

Bittersweet Journeys: Meanings of Leisure in the Institution-based Caregiving Context

Sherry L. Dupuis, Ph.D.

Department of Recreation and Leisure Studies
Brock University

Bryan J. A. Smale, Ph.D.

Department of Recreation and Leisure Studies
University of Waterloo

Research on leisure and caregiving has focused almost exclusively on caregivers providing care in the community. Guided by a symbolic interactionist approach and the conceptual framework of the caregiving career, the purpose of this study was to examine the meaning of leisure in the institution-based caregiving context. How family members define their roles and how those role definitions then influence the meaning of leisure was explored within a naturalistic, grounded theory approach using active interviews and personal logs as the data collection strategies. Five alternative caregiving role manifestations were identified and they very much affected the way that leisure was perceived in this context. The meanings of leisure—as *constriction*, as *moments*, and as *reclamation*—changed and evolved as the caregiving career did. The changeability and contradictions inherent in the meanings of leisure over the careers of caregivers are central concepts in an emerging grounded theory concluding the paper.

KEYWORDS: *Leisure meaning, caregiving career, leisure constriction, leisure moments, leisure reclamation*

Introduction

Brody (1985) has argued that caregiving has become a normative life crisis. She emphasized that although caregivers do not share a single developmental stage of life, most people will experience caregiving at some point in their lives. The caregiving role can significantly reduce a caregiver's leisure time and can alter the quality of their leisure lifestyles in negative ways (Bedini & Guinan, 1996a, 1996b; Brattain Rogers, 1997; Keller & Tu, 1994; Sneegas, 1988; White-Means & Change, 1994). At the same time, evidence also suggests that leisure may be beneficial in caregivers' lives, serving as an important coping resource for caregivers particularly in managing stress (Barusch, 1988; Bedini & Guinan, 1996b; Keller & Tu, 1994; Sneegas, 1988). Research on leisure and caregiving, however, has focused almost exclusively on caregivers providing care in the community even though the role typically

Authors' note: Dr. Dupuis may be contacted at the Department of Recreation and Leisure Studies, Brock University, St. Catharines, Ontario L2S 3A1, sdupuis@arnie.pec.brocku.ca. Dr. Smale may be contacted at the Department of Recreation and Leisure Studies, University of Waterloo, Waterloo, Ontario N2L 3G1, smale@healthy.uwaterloo.ca. Financial support for the study was provided by the Social Sciences and Humanities Research Council of Canada

continues after a care receiver is placed into a long-term care facility. "The careers of caregivers do not stop at the institution's 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). Given that the majority of older adults will spend some time in an institutional setting before they die (Dellasega, 1991), understanding the roles of family members in these settings has added importance. The work of gerontologists in helping to understand the nature of the roles taken by caregivers in an institutional setting provides a context within which to begin to understand how the meaning of leisure for caregivers may be affected. This, then, was the purpose of this study: to examine the meaning of leisure in the institution-based caregiving context, and specifically, to determine how family members defined their roles and how those role definitions influenced the meaning of their leisure in the institution-based caregiving context.

Very few studies have explicitly examined the roles of family members in institutionalized settings and how these roles are developed. Indeed, the bulk of the research on caregiving in the institutionalized context focuses on the behavior of family members (i.e., visitation patterns and task performance) in long-term care facilities and on the caregiving experience. This research demonstrates that family members continue to have frequent contact and close emotional ties with their older adult relatives after institutionalization (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Bitzan & Kruzich, 1990). Further, family members of institutionalized older adults provide both technical and non-technical types of care within the facility. Aneshensel and her colleagues (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 their relative was living in the community. Although some studies have suggested that institution-based caregivers experience relief from the emotional strains and burdens of caregiving in the community (e.g., Aneshensel et al., 1995; Zarit & Whitlatch, 1992), many more studies report the considerable pain and anguish that family members often experience in dealing with the institutionalization and gradual decline of a loved one. The stresses associated with the day-to-day physical care of a relative may be reduced with institutionalization, but the pain, anguish, and emotional strains of caregiving often continue (Dupuis, 1997; Riddick, Cohen-Mansfield, Fleshner, & Kraft, 1992) and may even become more pronounced (Carrilio & Eisenberg, 1983; George & Gwyther, 1984).

Two approaches to conceptualizing family member roles have been employed in the few studies that have examined more explicitly family member roles in institutionalized settings. Some researchers (Dempsey & Pruchno, 1993; Rubin & Shuttlesworth, 1983; Schwartz & Vogel, 1990; Shuttlesworth, Rubin, & Duffy, 1982) have used *a priori* definitions of family member roles based on Litwak's (1977, 1985) structural-functionalist framework. These authors conceptualized roles as a set of expectations, specifically a set of tasks, that the primary group (e.g., the family) is responsible for in relation to the formal organization (e.g., the long-term care setting). Considerable ambi-

guity was apparent concerning whether family or staff should be responsible for various caregiving tasks, and tasks were often perceived to be a shared responsibility.

Other researchers have questioned the usefulness of a task-based conceptualization of family caregiving and further questioned whether or not it is possible to differentiate roles simply by the specific tasks associated with those roles (Bowers, 1987; 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, a few 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. They found that family members do not think of their roles in terms of the tasks that they perform, but view their roles in terms of the meaning or purpose they attribute to their role. A major purpose of the familial caregiving role mentioned by family members, for example, was the preservation of the older relative's dignity and sense of self (Bowers, 1988; Duncan & Morgan, 1994; Dupuis, 1997). These studies have pointed to the diversity in orientation of the caregiving role among any one group of caregivers (Dupuis, 1997; Ross, 1991). More importantly, however, they have illustrated the importance of understanding the meaning of caregiving before we can begin to understand how the caregiving role gets played out by individual family members and how the role may have an impact on other aspects of caregivers' lives, such as their leisure lifestyles.

LEISURE IN THE CAREGIVING CONTEXT

Our understanding of leisure in the caregiving context is quite limited and in the very early stages of development. The vast majority of the research examines the cost of caregiving to individual caregivers, especially to their leisure time and experiences. Research consistently demonstrates that caregiving substantially reduces participation in recreation and leisure activities and significantly diminishes the opportunities for social interaction (Bedini & Guinan, 1996a; Chenoweth & Spencer, 1986; Dunn & Strain, 1998; George & Gwyther, 1986; Keller & Tu, 1994; Miller & Montgomery, 1990; White-Means & Chang, 1994). White-Means and Chang (1994) estimated that for the average caregiver, there was a 62 per cent likelihood that caregiving would limit family leisure time and an 81 per cent likelihood that the role would limit personal free time. Along with the loss of valued leisure activities or the reduction of time available to participate in these activities, caregivers experience a loss of freedom, independence, and spontaneity in leisure upon assuming the caregiving role (Bedini & Guinan, 1996a). Further, the leisure experience itself often changes after an individual assumes caregiving responsibilities. In a study of community-based, spousal caregivers, Weinblatt and Navon (1995) noted:

[T]he few leisure activities that they managed to maintain failed to provide the caregivers with the feeling of joy, the escape from routine, and the sense of self-

actualisation that had characterized these activities in the past. Most of them reported that even when crocheting or watching television, for instance, they constantly felt like prisoners, and that their minds were still preoccupied with caregiving-related concerns. (p. 314)

Among the constraints to leisure involvement, lack of time due to caregiving responsibilities is one of the most frequently identified external barriers to leisure participation (Bedini & Guinan, 1996a; Dunn & Strain, 1998; Horowitz, 1985b; Pratt, Schmall, & Wright, 1987; Sneegas, 1988). Other frequently reported external reasons for a reduction in leisure participation identified by caregivers include lack of outside help or scepticism of the quality of outside help, financial burden of caregiving, and weather restrictions (Bedini & Guinan, 1996a; Dunn & Strain, 1998).

Caregivers also have identified several internal barriers to leisure participation. The intense nature of the caregiving role often leaves caregivers feeling physically and emotionally drained. Thus, feeling too tired, feeling too stressed, and physical and emotional fatigue are common internal barriers to leisure involvement expressed by caregivers (Bedini & Guinan, 1996a; Dunn & Strain, 1998). The caregiver's own physical health also has been identified as an important reason for a change in leisure behavior (Dunn & Strain, 1998).

The perceived sense of obligation or responsibility to care, however, is perhaps one of the most important constraints to leisure experienced by caregivers. A strong moral obligation and the sense of filial responsibility have been found to be major motivating factors in providing care to an elderly parent, particularly in providing emotional support (Blieszner & Mancini, 1987; Hamon & Blieszner, 1990; Walter, Pratt, Shin, & Jones, 1989). Wolfson et al. (1993) concluded that this obligation may stem partially from life-long attachments and affections between parents and their children. Filial responsibility also may stem from the caregivers sense of reciprocity in care; that is, the feeling that because parents had once taken good care of them, it was now their turn to return the care to the parents (Dupuis, 1997; Norris & Tindale, 1994; Pratt, Schmall, & Wright, 1987). Thus, caregivers often feel that it is wrong to turn care over to someone else, even for short periods of time, and feel guilty when they do have to ask others for assistance (Zarit & Zarit, 1982). Further, some caregivers experience great anxiety with the prospect of leaving their care receiver in the hands of others, fearing that something might happen while they are away (Bedini & Guinan, 1996a; Weinblatt & Navon, 1995).

Women, particularly, feel a strong sense of duty towards their parents, husbands, and other family members that can cause them to give up valued leisure and social activities in order to concentrate on providing care (Brat-tain Rogers, 1997; Pratt, Schmall, and Wright, 1987). Feminist theorists (e.g., Baines, Evans, & Neysmith, 1991; Dalley, 1988; Gilligan, 1982; Henderson & Allen, 1991; Larrabee, 1993) argue that women are socialized into an ethic of care in that women are culturally conditioned to feel a sense of obligation

to care for others. Henderson and her colleagues (1996) stress that an ethic of care can prevent women from addressing their own leisure needs. Caregivers' concern for their own needs is often perceived as selfish, guilt-provoking, and shameful (Brody, 1985; Henderson & Allen, 1991; Hooymann & Lustbader, 1986; Weinblatt & Navon, 1995). Some researchers, however, have suggested that changes in leisure lifestyles may be due to the caregiver's lack of awareness of her or his own leisure needs (Bedini & Bilbro, 1991; Keller & Hughes, 1991).

Weinblatt and Navon (1995) critically examined the notion that leisure nonparticipation in the caregiving context was a result of passive reactions to structural, interpersonal, and intrapersonal constraints. They argued that caregivers might actively choose to avoid leisure given the problems that leisure may evoke for them. Despite the time-consuming nature of the caregiving role, they found that caregivers still had opportunities for participation in leisure activities, but often did not take advantage of them. Some of the caregivers perceived leisure as threatening and negative, antithetical to the war they were waging to keep their loved ones alive. Although these caregivers spent much of their time attending to their care receivers' leisure needs, leisure in their own lives was considered inactivity, a waste of time, and a breeding ground for feelings of anxiety, depression, loss of control, and betrayal of the care receiver. Due to the negative meanings ascribed to leisure, these caregivers actively rejected leisure in their own lives. Weinblatt and Navon suggested that the personal choice to abstain from leisure may actually help caregivers cope with their difficult circumstances by helping them maintain an illusion of control over the situation.

Other studies have examined the characteristics of the caregiving setting (e.g., characteristics of caregivers and care receivers) that may predict limitations in social and leisure activity in the caregiving context. Important predictors of the restriction in the number of personal, family, or social activities include the care receiver's level of impairment, the caregiver's assessment of difficulty in responding to the impairment, and the task demands associated with caregiving (Miller & Montgomery, 1990; Poulshock & Deimling, 1984). Also, caregivers who report leisure activity limitations are more likely to be women and immediate family members, to have children under the age of 18 years living in the home, to live with the care receiver, to have higher family incomes, to be more highly educated, to be more likely to use paid help, and to have fewer back up helpers (Miller & Montgomery, 1990; White-Means & Chang, 1994). Adult daughters struggling with meeting multiple roles (e.g., familial, employment, and caregiving roles) appear to have greater difficulty accessing leisure time when compared to other caregivers (Brody & Schoonover, 1986). Stoller (1983), for example, found that limitations in social activities was highest for adult daughters and wives compared to other caregivers, and that daughters were three times more likely to report limitations than wives.

Caregivers have identified the difficulty of accessing free time for themselves (Barusch, 1988; Chenoweth & Spencer, 1986; Zarit, Reeve, & Bach-

Peterson, 1980) and limitations in social life (Clark & Rakowski, 1983; Rabins, Mace, & Lucas, 1982; Stephens & Christianson, 1986) as major problems associated with the caregiving role. Reduced opportunities for social and personal recreational and leisure activities are associated with lower self-reported health (Keller & Tu, 1994) and greater levels of global stress (Miller & Montgomery, 1990). In fact, the lack of free time in caregiving is significantly related to higher levels of caregiver burden (Deimling & Bass, 1986; Dunn & Strain, 1998; Montgomery, Gonyea, & Hooyman, 1985; White-Means & Chang, 1994).

Although reductions in leisure time are inevitable in many caregiving situations, leisure participation also may serve as an important support for some caregivers. Considerable research supports the notion that participation in leisure activities contributes to life satisfaction and psychological well-being (Evans & Haworth, 1991; McTeer & Curtis, 1990; Smale & Dupuis, 1993; Wankel & Berger, 1990), to physical well-being (Nieman, 1998; Paffenbarger, Hyde, & Dow, 1991), and to the development and maintenance of friendships and social support networks (Adams, 1993; Coleman & Iso-Ahola, 1993, Kelly, 1983, 1993). Evidence also suggests that leisure may play an important role in coping with stress (Caltibiano, 1995; Hull & Michael, 1995). Coleman and Iso-Ahola (1993) argued that leisure participation helps buffer the effects of stressful life circumstances and, in turn, benefits physical and mental health. They suggest that leisure facilitates coping with life stress through the development of social support and self-determination dispositions that are generated through leisure involvements.

Within the caregiving context, leisure may serve as a means of coping by providing relief and escape from the responsibilities of caregiving and may serve to help caregivers become re-charged for the role (Bedini & Guinan, 1996a; Keller & Tu, 1994; Sneegas, 1988). This, in turn, helps to reduce tension and stress associated with the caregiving role and helps them handle the burden of caregiving more effectively (Bedini & Guinan, 1996a; Sneegas, 1988). Keller and Tu (1994), for example, found that caregivers with higher leisure participation rates and higher levels of leisure satisfaction or those who identified fewer barriers to leisure involvement reported fewer perceived burdens associated with the caregiving role. Caregivers in their study expressed that leisure provided them with rewarding relationships with other people, contributed to their self-confidence and their sense of accomplishment, helped them stay healthy, and helped restore them physically. Barusch (1988) examined the problems associated with caregiving and effective coping strategies for dealing with these stressors. The most effective coping response involved solitary leisure activities such as letter writing, listening to songs, or going for walks. Cultivating a support group of friends who shared leisure activities also was found to be an effective coping strategy in dealing with the stresses of caregiving. Given the potential benefits of leisure in the caregiving context, some researchers have argued for the importance of leisure education for caregivers and recommended that recreation and leisure services be incorporated into an interactive system with other

health care services (Bedini & Bilbro, 1991; Hughes & Keller, 1992; Keller & Hughes, 1991).

With the focus on participation, very few studies have investigated the *meaning* of leisure in the caregiving context, but the research that does exist suggests that caregivers may ascribe quite different meanings to leisure. Brat-tain Rogers (1997), for example, found that wives serving as primary caregivers to their spouses held two different perceptions related to entitlement to leisure. *Integrated Caregivers* felt that leisure was an important resource for coping with the stresses they experienced in their caregiving role and for maintaining their own identities. Thus, they actively sought the support they needed in order to maintain their leisure lifestyles. On the other hand, leisure had very little meaning for *Unintegrated Caregivers*. These caregivers were consumed by their caregiving responsibilities and did not actively pursue leisure. Bedini and Guinan (1996b) found four different approaches to leisure in their study of women caring for a variety of care receivers. *Repressors* expressed either no need for leisure in their lives or indicated that they survived by suppressing their desire for leisure. *Resenters* felt pressure to sacrifice their leisure pursuits in order to fulfil their caregiving responsibilities, but this resulted in great frustration, bitterness, and resentment at their inability to access desired leisure time. *Consolidators* valued leisure, but believed that accessing their own leisure required incorporating the care receiver into their leisure plans either by fitting the care receiver into their own pursuits or by adapting their leisure to the needs of the care receivers. This approach often affected the experience of leisure for these caregivers. Finally, *Rechargers* viewed leisure as an important coping tool in the caregiving context, and therefore, found ways to negotiate through constraints. Specifically, leisure was seen as a means of energizing or recharging themselves for the caregiving responsibilities.

Although the existing literature provides insight into some of the characteristics of institution-based caregiving roles and leisure within the caregiving context, several limitations are apparent. First, the majority of the research on leisure in the caregiving context has focused almost exclusively on community-based caregivers. Very little research has examined the nature of leisure for persons providing care for a loved one living in a long-term care facility. The little research that does exist focuses on leisure behavior and time use and suggests that caregivers living with their care receivers have significantly lower levels of both social participation and satisfaction compared to their counterparts caring for persons living in long-term care facilities (George & Gwyther, 1986). Further, evidence suggests that caregivers may gain some discretionary time after institutionalisation of a relative and that this "saved" time is often used for social time with family, recreation, and activities outside of the home (Moss, Lawton, Kleban, & Duhamel, 1993). However, the meaning of leisure in the institution-based caregiving role has yet to be explored.

Second, studies focused on leisure in the caregiving context have tended to examine quite diverse groups of caregivers assuming they face similar

issues. Yet, research suggests that the caregiving role and 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. Studies of both community-based and institutional-based caregivers, for example, have found that caregiving generally has a greater negative impact on women than on men (Brody, Dempsey, & Pruchno; 1990; Fisher & Lieberman, 1994), on spouses compared to adult children (Grau, Teresi, & Chandler, 1993; Riddick et al., 1992), and on those caring for persons with dementia compared to those caring for relatives with physical impairments (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). There also appear to be real differences in the types of assistance offered by men and women. Women tend to be more intensely involved in the overall assistance to their older adult relatives than men and are more likely than men to provide "hands-on" assistance in the areas of domestic and personal care (Chang & White-Means; 1991; Horowitz, 1985a; Stoller, 1990). Further, researchers examining community-based caregivers have found significant differences by type of caregiver (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 they were likely to perform during the week, or the frequency and duration of those activities (Jones, 1994; Ory et al., 1999). Given their different relationships to the care receiver and perhaps different life stages and situations, it is reasonable to assume that different caregivers (e.g., spouses and adult children, other relatives) approach their caregiving roles differently, and thus, have varying meanings of leisure related to their unique circumstances. Harper and Lund (1990), in fact, recommended that because situations differ for various types of caregivers, more homogeneous categories of caregivers should be considered in future analyses.

Third, leisure researchers have tended to treat the caregiving role as remaining relatively stable over time. Several gerontologists, however, have argued that the caregiving career goes through several phases as the older adult's needs change over time (e.g., Given & Given, 1991; Lewis & Meredith, 1988; Wilson, 1989). Our understanding of how leisure correspondingly changes as the caregiving role changes is extremely limited.

Finally, with only a few exceptions (see Bedini & Guinan, 1996a, 1996b; Brattain Rogers, 1990; Weinblatt & Navon, 1995), caregivers' own constructions of their caregiving experiences and the meaning of leisure within that context have largely been ignored. 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." Understanding individual caregivers' perceptions of their institution-based caregiving roles is essential in order to gain a deeper and more comprehensive understanding of how leisure is perceived in this specific context.

This study set out to address these limitations by seeking to understand the meaning of leisure for caregivers caring for a relative in a long-term care facility from their perspectives. Given Harper and Lund's (1990) recommen-

dation related to focusing investigations on more homogeneous groups, we chose to focus our investigation on the meaning of leisure for adult daughters caring for a parent with cognitive impairment living in a long-term care facility. Further, we chose to examine leisure within the institution-based context from a career perspective, recognizing the change that occurs over that career.

CONCEPTUAL FRAMEWORK

This research drew on symbolic interactionism and the conceptual framework of the caregiving career. Symbolic interactionists maintain that humans, in this case family members, do not merely passively conform to others' expectations as the task-based approach suggests. Instead, humans actively and creatively construct and modify their roles through interactions in specific social settings based on the meaning that they attach to actions or situations (R. H. Turner, 1962). From a symbolic interactionist perspective, caregiving roles are constructed and reconstructed over time in a dynamic and fluid role-taking and role-making process. This role-taking and role-making process includes defining and re-defining the situation, interpreting and re-interpreting the behavioral and verbal gestures and expectations of others, and ongoing negotiation processes (Blumer, 1969; R. H. Turner, 1962; Fife, 1994). The meaning that family members ascribe to their roles both influences and is influenced by role behavior and the activities that a family member may choose to perform. Therefore, the meaning of the caregiving role also is likely to influence how leisure is perceived in the caregiving context. Consequently, how caregivers view their caregiving roles must be understood before an understanding of leisure within that context can be developed.

In order to appreciate the meanings that family members express, it is important to understand the contexts of both behavior and its interpretations (Sankar & Gubrium, 1994). Context, in this study, refers to *positionality* (Jaff & Miller, 1994), or the unique personal circumstances or situations of individual family members. Family members bring to the caregiving situation a unique set of interconnected characteristics and unique biographies of experience. They include, for example, stocks of knowledge at hand, personality and psychological factors, health and physical factors, and life circumstances (e.g., marital status, working status). 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) summarized the importance of self-conceptions in role development by suggesting that they provide a sense of personal continuity across various settings as the individual works towards enacting a role appropriate to each setting. Self-

concepts play a particularly important function in the establishment of workable roles when the setting is not clearly defined.

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 helps people structure their perceptions of, and orientations to, others in the situation (Schutz & Luckmann, 1973). A "stocks of knowledge" warehouse includes knowledge of cultural frameworks, knowledge from past experiences in the specific role such as knowledge from experiences in the caregiving role or related to past leisure lifestyles, knowledge from past experience in other roles, and general inventories of role conceptions. These varied characteristics and "ordered experiences" are combined and recombined in order to interpret meanings in particular contexts (J. H. Turner, 1988). Thus, because family members bring different sets of characteristics to the situation, they may experience and define the caregiving situation differently, and therefore, may develop individualized roles according to their particular situations (Clair, Fitzpatrick, & La Gory, 1995). Leisure within these unique circumstances may then vary in just as individualized ways.

This study is informed further by the conceptual framework of the caregiving career to reflect the directions and patterns that the caregiving experience may take over time (Hughes, 1971). Several researchers have described the multiple phases and transitions of the caregiving career in the community (e.g., Given & Given, 1991; Wilson, 1989), and the institutionalisation of a care receiver represents a pivotal point in a caregiver's career (Aneshensel et al., 1995; Zarit & Whitlatch, 1992). The caregiving career continues to shift within the long-term care context (Dupuis, 1997; Rosenthal & Dawson, 1992) and each phase in that career represents only one piece of the entire caregiving career path. Further, as Aneshensel et al. (1995) emphasized, "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" (p. 19). Consequently, caregivers at different points in their caregiving careers may think about their roles differently, and in turn, may have different expectations for themselves and may react differently in their role behaviors. As a caregiver travels through each phase and turning point in her or his career, each set of roles will be constantly created and recreated into another set of roles. The entire career line thus will reflect periods of stability and periods of instability or change. Inevitably, caregivers' leisure also may change as they move from one phase to another in their caregiving careers.

In a grounded theory study such as this one, existing theories were used to provide a set of initial sensitising concepts (e.g., meaning, positionality, career phase) and relationships, and to stimulate "theoretical sensitivity" throughout the project (Strauss & Corbin, 1990). That is, these theories helped guide us in knowing where to begin looking, and sensitized us to the appearance of new concepts that may have appeared as data were collected and analysed.

METHOD

The data for this study came from a larger study focused on understanding the roles of adult daughters in long-term care facilities and how those roles impacted on the rest of caregivers' lives.¹ I chose a naturalistic methodological approach (Lincoln & Guba, 1985) employing the specific techniques of grounded theory methodology (Glaser & Strauss, 1967) for the original study. A naturalistic, grounded theory approach was consistent with the constructivist theoretical framework guiding the study in that it allows for the emergence of multiple perceptions or meanings held by the participants themselves (Lincoln & Guba, 1985; Schwandt, 1994). This kind of approach is especially useful when the phenomenon in question is neither well developed nor has received much attention in the literature. This method seemed well suited for the task given the paucity of research explicitly focused on the roles of family members in long-term care facilities and the nature of leisure within that context, as well as the limited presence in the literature of the family members' "voices" related to how they view their roles and leisure within those roles.

A combination of selective sampling procedures (Schatzman & Strauss, 1973) and theoretical sampling strategies (Glaser & Strauss, 1967; Strauss, 1987) was used to determine which family members within a long-term care facility in Southern Ontario would be asked to participate in the study. Initially, three criteria were used in the selective sampling to identify potential participants: (1) the 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 a cognitive impairment; and (3) the adult daughters had to be at different points or phases in their institution-based caregiving careers. I subsequently used theoretical sampling to guide my decisions concerning who else should be included as the study progressed and new concepts, patterns, themes, and issues emerged that provided greater insights. For example, early in the study, it became clear that women with both parents living might be defining their roles differently than those with only one parent living. Thus, adult daughters with both parents living were sought in order to examine their role perceptions further. Also, quite unexpectedly, some of the women in the mid-phase of their caregiving career described their caregiving as leisure. Subsequent interviews, therefore, further explored and expanded upon this notion. A traditional grounded theory approach recommends sampling until theoretical saturation occurs. Data from 38 adult daughters were collected before I was satisfied this had been achieved.

Table 1 presents some of the demographic characteristics of the 38 adult daughters who agreed to share their stories. Almost all of the women were over 40 years of age with most being 50 years of age or older. The majority

¹Whenever "I" or "me" is used, it is in reference to the principal author who undertook the original study on which this paper is based, and "we" is used when both authors have collaborated on this paper.

TABLE 1
Characteristics of the Adult Daughters

<i>Characteristic</i>	<i>n</i>	<i>Percentage</i>
<i>Age</i>		
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
<i>Marital Status</i>		
Married / common-law	30	81.1
Widowed	4	10.8
Separated or divorced	3	8.1
<i>Employment Status</i>		
Full-time homemaker	8	21.6
Employed full-time	12	32.4
Employed part-time	10	27.0
Retired	7	18.9
<i>Parent Receiving Care</i>		
Mother	30	78.9
Father	8	21.1
<i>Sibling Network</i>		
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
<i>Sibling Network in Area</i>		
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
<i>Caregiving Career Temporal</i>		
Early career	13	34.2
Mid-career	11	28.9
Later career	14	36.8

of the women were married and were working full- or part-time. Eighty per cent of the women were caring for their mothers. Parents living in the institution ranged in age from 66 to 95 years of age, the average age being 84.2 years. Finally, the women were split almost evenly among three caregiving career phases: 34.2 per cent were in early phases of their institution-based caregiving careers (1 to 9 months), 28.9 per cent were in the mid career phase (10 months to 2 years), and 36.8 per cent were in the later career phase (more than two years).

Two data collection strategies consistent with a naturalistic, grounded theory approach were employed in the original project. First, I conducted

in-depth, active interviews (Holstein & Gubrium, 1995) with all the participants. Active interviews emphasize the collaborative and interactional process between the researcher and participants, and recognize that all knowledge is co-constructed. Thus, active interviews incorporate a variety of techniques different from a structured or semi-structured approach in the search for mutual understanding. For example, active interviews recognize that the interview is very much shaped by the interviewer and her or his research agenda, and therefore, the topic areas of interest to and the position of the researcher are made explicit to the participants. The active interview is much more conversational in style, capitalizes on the dynamic interplay between the researcher and participants, and involves mutual disclosure.

An initial interview guide was prepared but as the study progressed, questions were continually revised and additional questions were added as patterns and themes began to emerge so they could be explored more fully with other participants. The interviews examined a number of issues related to the caregiving experience and leisure (e.g., how family members thought about and described their caregiving role within the long-term care facility, how caregiving had an impact on their leisure lifestyles, how they viewed leisure in the caregiving context, whether they considered any aspects of caregiving as leisure). All but one of the interviews were audiotaped and typically ranged between one and two and a half hours in length. Once the tapes were transcribed, I analyzed the narratives and added insights and interpretations as well as clarifying questions to the transcript. The transcripts were then sent back to the adult daughters as part of a member check (Lincoln & Guba, 1985). Each adult daughter was asked to indicate whether she agreed or disagreed with the interpretations of her experience, to answer the clarifying questions written in the margins, and to indicate whether or not the transcript accurately reflected her story or experience. The adult daughters also were encouraged to elaborate on or clarify issues raised in the interview that were important to them.

In order to identify the behaviors associated with the caregiving role and allow the family members to label and describe those behaviors in their own words, all participants were asked to keep a personal log for a two-week period. Personal logs were used to capture the "day-to-day flow of experience" in the caregiving role (Berman, 1994, p. 212). The adult daughters were asked to begin their logs immediately following their interviews. These logs were open-ended in nature every time a family member performed an activity that she perceived to be part of the caregiving role, she was asked to describe the activity in detail in the log. They also were asked to indicate whether the activity they were participating in at the time was considered "work", "leisure", "a mixture of work and leisure", or some other activity. If they considered the activity to be something different, they were asked to describe how they perceived the activity.

Eleven of the 38 women declined to complete personal logs for the study. Those who did not complete them defined their caregiving roles very differently than those who did complete the logs. For example, many of the women who preferred not to complete the personal logs felt they were not

coping well with the situation and indicated that the log would be too difficult for them to complete. Some of these women indicated that their difficulty in coping meant they would not be involved in any caregiving activities over the two week period following the interview.

Data analysis began with and continued throughout the interview process (Luborsky, 1994). The use of tacit knowledge and intuition were important components throughout the entire analysis process, however, they played a particularly important role in the 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)

Intuition helped in the identification of initial issues and patterns that were important to the women and required further exploration as the data collection process continued.

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 woman'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 transcripts as were questions that needed to be addressed by the participant. This was the point at which I shared the transcript with the participant along with my initial interpretations and further questions "for affirmation of its comprehensiveness and accuracy and for suggested deletions and additions" (Moustakas, 1990, p. 51). At the same time, I made note of emerging meaning categories and the suspected relationships between various other categories, patterns, and themes in the form of memos documented in a research log. This analysis process was completed for each participant involved in the project until I had gained an understanding of each participant's experience and the meaning of leisure within that experience (Moustakas, 1990).

During the data collection process and immediately following the collection of all of the interview and personal log data, a comparison of each of the women's experiences was conducted. The purpose of this exercise was to develop a composite depiction that represented the common meaning categories and themes that embraced the experiences of all the adult daughters (Moustakas, 1990). At this particular stage in the analysis process, the data from the interviews and the personal logs were analysed using a modified constant comparative method (Glaser, 1978; Glaser & Strauss, 1967; Strauss & Corbin, 1990). This process involved: (1) conducting a line-by-line

analysis of the transcribed interviews using open coding (Strauss & Corbin, 1990) in order to identify conceptual categories relevant to the meaning of caregiving for individual adult daughters and the meaning of leisure within that context; (2) comparing emergent patterns across individual caregivers and groups of caregivers at different phases in the caregiving career in order to identify common patterns in the data as well as negative cases; (3) identifying the substantive codes which “conceptualize the empirical substance of the area of research”, specifically related to the meaning of caregiving and leisure (Glaser, 1978, pp. 55-57); and (4) conducting theoretical coding (Dolan Mullen, 1985-86) in order to organize the many concepts and patterns into a more integrated set of relationships or configurations. A final and important step we conducted 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).

LEISURE IN THE INSTITUTION-BASED CAREGIVING CONTEXT

The adult daughters' stories represented a variety of ways that they viewed their roles in the care of their parents. These alternative role perceptions fell into five caregiving role manifestations which we came to label *active monitors*, *regular visitors*, *indirect supporters*, *unaccepting relinquishers*, and *accepting relinquishers*. Several features helped explain the differences in the role perceptions held by the adult daughters, such as phase in the caregiving career, visitation patterns and level and type of involvement in the facility, role definitions or meanings, the focus of support given by the daughters, their perceptions of the “thereness” of their parents, the pressure felt by the women to be at the facility, and the ability or inability to cope with and come to a place of acceptance of the situation. The way the adult daughters viewed their roles in the long-term care facility very much affected the way that they thought about leisure in the institution-based caregiving context.

Throughout the next several pages, we describe each of the role manifestations and how leisure was perceived within these manifestations. The caregiving role is described first to establish the context; then, the role that leisure plays within that context is explored. It is important to note that although we present the manifestations as distinct, they are not entirely mutually exclusive, but overlap to some degree. That is, the women in any one of the five manifestations may also share characteristics of the women in any of the other manifestations. For example, a woman categorized as an indirect supporter also may have a few characteristics similar to the women in the regular visitor role manifestation. Her perception of her role within the long-term care facility and how she perceives leisure in that context, however, “fits” more closely with the indirect supporter group. This also is true for the way in which leisure is manifested throughout the caregiving careers of the women. The different meanings that leisure holds for them evolve and change depending on the unique circumstances they each face.

Further, the women in any one role manifestation are not all at the same place within 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 is the *dominant* way that they define or think about their role within the facility and how leisure may be perceived at that phase in the caregiving career. Finally, 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 role manifestations may appear to be distinct, individual women's situations within any role manifestation are, in many cases, quite diverse.

Active Monitors

Women in the active monitor role manifestation tend to be in early temporal career phases, caring for their parent in the facility for no more than nine months. Of all the adult daughters, they are the most intensely involved in the facility, visiting their parents at least three times a week and often daily. These adult daughters describe their role primarily in terms of their purpose within the facility—to maintain normalcy in their parents' lives, to monitor their parents' care, and to preserve the parents' sense of self. Active monitors tend to define their role in terms of supporting both their parents and the staff, a role they perceive as "being there" for both. They provide a support system for their parents, and provide services and direct hands-on care that the staff might normally perform, thereby giving the staff some relief. Thus, active monitors view themselves as part of the care team. All of the adult daughters in this manifestation believe that their parents still have a strong psychological presence in their lives. Finally, active monitors describe a stronger sense of personal obligation or duty to be involved in their parents' care at the facility than any other role manifestation. In some cases, however, this pressure was rooted in either the adult daughters' dissatisfaction with the care provided in the home, or in their perceptions of what their parents expected of them.

Carrie-Ann is an example of an active monitor. Carrie-Ann is in her mid-forties, is married, and has two teen-aged 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. At the time of her interview, Carrie-Ann's mother had been living in the facility for approximately three months, and she was intensely involved in her mother's care. She usually visited her mother five times a week and regularly volunteered to play the piano at a weekly sing-a-long in the facility. At the beginning of her interview, Carrie-Ann described 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.

She saw her role as providing a sense of the familiar for her mother. By visiting her mother often she felt that she could maintain a sense of normalcy in her mother's life. Carrie-Ann also indicated how she places a great deal of importance in her monitoring role and her role in preserving her mother's sense of self.

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 recognize Carrie-Ann as her daughter. She did talk, however, about how difficult she feels it will be when her mother no longer recognizes 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 for 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 recognize 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 realize probably the difficult thing will be when my mother doesn't recognize me at all.

Carrie-Ann also emphasized in her narrative how her support role 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 take away some of it for them.

When asked if she considered herself a caregiver, she responded, "Yes, because I am doing things for her that the home here does."

Similar to caregivers based in the community, active monitors generally describe their caregiving as a constraint to their leisure. Alice, for example, 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. Alice emphasized that a large part of her role involves being a "voice" for her mother. Alice's mother is still cognitively alert and quite able to communicate with Alice, but only speaks Polish. Thus, Alice feels that she must be at the facility regularly to ensure that her mother's needs are being communicated to the staff. She described that because of this, she always feels like she is "on call" and cannot be away from her mother for any length of time. She explained, "I can't go away on vacation. There is no way mother 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." For these women, caregiving and their other responsibilities come first and so they have very little time for

leisure. When they do find time, the leisure experience is often altered for these women. For example, some of these women often feel guilty participating in leisure. Another active monitor, Eva, explained, "They had cards Wednesday night, but as long as my sister drove and came here, I used to think I can't go play cards when I have a chance to come here. So that is what I did. But now that she's not coming out no more, I go play cards but I always feel guilty at the card games." Active monitors, therefore, tend to define their caregiving roles as something other than leisure or work, but rather as a "duty" that has a work component.

Regular Visitors

Regular visitors tend to be in mid or later phases of their temporal caregiving careers, most caring for their parents for more than one year. Their parents generally are in a more advanced stage of their cognitive impairment at this point, sometimes losing the ability to recognize their adult daughters. Like the active monitors, they visit the facility regularly, but do not visit quite as often. Regular visitors visit their parents at least once a week and certainly no less than once every two weeks. Also similar to the active monitors, the regular visitors define their role in terms of their purpose within the facility. These purposes again have to do with maintaining their parents' normalcy, monitoring care, and preserving their parents' sense of self. Unlike active monitors, however, regular visitors focus all of their energy on supporting the parent and generally do not talk about their role in terms of supporting the staff. They describe their role as being more of an extension to what the staff provides within the facility; that is, providing more of the personal and emotional aspects of care and not wanting to be involved in the physical aspects of care. Another similarity between the active monitors and the regular visitors is the perception of the parent. For the most part, regular visitors still perceive their parents as still "being there" in terms of their personalities. Finally, although regular visitors do visit regularly, they do not describe the same sense of pressure to be at the facility as that described by the active monitors. They do talk about their role in relation to a sense of obligation, and in most cases as something they want to do, but they do not seem to experience the same degree of pressure to be at the facility as described in the active monitors' stories. Further, regular visitors tend to be much more satisfied with the care their parents are receiving. Knowing their parents are safe and well cared for gives the adult daughters in this role manifestation "peace of mind" and an enormous sense of relief from the pressures and concerns they once felt.

Sarah's story illustrates the regular visitor role. Sarah is in her fifties, is married, and has three grown children. She keeps very busy running the two small businesses she owns. Sarah's mother has lived in the facility for 2 years and 6 months. Sarah's role has changed dramatically over her caregiving career, especially as she became more comfortable with the care her mother was receiving. When asked how she defined her role now in the care of her

mother she stated, "I guess my role is very changed, I am just being a daughter again." When asked to elaborate, she explained:

I am just participating in mom's life. 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. I will change her diapers but I think my role is to visit, chat, and provide her with some humor . . . 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 . . . But, I guess my role is just to be with my mother. I enjoy her, you know, I really like my mother.

Sarah's role had once been very intense, but it became clear throughout Sarah's story that she now perceived her role in more social and emotional terms, primarily providing companionship and serving as a recreational organizer for her mother. Nonetheless, she also emphasized in her story how she monitors her mother's care primarily by observing her mother, the facility, and the staff and by ensuring that communication lines are always kept open. Sarah also described how part of her role involves trying to maintain her mother's sense of self:

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. In her changed role within the facility, Sarah now thought of her role as an extension of what the staff members were doing in the facility.

Sarah's narrative reflected a perception of her mother as still very much existing for Sarah. Her descriptions of her mother emphasized a woman still able to hold a conversation when alert, still having a "funny sense of humor," 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 recognize her much of the time now, Sarah still saw many glimpses of her mother during her visits and she continued to be a very important part of Sarah's life. This perception of her mother made it even more important for Sarah to have a regular presence in her mother's life.

For some regular visitors, leisure continues to be constrained, but the majority of these adult daughters talk about the "freedom from care" they now feel. For example, Candace described how her role has changed:

In the beginning when mother was more aware of what was going on around her, I spent a lot more time with her. It would be like an hour or two hours every visit. There was a stress and a burden to always be there. That was my leisure time. I feel healthier now because I am not going as much. I don't feel the stress and I don't feel the need to be there. And, now I feel better, I want to do it.

As regular visitors move forward in their caregiving careers and become more and more comfortable with the situation, they actually define their

role less as a “duty” and are more likely to describe situations within the caregiving context as leisure. Sarah described her caregiving as follows: “Only the laundry is work, everything else is just life. I don’t look at it as work at all. Probably just visiting, just like fun, like leisure. I guess when I come here I am coming because I enjoy it.” Similarly, Melissa emphasized, “It is not work, so it would be leisure. My mother is not work, she is part of me and it is something that I want to do. It is returning to a loving caring person what she gave to me all my life.” Regular visitors also find ways to negotiate their own leisure pursuits around their caregiving activities.

Accepting and Unaccepting Relinquishers

Two closely related role manifestations are the accepting relinquishers and unaccepting relinquishers. These adult daughters tend to be in, or moving into, the later temporal career phase. The women in both of these groups visit their parents irregularly (i.e., less than once a month). Relinquishers have essentially given over care to the facility or to another person—this includes both the physical and emotional aspects of care. They do not perceive any aspect of what they are doing as caregiving. Accepting relinquishers, for example, now view their roles as overseers of care, which involves visiting the facility once a month or less and assessing how the facility is functioning and how people are interacting within the facility. In overseeing care, they take a very hands-off approach.

Some of the reasons for relinquishing care are similar and some are different between the two relinquisher manifestations. In terms of similarities, the women in both of these groups are no longer able to see the parent in the person they visit because of the advancement of the cognitive impairment. Generally, these family members perceive their parents as being “gone”—their bodies still exist, but the parents and their personalities they once knew are now gone. Thus, these family members feel that they no longer have meaning in their parents’ lives. The women in both relinquisher manifestations also feel very satisfied with the care their parents are receiving.

In terms of differences, accepting relinquishers’ narratives 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’ conditions. In their stories, they shared the history of coming to terms with their parents’ illnesses and gradual deterioration, and how they have moved into a place of acceptance. Although they still find the situation difficult at times, all of these family members now describe themselves as being at peace with the situation. 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 accepting relinquishers, however, unaccepting relinquishers are having a very difficult time coping with the situation. They define themselves not in terms of 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 of the deep pain they feel. These women have a very hard time watching the deterioration of their parents, and also find the loss of their parents' ability to communicate very difficult. They feel an intense sense of helplessness in their visits; that is, they do not know what to do when they are at the facility or may freeze when asked to perform certain tasks. For these reasons, they avoid visiting as much as possible, visiting the facility maybe once every three months or even less. When they do visit, they seldom visit alone. Avoiding visits or making sure other people accompany them represent ways that unaccepting relinquishers deal with their inability to cope with the situation.

Dora's experience is illustrative of the accepting relinquisher role. At the time of the interview, Dora was 68 years of age and had been widowed for 12 years. Prior to her retirement in 1989, Dora had been a professor in a university Faculty of Nursing for 10 years and then had served on the board of directors of a local hospital. Dora cared for her mother in her home for five years before her mother was placed into the facility. Dora's mother has been living in the facility for approximately four and a half years. Dora talked about how her role has changed over the years from being relatively intense to almost non-existent. When asked to describe her role in the facility, she responded:

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 I think I get a sense of how the place runs. It is a little like, before 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.

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 asked 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. . . . 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 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.

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 acknowledge that and move on.

In contrast, Carol's story depicts the unaccepting relinquishers' role and their inability to come to this place of acceptance. Carol is in her fifties, is married, and works part-time in her husband's office. She has two older brothers, but neither of them lives in the area. Carol's mother has lived in the facility for two years and eight months. When asked to describe her role in her mother's care, Carol stated:

I think I've defined my role as: I've left the facility to take care. . . . it probably sounds very non-caring. It isn't a case of non-caring. Once I lost my mother is what I call it, I find it incredibly stressful to go and see her. I guess it's because it's *my* mother and because my mother was widowed when I was 16 [and] we had a very, very close relationship and I haven't accepted it well, that's the bottom line. The only thing I can really care about right now is that she is well looked after and in my opinion they do a tremendous job. They're taking good care of her and I find it terribly stressful to see her.

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 well with that. . . . I guess that's the feeling, like I go and I just sit there and I just feel bad and my friend's [mother'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.

She also described how she has depended on her daughter to visit with her when she does visit her mother:

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 I'm afraid that's what I do—If my daughter can't go, I don't go.

In these relinquisher role manifestations, leisure is not at all constrained and because of the difficulties in the role, these women never experience leisure in the caregiving role. These women, however, emphasized the importance of the re-establishment of their own lives and their leisure lifestyles and how leisure has helped them cope with the situation. Dora described how she now focuses more on her own life by becoming involved in a variety of programs offered by ElderHostel. Rae Ann, an unaccepting relinquisher, was having a very hard time dealing with the deterioration of her mother. She described how she has come to concentrate more on her own life and outlined with great enthusiasm all of her new leisure pursuits:

. . .so now I volunteer three sometimes four days a week at [a local hospital] in the gift shop and I participate in carpet bowling over at the community centre. I am involved in a lot of crafts and I love to play cribbage which is what I am doing this afternoon, we are in a tournament. In fact I won last year! . . . And I got myself involved at the church. When necessary I fill in on the organ. I belong to the Golden Girls on the Sunny Side of 50 and we go out to various functions.

Another unaccepting relinquisher, Grace also described her role as very painful, "a never-ending funeral." She explained in her story how difficult caregiving became for her:

As time went on, it's just so painful, I mean I don't go. You think of going and your stomach crunches up and you got to get yourself to that day. Then you get there and there's only so much time you can spend in that environment and you got to leave. Half the time dad 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.

She also described how she has tried to get involved in more activities for herself and how that has really helped her cope:

It's only in the last year that I actually get together with friends and do board games and stuff on Saturday nights. Also, it's just this year that I've gotten in with a wonderful church and they have fellowship and they really believe that being Christian is spending all kinds of time together, not just 11:00 until 12:30 Sunday mornings. And, it has been wonderful. . . that has really helped me cope.

These women describe their caregiving roles as neither work nor leisure, but as "pain," "a nightmare," and a pleasureless duty. Indeed, their leisure occurs completely outside of their caregiving role.

Indirect Supporters

Finally, the women in the indirect supporter role manifestation appear across all of the temporal career stages. For this manifestation, the most

important factor seems to be the presence of another parent living in the community who is quite independent and relatively healthy. Thus, these women define their roles very differently than any of the women in the other four role manifestations. The indirect supporters view their role as providing support for the other parent who is providing the primary care. They feel confident that their ill parent is being well cared for by the facility and by their other parent. Thus, someone has to care for the well parent, and that, essentially, is where they feel their responsibility lies.

The things that these adult daughters do in supporting the other parent fall into two purpose categories. First, they see their role as assisting the other parent in the care of the parent living in the facility. In assisting with the caregiving role, for example, they help their well parent make all care decisions and step in to provide direct care if the other parent makes such a request (e.g., help with feeding if the well parent is unavailable). Second, much of their role involves monitoring their other parents' health and well-being. This involves ensuring that the well parent does not become overwhelmed in their caregiving role and overtired and that they have distractions from the caregiving role. These women also recognize the emotional loss and pain their other parent is experiencing and so try to serve as an emotional support system and being there to help the other parent deal with the emotional aspects of caring. Focussing on the other parent does not mean that they do not visit their parents in the facility—they all do. However, when they talked about their role in the facility, they described their role in terms of serving as a support for the "other" parent.

Diane's story represents a typical indirect supporter. Diane is in her forties, is married, and has two sons—one living at home and one away at university. She works part-time as a physiotherapist specializing in arthritis. Diane's mother cared for her father in the family home until 1994 when he was admitted to the long-term care facility. At the time of her interview, Diane was in a mid-temporal phase of her institution-based caregiving career. Diane expressed how she thought about her role:

In reality, and I mentioned it to my husband, and 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 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.

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 things through with her mother, confirming or not confirming her mother's perceptions of things and providing reassurance to her mother regarding her father's care. Providing support for her mother is and has always been very time consuming

and demanding for Diane. She described the feeling of being “sandwiched in the middle” and 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. . . . 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 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.

In fact, the women in the indirect supporter role manifestation all described the intensity of the role, the feeling of being “sandwiched in the middle,” and being pressured by the multiple roles they were struggling to perform. Thus, not unlike the active monitors, these women experienced a loss of personal leisure time and family leisure due to the multiple roles they were juggling. Leslie explained this:

I have to be here every day at my job, I have a teenage son, I have a daughter who just got married, I’m going through menopause, and I just figured I’m just getting hammered here with absolutely everything all at once. . . . We’ve gone from one crisis to another, mostly with mom, just trying to get her organized . . . like she’s still got a whole house full of his clothes. 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 don’t want to be with her but it just, and I keep thinking, oh my kids. When [my daughter] 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.

Similarly, Jessica described her frustrations with not being able to run regularly because of her caregiving role. She tries to relieve her father from his primary caregiving role by going to the facility regularly to feed her mother. She explained: “My leisure time is extremely limited. I work full-time and try and keep the house together and try keep fairly fit and I mean if I have to go and feed [mother] I certainly don’t get a run in on those days or any exercise.”

Interestingly, even though indirect supporters often feel like their own leisure time is being "pushed aside," they place great importance on the role of leisure as a coping mechanism in their other parents' lives. Thus, these women adopt a recreation director role and spend a large part of their role trying to find distractions or social activities for their well parents. Diane, for example, believes part of her role involves monitoring her mother's well-being. A large part of this purpose involves trying to find enjoyable activities in which her mother can participate. She explained how she got her mother involved in volunteering to help her form other support networks:

It is important to try 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 . . . they just loved mother 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 as well.

Leslie spends a great deal of her time trying to organize her mother's free time:

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 she still has lots of opportunities to learn some new things and so on and that's what she needs to do now. . . So we encourage her, she could go to lots of places more than she does. . . . I would say it's constantly thinking, more the thought processes of okay, what's mom going to do this weekend. If I go to this conference, for example, next weekend, what will my mom do? Should I phone my brother to say why don't you and [Beth] come up. . . . I said to [my brother], 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. . . . 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.

Although indirect supporters place much importance on organising their other parents' leisure time, for the most part, these activities contribute even more to their inability to enjoy leisure in their own lives.

THE CHANGEABILITY AND CONTRADICTIONS OF LEISURE: THE BEGINNINGS OF A GROUNDED THEORY

The stories told by the women in this study reflected anything but a stable, uniform, and single caregiving role in the long-term care context. On the contrary, the adult daughters' descriptions portray the dialectic nature of the caregiving role and the perception of leisure within that context. The women describe quite different perceptions of their roles in the care of their parents. These varying perceptions of the caregiving role, in turn, lead to different and frequently contradictory perceptions of leisure in the institution-based caregiving context. As Henderson (1996) has emphasized, leisure appears to have multiple and varied meanings for women based on how they

view their individual circumstances. Bedini and Guinan (1996b) and Braitain Rogers (1995) also found that family members may ascribe different perceptions to leisure in the caregiving context.

Perhaps more importantly, in their recounts of the history of their caregiving roles, the women talked about the *changeability* of the role—how their roles have changed, often many times, over their caregiving careers and how those changes altered the nature of leisure within that context. 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 continually shifts as the women adapt to the changing circumstances within or outside the role. The role continues to shift, adjust, and develop in the institution-based context. For example, Sarah described 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.

Similarly, Diane emphasized how her role has gone from being fairly stable to hectic and changeable, back to being more stable:

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. . . try to adapt and change as needed. . . It fluctuates.

Thus, the women themselves conceptualized their caregiving roles as a process, a journey. As caregivers' perceptions of their role changed over their institution-based caregiving careers, so did the meaning of leisure in their lives. Using the accounts of the history and the process of caregiving described by the adult daughters, we began the development of a substantive grounded theory that draws on this overarching theme of *role changeability* in the caregiving role and of the meaning of leisure within that context. This theory takes into account the alternative approaches to caregiving described

by the adult daughters (i.e., the "caregiving role manifestations") and how the perceptions of leisure get re-defined throughout the process (i.e., the "leisure manifestations"). It begins to identify some of the key factors that help explain why family members perceive both their roles and their leisure the way they do. Although this emerging theory is based only on the experiences of adult daughters, it provides us with the beginnings of a conceptualization of the meanings of leisure in the institution-based caregiving context. Nevertheless, this approach to grounded theory draws on the definition put forward by Glaser (1978). Glaser argues that "the goal of grounded theory is to generate a theory that accounts for a pattern of behavior which is relevant and problematic for those involved. The goal is not voluminous description, nor clever verification" (p. 93). Our goal was to initiate the development of a theory that helped to explain the behavior of adult daughters caring for a parent in a long-term care facility and how their roles had an impact on their leisure.

The women's stories suggest that adult daughters are intensely involved in the long-term care setting when the parent is first admitted to the facility and take on more of an active monitor role. If both parents are still living and the well parent is capable of taking on the primary caregiver role, then these adult daughters appear to take on an indirect supporter role. They focus most of their energies on supporting the other parent. Due to the intense pressures felt by the women at this phase of the institution-based caregiving career, caregiving tends to be viewed as a constraint to leisure and within this context, leisure is manifested as leisure constriction. That is, these women's identities are so embedded in the caregiving role that they experience a constriction of the opportunity for leisure, and perhaps more importantly, caregiving may have negative implications for the leisure experience itself. Our findings support previous research focused on community-based caregivers which suggests that caregiving is often a constraint to leisure and can significantly reduce a caregiver's leisure time (Bedini & Guinan, 1996a; Chenoweth & Spencer, 1986; Dunn & Strain, 1998; George & Gwyther, 1986; Keller & Tu, 1994; Miller & Montgomery, 1990; Sneegas, 1988; White-Means & Chang, 1994), but not only is their leisure time at this stage of the caregiving career "squeezed", but so too is its quality. These findings suggest that the admission of a care receiver to a long-term care facility does not necessarily mean that caregiving will no longer have an impact on caregivers' leisure lifestyles, at least in these early phases of the career.

Many of these adult daughters described their involvement in caregiving as an obligation, their responsibility or duty as a family member. This strong ethic of care resulted in the women placing the needs of their parents and other family members before their own needs (Henderson et al., 1996). Thus, although most of these women were aware of the change in their leisure lifestyles and their own leisure needs, caregiving continued to act as a constraint to leisure or qualitatively changed the leisure experience for some of these women (Henderson et al., 1996). These women often found

it very difficult to find a balance between caring for their loved ones' needs and at the same time addressing their own needs, particularly their leisure needs (Henderson & Allen, 1991). Unlike the findings of Weinblatt and Navon (1995), however, these women never perceived leisure in a negative or threatening way. Leisure was still very much valued by the women in this study, but because of the time pressures of the caregiving role or multiple roles they held, some of the women found it very difficult to access free time to enjoy their own leisure pursuits or even family leisure without the parent. The women in our study, however, were caring for parents, not spouses, and they were not living with the care receivers. It is likely that spouses or other caregivers living with the care receiver may describe the impact of their roles on leisure in more negative ways.

As long as the other parent is able to continue as the primary caregiver, indirect supporters continue to focus on supporting the other parent. This role continues to be quite intense, and thus, indirect supporters continue to experience leisure constriction. Providing meaningful leisure lifestyles for the other parent, in fact, contributes to their inability to maintain their own leisure lifestyles. Adult daughters in the active monitor role manifestation, however, appear to feel some relief as the caregiving career progresses. Once active monitors adjust to the new facility and become more comfortable in the care their parents are receiving, they gradually turn the focus of their role from supporting both the parent and staff to supporting only the parent. They now concentrate on providing more of the emotional and social aspects of care—they begin to take on the regular visitor role. It is at this stage that the women talk about a sense of "freedom in care." They are more likely to perceive caregiving less as an obligation and more as something that they want to do. At this phase of the caregiving career, adult daughters actually describe caregiving as a potential container for leisure (Henderson, 1990; Henderson et al., 1996). Caregiving, in many instances, becomes much more satisfying, pleasurable, rewarding, and an escape from other life pressures. Within this context, adult daughters are able to experience *leisure moments* in their caregiving roles. Leisure moments are defined here as brief episodes in obligatory social roles or in daily life that are experienced as leisure. Other researchers (e.g., Allen & Chin-Sang, 1990; Henderson, 1990; Henderson & Rannels, 1988; Henderson et al., 1996) have argued that leisure-like activities could be experienced in a variety of settings and contexts, including contexts that are typically not thought of as leisure. For example, Henderson (1990) found that American farm women enjoyed leisure-like experiences in both their farm work and in their family roles. Similarly, Allen and Chin-Sang (1990) found that church-related activities were often defined as leisure for African-American women. Our results suggest that women caregivers, particularly those in mid-phases of the institution-based caregiving career, also may experience leisure within their caregiving roles.

As time goes by and the parents begin to deteriorate more and more, the adult daughters appear to struggle with the growing emotional stresses of their role, particularly with the ambiguity related to the psychological

presence of the parent. If these 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 on re-establishing their own lives and well-being, including their own leisure lifestyles. However, if family members are unable to cope with the situation, they may turn to avoidance of the situation as a coping strategy in an attempt to protect themselves from the situation and take on an unaccepting relinquisher role. Leisure, at this phase of the caregiving career and for both relinquisher manifestations, is perceived as an important coping resource (Bedini & Guinan, 1996a; Keller & Tu, 1994; Sneegas, 1988) and is manifested as *leisure reclamation*. Leisure serves in the reclamation of an identity outside or apart from the caregiving role, and ultimately, plays an important part in the establishment of a new sense of identity or the re-establishment of a previous one (Kelly, 1983). Further, the women in both relinquisher manifestations described how they did not feel it was beneficial for their parents or themselves to continue to be intensely involved in care when it was deteriorating their own health and well-being. Accepting relinquishers use leisure to help them cope with the perceived loss of their parents, but more importantly, in the re-establishment of their own lives. Women in the unaccepting relinquisher manifestation found the situation so emotionally painful that they actively chose to use leisure as a distraction from the situation and to build social support systems to help them cope.

A central factor which appears to be very much related to this re-focus on the self is the progression of the parent's disease and the gradual loss of psychological presence of the parents in the daughters' lives. In fact, the adult daughters seemed to connect changes in their role, and thus changes related to leisure, to changes associated with the progression of the disease. Gretta, for example, stated, "[my role] changed as the disease progressed." 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 reshape how the adult daughters thought about their continued role in the care of their parents and to change their perception of leisure in that context. Ambiguous loss or boundary ambiguity (see Boss, 1991; Boss & Greenberg, 1984) refers to the ambiguity that family members experience regarding whether or not another family member still exists as part of the family unit. 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 sys-

tem 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 original)

Doka and Aber (1989) suggested that ambiguity may become even more problematic when the care receiver is institutionalized 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).

The concept of anticipatory grief (Rando, 1986) may also 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. Walker, Pomeroy, McNeil, and Franklin (1994) defined anticipatory grief as "the progressions through phases of grief prior to the death of a loved one" (p. 23). 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 unlikely that they 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 behaviors seem to decrease (Ponder & Pomeroy, 1996). This phase of the anticipatory grief process—coming to a place of acceptance—is important in understanding leisure at this phase of the caregiving career as it is crucial for the re-establishment of full leisure lifestyles. These renewed leisure pursuits, in turn, help family members cope with the continued deterioration of their loved ones.

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 likely related to differences in coping styles and resources available throughout the process as well as a number of other factors (Rando, 1986). Unaccepting relinquishers come to a point where they realize they are not coping well in the role and gradually relinquish care completely to the facility. Avoidance of the situation is viewed as an important coping strategy that these women use to protect themselves from the situation. These women also perceive the reclamation

of leisure lifestyles as crucial to coping with the emotional distress of the caregiving situation.

Unlike the findings from studies focused on community-based caregivers, however, leisure is not used to help re-charge the caregiver nor to help restore them physically for the role (Bedini & Guinan, 1996b; Keller & Tu, 1994; Sneegas, 1988). Leisure is used to help them cope with the emotional aspects of watching their parent continually deteriorate before their eyes, to help them cope with the fact that their parents no longer recognize them, and are no longer able to communicate with them. Participation in leisure activities provides important resources that may assist people in dealing with stressful life events or circumstances (Caltabiano, 1995), especially the opportunity for the development of companionships, friendships, and new social support networks (Coleman & Iso-Ahola, 1993). This appeared to be an important role of leisure among caregivers, particularly in the experiences of unaccepting relinquishers. But given the lack of control over the situation felt by many caregivers at this phase of the caregiving career, leisure also may help caregivers regain some sense of control over their lives (Coleman & Iso-Ahola, 1993).

CONCLUSION

To summarize, what we are suggesting is that the meaning of caregiving for caregivers in the institution-based context is continually being altered and changed (i.e., *role changeability*). As circumstances change and crisis situations arise or are resolved, caregivers move into new roles—what we refer to as *role manifestations*—or return to roles they had played previously. As the meaning of the caregiving role changes, so too does the meaning of leisure and leisure is thereby manifested in different ways within the institution-based context—what we refer to as *leisure manifestations*. The dominant leisure manifestations in this context appear to be *leisure constriction* in the early phases of the caregiving career, *leisure moments* in the mid-phases, and *leisure reclamation* in the later phases.

Several factors appear to play an important part in how the caregiving role is perceived, and therefore, how the meaning of leisure in that context is realized. These factors include: the family member's sense of obligation to care or an ethic of care, the family member's comfort with the facility and satisfaction with the care being provided by the staff, the progression of the cognitive impairment and the degree of ambiguous loss felt by the family member, the degree of sense of connectedness to the parent felt by the family member, the ability of the family member to cope with the situation and work through the anticipatory grief process, and the presence of the "other" well parent living in the community.

The emerging theory presented here is in the early stages of development. It focuses on the caregiving roles of adult daughters caring for a parent with a cognitive impairment. We are in the process of examining the theory in other contexts, such as for other family caregivers and for caregivers of

persons with physical impairments. At this point, however, it is unclear whether other caregivers will define their roles in similar ways and whether leisure will be manifested in the same way and at similar stages of the careers within these other contexts. In addition, this theory is based on the retrospective accounts of the caregiving history shared by the adult daughters. A longitudinal approach would allow us to follow individual caregivers across their institution-based caregiving careers and more closely examine the interplay of evolving roles and their concomitant manifestations of leisure. Ultimately, each of these explorations will further contribute to the development of the theory.

Regardless of how other caregiving contexts may be defined and how leisure manifests itself within them, it seems likely that we will find parallels to what Shaw (1997) has described as the inherently contradictory nature of family leisure and the need to understand how a complex mix of factors influence the way in which it is perceived and experienced. The caregiving context is also one filled with such contradictions. Indeed, the entire caregiving career can be represented as a bittersweet journey experienced by family members with experiences perceived as both positive and negative, difficult and satisfying, painful and pleasurable, depending on the circumstances at any one time. Leisure in this context also appears to manifest itself in quite distinct and seemingly contradictory ways, and, it seems, is both bitter and sweet.

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