being a full-time student, for instance, may follow a different career path than those who also choose to or need to work throughout their student careers. Whatever the case, each student's career path involves a continual adjustment-crisis-adaptation process as students deal with new challenges and struggles and as they attempt to continually balance the perceived demands of the role with their own capabilities and resources. Thus, this dialectic model taken at a broader level may help further explain the dynamics of the student role as well as the nuances of many other life roles.

Limitations and Implications of this Research

My use of a multidimensional conceptualisation of roles allowed for the development of a more rich and broad understanding of the roles of family members in long-term care facilities; one that incorporates role meanings, role behaviours, the role experience and the demands associated with the role, and the strengths and resourcefulness of caregivers. The findings from this study demonstrate that institution-based caregiving roles are far more complex than existing models suggest. Future research should explore these complexities further by trying to gain a deeper understanding of the factors that contribute to the development of different role manifestations. A multidimensional conceptualisation of roles is crucial in gaining a more "complete" picture of family member roles in the institutional context.

The accounts of the women's experiences in the caregiving role, although rich and detailed, were nonetheless retrospective. Longitudinal studies which follow family members from the admission of a relative to a long-term care facility until the death of the loved one or even longer may help us better understand the changing nature of the caregiving role. Following family members throughout their institution-based caregiving careers may help identify the crises, turning points, and phases along various caregiving career paths as well as the changing meaning of the role over time. Following caregivers after the death of a loved one will also increase our understanding of how family members cope with the death and how the death changes the role. Longitudinal research may also lead to the expansion of our understanding of the types of resources utilised by institution-based caregivers, when various types of resources are drawn upon, and how caregivers adapt to specific changes in the situation. Longitudinal studies starting at the community-based caregiving career phase and following caregivers over their institution-based caregiving careers would also help us understand the relationship between these phases in the caregiving career and how the community-based and institution-based roles come together or influence one another.

Throughout this project I chose to focus my examination of caregiving roles on adult daughters. Although focusing on one group of caregivers allowed for a more in depth investigation of caregiving roles for this particular group, future research should focus on family members of dissimilar relational backgrounds (e.g., wives, husbands, adult sons, and so forth). Some of the women, for instance, talked about the involvement of their brothers in the care of their parents living in the facility. An intriguing question for me is how adult sons define their roles in the care of their institution-based parents and how these role definitions compare to those of adult daughters. Further, it would be interesting to examine whether or not a range of role manifestations emerges in the stories of adult sons as they did in the adult daughters' narratives.

Throughout my search of the literature, I was not able to find research which has explored the role perceptions specifically of sons in the care of their institutionalised parents. In fact, the literature on the meaning of caregiving tends to group all caregivers together (Bowers, 1988; Duncan & Morgan, 1994; Farran et al., 1991; Hasselkus, 1988; Noonan et al., 1996) or focus only on women (Ross, 1991; Rubinstein, 1989). One exception is Reisman's (1986) description of the role he played in helping his father through the early adjustment of living in a long-term care facility. His account, however, does not describe how his role continued after this adjustment phase. Bennett, Dellmann-Jenkins, and Lambert (1996) examined the types of support given to institutionalised older adults specifically by adult sons. These authors found that adult sons perform a variety of tasks in the care of their parents in the long-term care setting such as visiting weekly and updating parents on family news (87%), taking care of financial affairs (75%), participating in care management and monitoring (44%), providing transportation and shopping for the parent (25%), and caring for the parent's home (20%). A small percentage of the men reported that they participated in more direct, hands-on types of care such as helping with ADLs (e.g., bathing and feeding) (13%), and doing the parent's laundry (9%). Nonetheless, the gender of the parent may play an important role on whether or not adult sons provide the more personal types of care (Lee, Dwyer, & Coward, 1993). This research suggests that some men may perform some of the same types of care as women in the institutional-based context. Our understanding of whether or not men define their roles in alternative ways and, if so, how, remains limited.

Some researchers examining the types of care provided by men and women to community-based elderly have found that there are real differences in the types of assistance offered by men and women (Chang & White-Means, 1991; Dwyer & Coward, 1991; Horowitz, 1985b; Stoller, 1990). Evidence suggests that sons may feel as obligated as daughters to provide care, but they choose different types of tasks to perform in providing care and do fewer actual tasks than daughters (Montgomery & Kamo, 1989). Nonetheless, it is not clear whether or not these differences persist in the institutional context. Further, an understanding of institution-based caregiving roles would not be complete without an investigation of the "we" involved in the caregiving and how the family as a unit comes together to contribute to or share in the care of an institutionalised relative.

I also limited my investigation of caregiving roles only to those family members caring for a person with a disease causing cognitive impairment. It became clear that, for these caregivers, the disease process and degree of cognitive impairment, or at least the meaning of these for the women, were central to how caregivers defined their roles within the institution and were also linked strongly to the caregiver career paths chosen by the adult daughters. In other contexts, such as in the case of family members caring for persons with physical impairments, the roles may or may not be as closely connected to the disease process. Ross (1991), for example, found that wives caring for persons with physical impairments were less likely to relinquish aspects of care over time than those caring for a person with cognitive impairment. Clearly, research which includes caregivers caring for persons with physical and sensory impairments is needed in order to determine the relative importance of different ailments and impairments on the institution-based caregiving role.

Guided by aspects of an ecological perspective, I felt that it was important for me to understand the context within which family member roles get played out. I wanted to be able to describe the roles that emerged in context. Thus, I chose to focus this investigation of family member roles on one long-term care facility. The particular facility chosen for this project was driven by a philosophy committed not only to residents but also to their family members; a philosophy which recognised the importance of the family unit to the resident. This facility also had a few programs in place to help family members cope with the transition to nursing home care. This facility was characterised by many of the features associated with Montgomery's (1982; 1983) "family as client" orientation. Further, a large majority of the adult daughters were very satisfied with the care being provided within the facility and described the facility as "excellent", and the staff as "caring" and "supportive". Nonetheless, in listening to the adult daughters' accounts of experiences in other facilities it became clear that family member roles may be defined and played out very differently in homes that do not recognise family members in their mandates or in facilities where family members are unsatisfied with the quality of the care provided. A facility's level of inclusion and integration of family members in the home has been shown to affect both resident-family and staff-family relations (Montgomery, 1982, 1983). Further, satisfaction with care has been found to be related to the experience of caregiving in institutional settings (Riddick et al., 1992; Ross, 1991). Researchers need to explore the varying orientations facilities take towards family member involvement and how those orientations influence family member roles in long-term care facilities. In addition, research is needed which explores how satisfaction of care is related to the development of roles for family members in institutionalised settings. Some adult daughters who were very satisfied with the care still perceived the atmosphere of the facility very distressing and almost paralysing, particularly in terms of the amount of illness and deterioration present within the home. This factor appears to be an important aspect for some family members in influencing how roles are defined and how individual caregivers adapt over time, and thus warrants further investigation.

Another aspect related to context mentioned in the women's stories has to do with the allocation of space in the facility and the issue of privacy. Despite their satisfaction with care, the adult daughters in this study discussed the difficulty in visiting when their interactions with their loved ones were so public. Although this particular facility was very much family oriented, they chose to give one of the few spaces for family visitation over to a research project. This clearly had caused problems for some adult daughters as they no longer could find a private place within the facility for visits. This raises the question of who should have priority in these settings in terms of the usage of the space. My own personal feeling is that these facilities are meant to be the new homes of the residents who live in them. Just as family members would be able to visit their loved ones in privacy if the residents lived in their own homes in the community, family members should be able to visit in privacy in their loved ones' new home, the facility. Thus, residents and their families should get first priority in terms of space within the home. Nonetheless, researchers need to examine how the physical environment of the facility affects both the experience in the caregiving role and the development of caregiving roles in long-term care facilities.

Few studies on caregiving have been able to capture the day-to-day nuances of the caregiving role. I hoped that by employing a personal log approach that I would be able to gain an understanding of day-to-day work, the shifts, and the experience in the institution-based caregiving career. Unfortunately, some of the women, especially those who continued to be intensely involved in the care of their parents, found the personal log component time consuming and had difficulty filling it out. Also, because the focus of the adult daughters was so much more on their purpose within the role rather than the tasks associated with it, I did not find that the personal logs contributed much more beyond the depth of information I was able to capture in the interviews. In addition, being able to get feedback from the women on their transcripts as well as on some of my insights on the patterns and themes important to them greatly enhanced the richness of the data. Nonetheless, more innovative and creative ways of examining the roles of family members in long-term care facilities on a daily basis that are less onerous on the caregiver are needed. Observations of family members within the facility may contribute to our understanding in this area, but observations alone will not be able to capture the types of activities family members do in their role outside of the facility. The personal logs were able to capture the types of caring work women do outside of the facility.

Finally, the women's stories described the connection of their roles to the staff within the facility. Many worked closely with staff members in order to monitor their parents' care. Some of the adult daughters saw themselves as part of the care team and volunteered in different capacities within the home in an attempt to ease the work load even slightly for staff members. Others drew on the emotional and instrumental support offered by the staff. Regular communication with staff was viewed as an important activity by many of the adult daughters in ensuring their relatives were receiving quality care. It became clear to me that the staff roles and family roles within long-term care contexts were closely linked to one another.

This observation is consistent with the findings of Bowers (1988) and Duncan and Morgan (1994). In both of these studies, a collaboration or partnership in care was stressed by family members as opposed to a strict division of labour. In fact, the family members in these studies felt that it was important for them to build strong relationships with the staff, particularly with front-line staff who have daily and direct contact with the residents. Thus, an understanding of family member roles requires an equal understanding of staff's roles, particularly their perceptions of the roles of family members in long-term care facilities.

This area of research, particularly examinations into staff members' perceptions of family and working with families, has been largely neglected by gerontologists (Duncan & Morgan, 1994). Research needs to explore the staff members' perceptions of family member roles in long-term care facilities at all levels of staff and how those perceptions influence the family members in their roles. For example, the Director of Nursing Care had assumed that many of the family members involved in the facility participated primarily out of guilt. Although guilt certainly played a part in some of the women's stories, it certainly was not the only reason why they were involved and does not capture the complexity of family member roles and motivations.

Discrepancies in perceptions and expectations and ambiguity in terms of what is expected can result in what the role theorists have labelled role conflict and role ambiguity (Kahn, Wolfe, Quinn, Snoek, & Rosenthal, 1964; King & King, 1990; Rizzo, House, & Lirtzman, 1970; Van Sell, Brief, & Schuler, 1981). For instance, conflict may occur when staff fail to recognise the contribution family members make to the facility or fail to appreciate the caregiver's biographical expertise (Bowers, 1988; Duncan & Morgan, 1994). Family members' dissatisfaction with specific aspects of care or the overall care in general can result in tension between staff and family members (Vinton & Mazza, 1994). Conflict can also develop when staff members feel under-appreciated, mis-understood, or attacked by family members (Heiselman & Noelker, 1991). Ambiguity about specific responsibilities can further result in problematic staff-family interactions and may ultimately limit the quality of care (Rubin & Shuttlesworth, 1983; Shuttlesworth et al., 1982). In fact, role ambiguity and conflict can have consequences at both the individual and the organisational levels. Safford (1989) argued that partnership models of care in long-term care facilities require reciprocal understanding and honest communication between family members and staff. A deeper or more comprehensive understanding of the role perceptions of both staff and family and the communication of these perceptions to both groups can only help strengthen the relationships between staff and family and lessen the possibility of role conflict and ambiguity.

The findings of this study also have practical implications. The adult daughters in this study defined the situation and their roles differently for themselves and clearly had varied needs based on their role definitions. These findings suggest that it is important for facility staff to talk to family members about how they view their roles within the facility and find ways to accommodate those roles and needs. Open communication channels between staff members and family members are crucial both to strong partnerships in care and to quality care. Montgomery (1982) stressed that staff training in communication skills is one of the key components of an optimum care policy which included an integration of family members. Bouchard Ryan, Meredith, MacLean & Orange (1995) proposed a Communication Enhancement Model as a tool in enhancing the communication between professionals, older adults and their family members. Models such as this should be utilised to help facilitate better communication between staff and family members. Further, those family members who define themselves as part of the care team, as in the case of active monitors, need opportunities within the facility to play a more active role and should be recognised as legitimate members of the health care team. Further, a strict division of labour may be beneficial for some caregivers (some regular visitors) but may cause stress and conflict for those who wish to have a more active involvement in the home (Duncan & Morgan, 1994).

Other family members may not see a role for themselves within the long-term care facility. It is important for staff members to understand why family members have chosen to relinquish all care. Support and therapeutic programs are needed for those who are having a particularly difficult time dealing with the institutionalisation of a loved one, anticipatory grief, and ambiguous loss. The objective of these programs should be to find ways to help these family members re-frame the situation so they can cope with the situation more positively and perhaps, if desired, even resume some involvement in the care of their loved ones. With a focus on community care and the moral obligations of family members to care for their older relatives, it is also important to recognise the importance of acceptance of the situation and relinquishment of care as a positive coping strategy. Staff members again need to be made aware of the reasons why a family member has chosen to have little involvement in the care of their loved one and begin recognising this process as a move towards personal growth for the caregiver rather than the abandonment of the institutionalised relative.

Also, the facility needs to recognise that there may be family members involved in the caregiving system who do not have a presence in the home but who are playing an important role nonetheless in caring for the caregivers. Gaining an understanding of the needs, if any, of these caregivers -- the indirect supporters -- should be an important goal of the long-term care staff.

The women's stories reflected several pressures and stresses associated with the institution-based caregiving role (e.g., guilt, helplessness, failure and so forth) at different points in the caregiving career. For example, the transition to the home was particularly stressful for most of the adult daughters I spoke with. The literature supports the profound impact, particularly the emotional impact, that the institutionalisation of a relative can have on the family caregiver (Brody, 1977; Greenfield, 1984; Hatch & Franken, 1984; Riddick et al., 1992; Schneewind, 1990; Tobin & Kulys, 1981). Aneshensel and her colleagues (1995) point out that even though family members experience the transition to long-term care differently, some having little difficulties with it and others experiencing severe problems, many family members experience both anticipatory stress and transitional stress as they anticipate and prepare for the institutionalisation of a loved one as well as impacts after the institutionalisation. Staff members need to look at ways to ease this transition for both residents and family caregivers. Morgan and Zimmerman (1990), in a qualitative study of spouses who had recently experienced the institutional placement of their partners, found that emotional support (family approval and shared decision making), control of the situation (participation in care, assuming responsibility, knowing the staff), acceptability of the nursing home and acceptance of the situation (accepting the diagnosis and the need of constant care), and permission or command from an authority figure (e.g., a doctor) appeared to help caregivers with the transition to nursing home placement.

The adult daughters I met with discussed how pressured they felt to move their relative to the home within a very short period of time. Perhaps other alternatives need to be made so that family members can have a little more time to prepare for the move. Also, support systems should be in place to help family members over the transition period. Some of the adult daughters suggested pairing family caregivers in later phases of their institution-based caregiving careers who are coping well with the situation with those who are just new to the institution-based caregiving role. Whatever the case, support needs to be in place at the time of admission to assist both residents and family members with the transition to a long-term care facility. Further, staff members and support systems need to be available throughout the institution-based caregiving career to help families deal with the emerging challenges and stresses of the role (Riddick et al., 1992).

The women also described the difficulties they have in visits with their loved ones, particularly when the residents are no longer able to communicate with them during visits. The adult daughters themselves discussed the sense of helplessness they felt in visits and the longing for something meaningful to do during visits with their relatives. Recent research (Dupuis & Pedlar, 1995) suggests that therapeutic family leisure programs may provide opportunities for family members to have quality visits with their loved ones.

Instead of focusing only on the residents in designing recreational programs, staff need to consider ways in which family members can be included in recreational programs in meaningful ways that enhance the visits for both the residents and their family members.

Conclusion

My heightened awareness of the presence of family members in long-term care facilities and my growing intrigue with the roles of this group of people in the care of residents in long-term care facilities led me to this project over a year and a half ago. Unsatisfied with existing conceptualisations of family member roles in the institutional context, I wanted to hear from the family members themselves about how they thought about their institution-based caregiving roles and use their descriptions and their insights to develop a substantive theory that was grounded in real experiences. In developing my model of institution-based caregiving career paths, I found several parallels between the women's stories and some of the relevant literature, particularly the literature on adapting and coping to the chronic illness of a loved one. I was able to integrate some of this literature such as the FAAR model into my model, thus grounding the theory not only in lived experiences but also in the literature.

My own personal understanding of this phenomenon and the experience of caregiving for family members has expanded by being able to spend even a brief amount of time with 38 women living this reality every day of their lives. I feel privileged to have had the opportunity to have met with each of these women, if only for a brief amount of time. Further, I believe the insights from these women and from this project broadens our conceptualisations of institution-based caregiving roles and career paths in several significant ways. As I bring some closure to this project, however, I am left with several new questions in need of exploration. I am reminded of the words of T. S. Eliot: “We shall never cease from exploration and the end of all our exploring will be to arrive where we started and know the place for the first time”. This journey has led me to a more comprehensive understanding of family member roles in long-term care facilities but as I end this journey I realise that there is still much exploring to be done before we will fully comprehend the complexities and intricacies of institution-based caregiving roles and career paths. Thus, my quest continues……

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APPENDICES

Appendix A
Interview Guide for Key Administrative Members

1. What is your philosophy regarding family members of residents living in your long-term care facility? Could you describe this facility's view of the family member's role in this facility?

2. Does this facility have a policy regarding family visitation? If so, what is that policy? Are there set visitation hours for family members? If so, what are those hours? How flexible is your facility regarding family visitation?

3. Does this facility have a policy regarding resident outings with family? If so what is that policy?

4. Are family members of residents living in this facility invited to take part on the care team or in the development of a care plan? If so, how is the invitation given (e.g., telephone call, mail, personal communication in the home)? What is the family member's role on the care team?

5. Do you offer any programs specifically for family members in this facility (e.g., family support groups, family counselling, family/resident activity programs, family councils, family volunteer programs, family educational programs, etc.)? If so, what types of programs do you provide for family members? How are family members made aware of the programs? Are their eligibility criteria for family involvement in these programs?

6. Would you say that your mandate includes family members as well as residents? If so, how?

7. Does this facility provide rooms or other locations other than the resident's room for family visitation? If so, what kinds of accommodations have been made for family visitation?

8. Are there specific activities or specific areas of care in which you would discourage family member involvement?

Appendix B
Family Caregiver Demographic Profile

Thank you for the information you shared with me during our recent meeting. As a final step, I am trying to put together a profile of some of the characteristics of the family members I have interviewed during this project. Could you please check the response to each question below which best describes you now.

1. In which of the following age categories do *you* fall?

   ☐ 20 to 29 years
   ☐ 30 to 39 years
   ☐ 40 to 49 years
   ☐ 50 to 59 years
   ☐ 60 to 69 years
   ☐ 70 years or older

2a. How would you describe yourself at the present?

   ☐ full-time homemaker
   ☐ employed full-time
   ☐ employed part-time
   ☐ retired
   ☐ unemployed or on strike
   ☐ other: ____________

b. If you currently work full-time or part-time, what type of work do you do or what is your job title (please be specific)?

c. If you are currently retired or unemployed, for how long (years, months) have you been retired or unemployed?

3. What is your marital status at present?

   ☐ married or in a common-law relationship
   ☐ widowed
   ☐ separated or divorced
   ☐ single (never married)

4. How many brothers and/or sisters do you have?

   ________ brother(s)
   _________ sister(s)

5. How many of your brothers and/or sisters live within a 60 minute drive of Winston Park?

   ________ brother(s)
   _________ sister(s)

6. Considering all of the members in your immediate family, how would you describe *yourself* (check one)?

- [ ] I am the primary family caregiver to my parent at Winston Park.
- [ ] I share equally with *one* other family member the care of my parent at Winston Park.
- [ ] I share equally with *two or more* family members the care of my parent at Winston Park.
- [ ] I am a secondary family caregiver to my parent at Winston Park providing support when needed to the primary family caregiver.
- [ ] I am not at all involved in the care of my parent at Winston Park

7. How old is your parent or spouse living at Winston Park ? ________________

8a. Do you have any children living at home with you under the age of 18 years?

[ ] yes [ ] no

8b. If yes, how many children do have living in your household and what are there ages?

number of children _________ ages of children _________

Thank You For Your Help In This Project!

Appendix C1
Original Interview Guide

1. Could you describe for me a typical visit with your parent in the long-term care facility?

2. Can you describe how you think about your role in the long-term care facility? How do you define your role in relation to the staff?

3. How did you come to view your role in those terms?

4. Can you describe the things that you do in your role within the facility?

5. Are there things in your role that you do outside of the facility? If so, could you describe those things to me?

6. Do you have any expectations for yourself in relation to your role in the long-term care facility? Could you describe the things you feel are most important for you to do in your role?

7. Have the staff here expressed any expectations about what you should or should not be doing in the home? If so, what sorts of things do they feel you should or should not be doing? If no, what sorts of things do you think they expect of you, if anything?

8a. Could you tell me about yourself and your life -- start where you want and end where you want? How would you describe yourself?

8b. How does your role caring for your (husband, parent) fit into the rest of your life?

9. Has your caregiving role affected other aspects of your life? If so, what other aspects of your life have been affected by your role? How has your role affected these other aspects of your life?

10. Has your caregiving role affected the way you think about your self? If so, could you explain how?

11. What are the most difficult aspects of your caregiving role for you?

12. Could you describe the most positive or pleasant aspects of your caregiving experience for me?

13. Could you talk about what your involvement in the home means to you?

14. Are there changes you would like to make to your role within the facility? If so, what would you like to change?

15. What things would help you in your role?

16. Are there factors within the facility that make it difficult for you to perform your role within the facility the way you would like to? If so, could you discuss those factors with me.

17. Are there factors outside of the facility that make it difficult for you to perform your role the way you would like to? If so, could you discuss those factors with me.

18. Are there any factors within the facility that really assist you in performing your role the way you want to? If so, what are they?

19. Are there any factors outside of the facility that really assist you in performing your role the way you want to? If so, what are they?

Appendix C2
Examples of Questions Added to Interview Guide

1. Just before we begin with some of the specific questions that I have for you which pertain more to your role now at [the facility], I was wondering if you could describe for me the history of your mother's [father's] illness and how she [he] came to be here at Winston Park?

2. What was your role during this period of time before your mother [father] was admitted to this facility in caring for your parent?

3. Could you describe the day of admission for me?

3. Do you still see glimpses or characteristics of your mother [father] when you visit? Does the woman [man]that you visit still seem like your mother [father] to you?

4. Do you consider yourself or call yourself a caregiver? If so, why do you consider yourself a caregiver? If not, why do you not consider yourself a caregiver?

5. Do you feel that part of your role in any way is to monitor your mother's [father's] care in the facility? If so, how do you do that – what do you do to monitor your parent's care?

6. Some of the women have talked to me about how they feel that part of their role is to try and maintain their parent's sense of self or personhood? Would you describe part of your role in this way? If so, how do you go about trying to maintain your mother's [father's] sense of self?

7. You appear to be very satisfied with the care your parent is receiving. Do you think that your role would be different if you were not satisfied with the care that your mother [father] was receiving? If so, how would it be different?

8. Has your role in the care of your parent changed over the years? If so, could you describe for me how your role has changed over the years?

Appendix D
Personal Log

Date:__________ Time of Activity _____________Time Activity Ended ______________

Where did this contact/activity take place?

What were the ***main*** things you were doing?

What was the purpose of the contact/activity?

Who did you interact with during your contact/activity?

Describe the contact/activity briefly.

Describe how you were feeling during this contact/activity:

	Very	Quite	Some	Neither/Not Sure	Some	Quite	Very	
Alert	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	Drowsy
Happy	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	Sad
Irritable	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	Cheerful
Energetic	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	Tired
Upset	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	Calm
Worried	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	Carefree
Relaxed	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	Distressed
Good	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	Bad
Constrained	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	Free
Rushed	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	[ ]	At ease

How else would you describe the way you were feeling during this contact/activity?

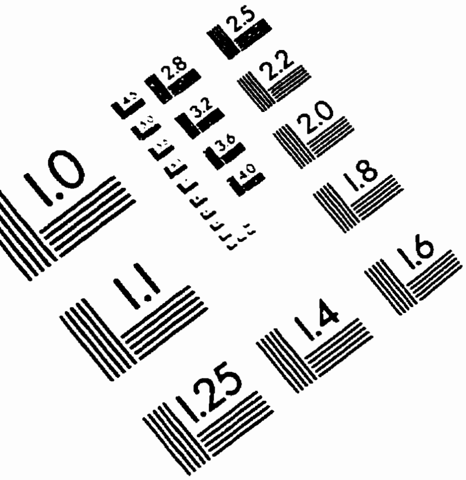
Appendix E
Concepts, Sensitising Questions, and Operationalisation of Key Concepts

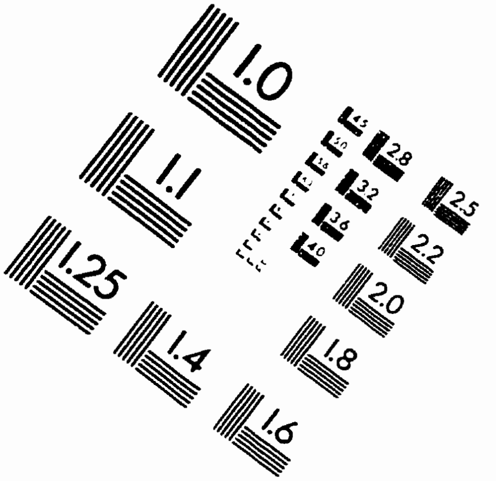
Sensitizing Concept	Sensitising Question	Operationalisation
Meaning	1a. What does caregiving mean to adult daughters of institutionalised older adults living in a specific long term care facility? How do adult daughters define their roles in relation to the staff? How do adult daughters think about and describe their roles?	***Interview Guide*** 1. Could you describe for me a typical visit with your parent in the long-term care facility? 2. Can you describe how you think about your role in the long-term care facility? How do you define your role in relation to the staff? 9. Has your caregiving role affected other aspects of your life? If so, what other aspects of your life have been affected by your role? How has your role affected these other aspects of your life? 10. Has your caregiving role affected the way you think about your self? If so, could you explain how? 11. What are the most difficult aspects of your caregiving role for you? 12. Could you describe the most positive or pleasant aspects of your caregiving experience for me? 13. Could you talk about what your involvement in the home means to you? 14. Are there changes you would like to make to your role within the facility? If so, what would you like to change? 15. What things would help you in your role? ***Personal Log*** What was the purpose of the contact/activity? Describe the contact/activity briefly. Describe how you were feeling during this contact/activity.
	4. What factors affect the way that adult daughters think about and act their roles within a specific facility?	***Interview Guide*** ***3. How did you come to view your role in those terms?***

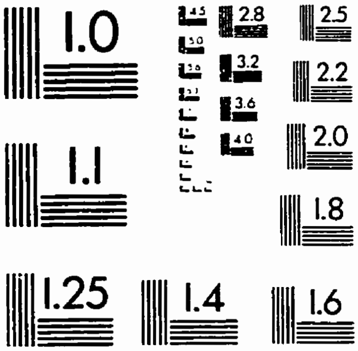
Meaning in Context		8a. Could you tell me about yourself and your life -- start where you want and end where you want? How would you describe yourself? 8b. How does your role caring for your (husband, parent) fit into the rest of your life? 16. Are there factors within the facility that make it difficult for you to perform your role within the facility the way you would like to? If so, could you discuss those factors with me. 17. Are there factors outside of the facility that make it difficult for you to perform your role the way you would like to? If so, could you discuss those factors with me. 18. Are there any factors within the facility that really assist you in performing your role the way you want to? If so, what are they? 19. Are there any factors outside of the facility that really assist you in performing your role the way you want to? If so, what are they?
	1b. Does the way adult daughters think about and define their roles in a specific setting differ by their stage in the institution-based caregiving career?	Comparison of the meaning concepts and patterns identified by caregivers in their early caregiver careers with those identified by caregivers who are in the mid and later stages of their career. Examination of facility documents. Formal interviews with members of Administration (See Appendix A).
Expectations	2a. What do adult daughters expect of themselves in their role within the specific facility? What are adult daughter's perceptions of the expectations of others for them?	***Interview Guide*** 6. Do you have any expectations for yourself in relation to your role in the long-term care facility? Could you describe the things you feel are most important for you to do in your role?

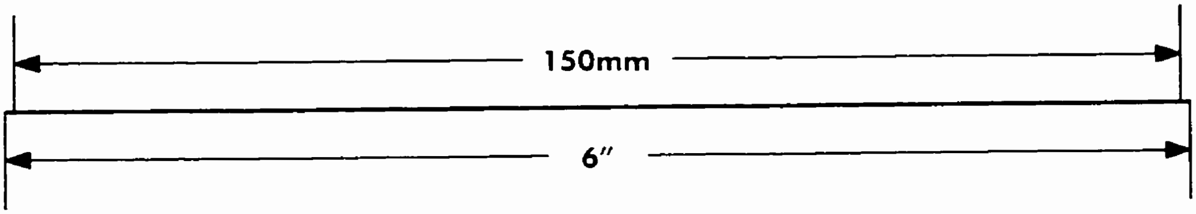
Expectations con't		7. Have the staff here expressed any expectations about what you should or should not be doing in the home? If so, what sorts of things do they feel you should or should not be doing? If no, what sorts of things do you think they expect of you, if anything?
	2b. Do adult daughters' expectations in their caregiving role differ by the adult daughters' stage in their institution-based caregiver career?	Comparison of the concepts and patterns related to expectations identified by caregivers in their early caregiver careers with those identified by caregivers who in their mid and later stages of their career.
Behaviour	3a. How do adult daughters describe their behaviours within a specific facility?	***Interview Guide*** 4. Can you describe the things that you do in your role within the facility? 5. Are there things in your role that you do outside of the facility? If so, could you describe those things to me?
	What behaviours do they perform as part of their role?	***Personal Log*** What are the main things you were doing during your contact with the facility?
	3b. Do adult daughters' caregiving behaviours differ by the caregiver's stage in their institution-based caregiving career?	Comparison of the concepts and patterns related to behaviours identified by caregivers in their early caregiver careers with those identified by caregivers who are in their mid and later stages of their career.

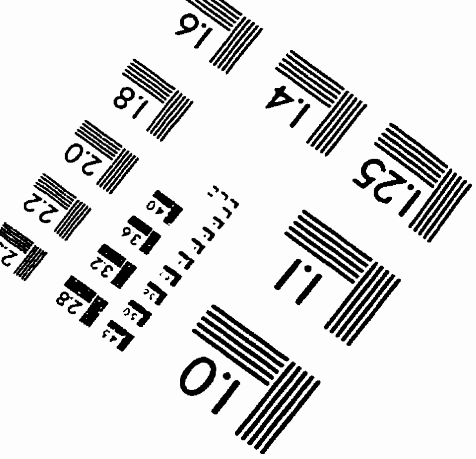
IMAGE EVALUATION TEST TARGET (QA-3)











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