Ontario Dementia Caregiver Needs Project
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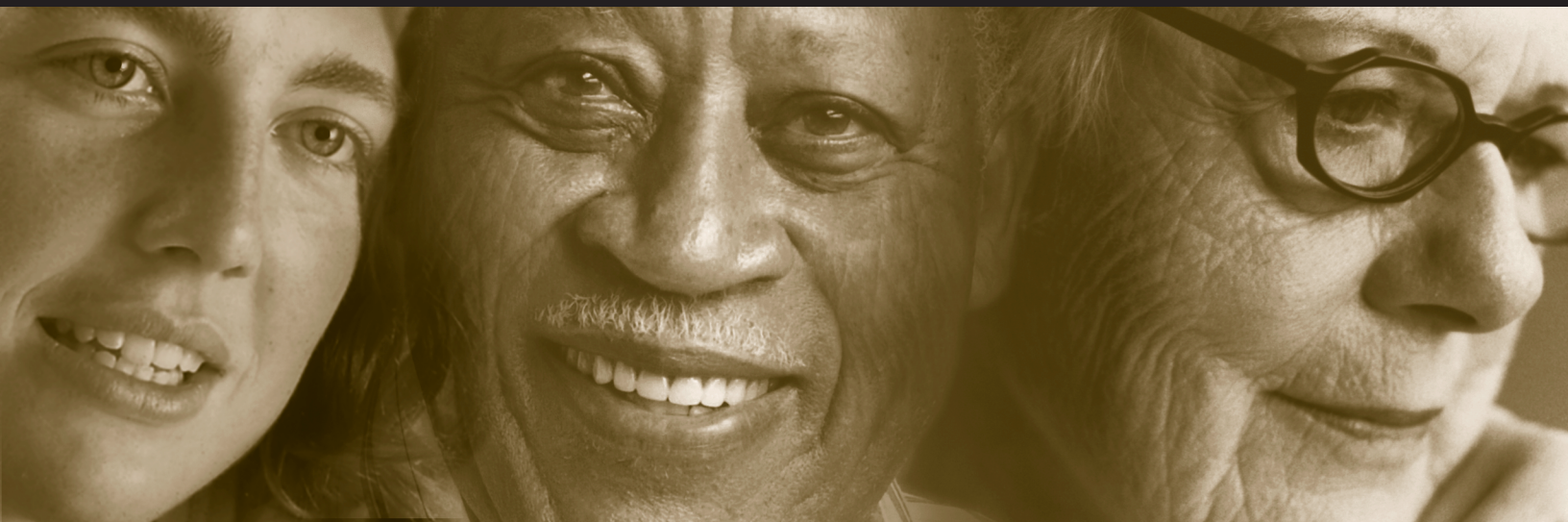
A Literature Review

Caregivers of Persons with Dementia: Roles, Experiences, Supports and Coping



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A Literature Review

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CHAPTER ONE
AN INTRODUCTION

According to the Canadian Study of Health and Aging (CSHA, 1994c), one in thirteen Canadians over the age of 65 years is affected by Alzheimer Disease or a related dementia. An estimated 364,000 older adults in Canada have an illness causing dementia (CSHA, 1994c), of which over 64% has Alzheimer Disease, the leading cause of dementia (Johnson, Davis, & Bosanquet, 2000). Further, an estimated 83,200 new cases of dementia emerged in 2001 (CSHA, 2000) and the fastest increase in persons with dementia is occurring for those over 75 years of age (Gautrin, Froda, Tetreault, & Gauvreau, 1990). One in nine Canadians between the ages of 75 and 84 years is estimated to have an illness causing dementia and this statistic rises to one in three among those over the age of 85 years (CSHA, 1994c). Nonetheless, the incidence of dementia in the community often is underestimated because caregivers might mistake memory changes as part of the normal aging process (Sternberg, Wolfson, & Baumgarten, 2000) and many older adults are likely to have dementia for several years prior to diagnosis (Keating, Fast, Frederick, Cranswick, & Perrier, 1999).

With the rapidly increasing older adult population, the numbers of persons with dementia in Canada is projected to increase dramatically over the next several decades. The proportion of the Canadian population aged 65 years and older is predicted to increase from 11.4% in 1991 to an estimated 21.7% in 2031 (Statistics Canada, 2000). Consequently, the number of people with dementia in Canada is predicted to rise from 322,000 in 1997, to 548,000 by 2016 (Bland, 1998) and to 592,000 by 2021 (CSHA, 1994c). By the year 2031, over three-quarters of a million Canadians are estimated to have Alzheimer Disease or a related dementia (CSHA, 1994c). Similar increases have been predicted for other developing countries, including the United States and Sweden (Aevarsson & Skogg, 1996; Katzman & Bick, 2000).

In Ontario, according to a recent research bulletin published by PCCC Mental Health Services in Kingston, Ontario (see Hopkins & Hopkins, 2002), there are currently an estimated 139,754 cases of dementia, with most being 75 years of age or older (i.e., 119,807 or 86% of people with dementia). Similar to national trends, the number of cases of dementia in Ontario is predicted to increase dramatically over the next two decades as the older adult population grows. By 2010, the number of cases of dementia is estimated to increase by nearly 40% over current levels and to increase by nearly 85% by 2020. By 2028, the number of cases of dementia will have grown by approximately 140% over 2000 levels (Hopkins & Hopkins, 2002).

These trends mean that approximately 181,306 people with dementia in Ontario will need some level of formal and/or informal care in 2010, rising to over 300,000 people needing care by 2028 (Hopkins & Hopkins, 2002). Nationally, the Canadian Study of Health and Aging Working Group estimated "that there will be approximately 60,150 new cases of dementia in Canada each year. Of these, 36,320 will be women and 23,830 men" (CSHA, 2000, p. 69). A sizable majority of these new cases of dementia will be persons living in the community (CSHA, 2000). The rapid increase in numbers of people with dementia and the efforts of the lay advocacy movement led by the Alzheimer's Association in the United States and by the Alzheimer Society of Canada have identified dementia as an international health priority, both for persons with dementia and for their caregivers (Gillick, 1999).

WHAT IS DEMENTIA?

Dementia has been defined as "an acquired syndrome of intellectual impairment produced by brain dysfunction...which compromise in at least three of the following spheres of mental activity: language, memory, visuospatial skills, emotion or personality, and cognition (abstraction, calculation, judgment, [and] executive function)" (Cummings, 1992, p.1). Dementia may be distinguished from other forms of cognitive impairment by its persistent, progressive, and often irreversible deterioration.

In general, dementia involves three main types of symptoms: losses in cognitive capacities;

difficulties in performing instrumental and personal activities of daily living; and changes in mood or personality and declines in interpersonal functioning (Le Navenec & Vonhof, 1996).

Dementia as a general category can be further divided into reversible and irreversible types (Kaplan, 1996). *Reversible dementia* may be caused by factors including reactions to medications, depression, occlusive cerebrovascular disease, normal pressure hydrocephalus, brain tumours, environmental toxins, nutritional deficiencies, infections, inflammatory illnesses, and other metabolic disorders. *Irreversible dementia* is caused by factors including Alzheimer Disease, vascular (multi-infarct) disease, Parkinson's disease, head trauma, and genetic background (Kaplan, 1996). Other causes of dementia include cardiopulmonary disorders, hepatic disturbances, renal failure, and chronic excessive use of alcohol or other substances (Cummings, 1995).

Types of Dementia

The Diagnostic and Statistical Manual of the American Psychiatric Association (1994) defines Alzheimer Disease (AD) as a leading cause of dementia in the elderly (DSM-IV). In fact, Alzheimer Disease accounts for between 75 and 85% of all cases of dementia among older adults, either by itself or in combination with other types of dementia (Ebly, Parhad, Hogan, & Fung, 1994; Hopkins & Hopkins, 2002). Discovered in the late 19th century, Alzheimer Disease is a progressive degenerative disorder, insidious in onset, followed by gradual deterioration and death (Cummings, 1995). Histological hallmarks of Alzheimer Disease include neuronal loss, neurofibrillary tangles, and the production of neuritic plaques, leading to neuronal toxicity and cell death (Cummings, 1995). Other types of dementia include:

- Vascular (multi-infarct) dementia,
- Lewy body disease,
- Frontotemporal dementia, and
- Dementia in Down's Syndrome.

In Canada, Alzheimer Disease accounts for 75% of dementia in women and approximately 52% of dementia in men whereas vascular dementia accounts for 14% of dementia in women and 30% of dementia in men. Other causes account for approximately 11% of dementia in women and 18% of dementia in men (see Hill, Forbes, Berthelot, Lindsay & McDowell, 1996). For further discussion on types of dementia, see Appendix A.

Most of the dementia prevalence studies in Canada have focused on adults who are 65 years of age and older (CSHA, 2000). Therefore, epidemiological studies of early onset dementia – that is, dementia of onset before the age of 65 – are scarce (Ferran et al., 1996) and our understanding of the prevalence rates of early onset dementia in Canada remains limited. Studies in the United Kingdom (UK) suggest that the estimated incidence of early onset Alzheimer Disease ranges from 7.2 (Newens et al., 1993) to 22.6 (McGonigal et al., 1993) cases per 100,000 population among those under 65 years of age. Other studies in the UK have reported the prevalence of early onset dementia of the Alzheimer type as well as other types of dementia to range from 42 to 78 cases per 100,000 population in either the 30 to 64 years or the 45 to 64 years of age group (see Freyne, Kidd, & Lawlor, 1998; Harvey, 1998; Williams, Dearden, & Cameron, 2001). Alzheimer Europe (1998) suggests that early onset dementia accounts for 10% of all cases of dementia. Understanding of the prevalence rates of early onset dementia in Canada is increasingly important because younger adults with dementia are very likely to have very different needs than older adults with dementia (Williams et al., 2001).

Implications of Dementia

With the rapidly changing demographic structure of contemporary society, more and more adults are finding themselves providing care for a family member or friend with dementia. Moreover, changes in the health care system and social services in Canada, such as shorter hospital stays, greater use of outpatient treatment, and longer waits for admission to a long-term care facility, have put even greater pressures on families and friends to take on the caregiving role (Cranswick, 1997). It has been estimated that over 90% of elder care in Canada is provided informally, with the bulk of this care being provided by family members and friends (Angus, Auer, Cloutier, & Albert, 1995; Cantor, 1991). The caregiving roles and responsibilities taken on by families and friends can often be intense and time consuming, and therefore, can have major impacts on caregivers' health and overall lifestyles (e.g., Lieberman & Fisher, 1995; Schulz, O'Brien, Bookwala, & Fleissner, 1995).

Furthermore, the caregiving role often spans a period of several years. The Canadian Study of

Health and Aging (2000) estimated the average duration of dementia to be approximately 5.8 years (6.7 years for women and 4.6 years for men). Research on caregivers suggests that 6 in 10 caregivers provide care to an elderly family member or friend for more than two years (Keating, Fast, Frederick, Cranswick, & Perrier, 1999), with one-fifth of caregivers providing care for 5 years or more (Stone, Cafferata, & Sangl, 1987). Dowler, Jordan-Simpson, and Adams (1992) estimated that a woman could expect to spend an average of 18 years providing some form of care to her elderly parents. The caregiving role and responsibilities change dramatically as the care receiver's needs gradually shift and increase over time.

Caregivers play a critical role in all stages of care for persons with dementia, including diagnosis, treatment, symptom management, and placement (Rabins, 1998). However, they seldom are provided with adequate resources for these tasks and face increased difficulties in meeting their care receivers' needs in light of increasing costs of care. Besides *direct* financial costs (e.g., costs of services, drugs, professional healthcare workers, and physicians; additional household expenses incurred as a result of the caregiving situation; direct costs of time in caregiving), informal caregivers also face *indirect* financial costs related to care (e.g., costs associated with the loss of opportunity; impacts of caregiving on future career prospects and upon future pension entitlements; other medical costs) (McDaid, 2001). In addition, dementia care has serious implications for the caregiver's physical and psychological health and well-being.

In short, the outlook for dementia care is one that will see significant increases both in the costs and in the burden of care, and these increases are most likely to be felt by informal caregivers (Johnson, Davis, & Bosanquet, 2000). If families are going to continue to provide the majority of care, effective community support services need to be in place to assist them in their caregiving roles. Nevertheless, we know very little about the experiences of caregivers in the Canadian caregiving context and especially those caring for a person with dementia in Ontario.

LITERATURE REVIEW

This review of the literature grew out of a need to better understand the experience of caregiving for informal caregivers in Canada, as well as the needs of these caregivers and the supports available to them to assist them in their caregiving roles. It represents a synthesis of the immense amounts of information that currently exists on informal, community-based caregiving. This review was very much guided by the *Family Adjustment and Adaptation Response Model* (FAAR) developed by McCubbin and Patterson (1983a, 1983b; McCubbin et al., 1982; Patterson, 1988). According to Patterson (1988), family members dealing with chronic illness, or the entire family system, go through a continual, cyclical *adjustment-crisis-adaptation* process. Throughout this process, family members are continually trying to maintain balanced functioning by developing and using their resources and coping behaviours (i.e., *capabilities*) to meet the stresses, strains, and pressures (i.e., *demands*) of the situation. Patterson emphasised that an important component of the model is the meanings family members ascribe to the situation, not only in terms of how they are thinking about what is happening to them, but also in terms of their perceptions of their ability to cope. Because family members will have different perceptions of both the demands of the situation and their capabilities to cope, their experiences and responses to the situation also will be varied.

The FAAR model includes two primary phases, an *adjustment phase* and an *adaptation phase*, which are linked by *crises situations* (Patterson, 1988). The adaptation and adjustment phases are conceptualised along a continuum ranging from good to poor representing how well the family member is faring at each phase. According to Patterson, "[t]he adjustment phase is intended to denote relatively stable periods during which families resist major change and attempt to meet demands with existing capabilities" (p. 76). During this phase, if the family member is coping relatively well with the situation and is able to balance the perceived demands with the resources she or he have available, then the caregiving role can remain relatively stable for a time and adjustment in the role can be relatively good. If the situation changes or a crisis situation arises, however, the demands of the role or situation may become overwhelming given the family member's resources and ability to cope. At this point, the family member then goes through a process of re-defining the situation and making changes in an attempt to restore equilibrium; in other words, adapting to the new circumstances. Patterson described the adaptation phase as follows:

> During the adaptation phase, families attempt to restore homeostasis by (a) acquiring new resources and coping behaviours, (b) reducing the demands they must deal with, and/or (c) changing the way the view their situation. (p. 76)

Dealing with chronic illness, such as in the case of Alzheimer Disease, is a continuous process with family members going through several cycles of adjustment-crisis-adaptation. If a family member's overall adjustment is quite poor, they may be even more vulnerable to crisis situations. Nevertheless, Patterson (1988) emphasised that a crisis situation is not necessarily always negative. A crisis situation can allow the family member an opportunity to re-think or re-frame the situation in more realistic terms, to grow as a person, to become more resilient, and to move towards recovery and better coping capabilities.

Thus, in any review of literature on caregiving, particularly caregiving in the dementia context, it is important to explore both the demands of caregiving (the caregiving experience) as well as the resources and coping strategies available to caregivers (community supports and personal resources) that might help them cope with the stresses and strains of the role. The review presented here examines three broad areas related to caregiving. The first area focuses on the characteristics of caregivers in the dementia context. The next area explores the experience of dementia caregivers. The final area describes the personal coping strategies and community support services utilised by caregivers to help them cope in their caregiving roles. The review ends with a list of recommendations for future research that grew out of gaps identified in our current understanding of informal caregiving in Canada, and more specifically, in Ontario.

CHAPTER TWO
CHARACTERISTICS OF CAREGIVERS IN THE DEMENTIA CONTEXT

A DEMOGRAPHIC PROFILE OF CAREGIVERS

Approximately 1 million Ontario residents, or 15% of the province's adult population aged 15 to 64, provide care for an infirm relative or friend (Cochrane, Goering, & Rogers, 1997). An increasing number of caregivers are 65 years of age or older. However, inconsistencies in the definition of "caregiver" make it difficult to estimate the total number of dementia caregivers. The spouse and other relatives of the disabled elderly person are often assumed to be providing care because of their relationship to the care receiver and/or because they might live with him or her, despite there being no direct evidence on record concerning just how much care is actually being provided (Schulz, 2000; Schulz, Newsom, Mittelmark, Burton, Hirsch, & Jackson, 1997). While informal caregivers have often been depicted as family caring for a relative with dementia (Aneshensel et al., 1995), in this review we will explore a broader definition of caregiver that includes the caregiving activities of both primary and secondary caregivers, family, friends, and neighbours.

Approximately half of the individuals with dementia in Canada live in the community (CSHA, 1994a). Almost all of these individuals (94%) are cared for by family or friends, up until these caregivers are no longer able to maintain them at home due to factors such as care recipient deterioration, increased problem behaviours in the care recipient, and/or caregiver depression (Gold, Reis, Markiewicz, & Andres, 1995; Whitlatch, Feinberg, & Stevens, 1999). Caregivers for elderly persons with dementia in Canada are most often spouses (36%), daughters (28%), or sons (9%) (Cohen, Pringle, & LeDuc, 2001), and women represent the majority of caregivers (Baines, Evans, & Neysmith, 1991; Keating, Fast, Frederick, Cranswick, & Perrier, 1999). Indeed, according to the Canadian Study of Health and Aging (1994a), approximately 70% of caregivers of persons with dementia are women, either wives (24%) or daughters (29%). Other research suggests that between two-thirds (Keating et al., 1999) and three-quarters (Penrod et al., 1995) of caregivers are female. Men are less likely to be caregivers, although changing demographics are resulting in increasing numbers of husbands and sons taking on caregiving roles (Harris 1993; Harris, Long, & Fujii, 1998; Kaye & Applegate, 1990a, 1990b; Mathew, Matocks, & Slatt, 1990; Siriopoulos, Brown, & Wright, 1999). In fact, some reports suggest that sons may constitute up to 30% of caregivers for the elderly in Canada, with some of these being sole caregivers (Delgado & Tennstedt, 1997; Thompson, Tudiver, & Manson, 2000). In addition, 41% of caregivers live on their own or with their elderly relative with dementia, and just under one-third of Canadian caregivers are employed (CSHA, 1994c).

Although much attention has been placed on the role of the primary caregiver, the caregiving system often extends beyond this individual. Children in older families often share caregiving responsibilities. While one or two family members may take primary roles in this process, other family members are involved regularly, if peripherally (Matthews & Rosner, 1988). Family members adopt different caregiving styles within the family caregiving system, including the routine provision of care, providing backup support for the primary caregiver, limiting care to certain "circumscribed" tasks, providing care only sporadically, or disassociating one's self entirely from the care process (Matthews & Rosner, 1988).

In addition to the primary caregiver model, Keith (1995) identified families that practiced a partnership model of care and those that utilised a team model. In a partnership caregiving system, two or more adult children "contribute relatively equitably to the caregiving work and, more importantly, in making and implementing decisions" (Keith, 1995, p. 183). In contrast, the team approach involves adult children working together and taking on various roles in a planned and integrated manner, essentially operating as an organised unit. Family caregiving systems can also be classified as individualistic and collectivist in nature (Pyke & Bengtson, 1996). "Individualist families minimise their caregiving and rely on formal supports,

collectivists use caregiving to construct family ties, sometimes prompting over-care" (Pyke & Bengtson, 1996, p. 379). Because the nature of the caregiving system can serve as an important resource to primary caregivers, it is important to consider both primary and secondary family members involved in the care process as well as the nature of the entire family caregiving system.

Given that caregivers of older adults tend to be immediate family members, the research thus far has focused almost exclusively on family caregivers. This means that our understanding of other caregivers, such as extended kin, friends, and neighbours, is quite limited. What we do know is that older adults do receive assistance from these other caregivers. For example, Penrod and associates (1995) found that other relatives and non-relatives made up approximately 24% of all community caregivers. The Canadian Study of Health and Aging also reports that other family and friends constitute "a significant proportion of caregivers for those in institutions (22.8% of those with dementia and 39.5% of those without) and of those with dementia living in the community (24.1%)" (CSHA, 1994a, p. 478). The study also found that 92% of people living with dementia in the community have two or more relatives or friends in addition to their primary caregiver who are providing assistance. Several caregivers (9%), however, have no backup support from family and/or friends (CSHA, 1994a). Spousal caregivers are less likely to have backup support than others, and yet are more likely to be caring for a person with severe dementia (CSHA, 1994a).

A large percentage of caregivers are elderly themselves. Many female caregivers are aged 65 years or older, and married men who are caregivers are, on average, 73 years of age (Keating et al., 1999). The Canadian Study on Health and Aging suggests that over a third of caregivers (34%) are aged 70 years or older, while 11% are aged 80 years or older (CSHA, 1994c). As a consequence, these caregivers are often faced with their own health-related concerns (Ballard, 1999; Baumgarten, Battista, Infante-Rivard, Hanley, Becker, Bilker, et al., 1997), and the physical and emotional demands placed on elderly caregivers often result in furthering the decline in their health (Greene, Taylor, & Johnson, 1993).

Caregivers most often care for more than one person. In analysing General Social Survey data from 1996, Keating et al. (1999) found that women and men cared for an average of two and as many as nine people. However, women may be more prone to caregiving for more than one person at a time because they tend to have wider social networks than men (Campbell & Lee, 1992).

Rates of dementia have been shown to vary among ethnoracial groups (Gurland et al., 1999). For example, higher rates of dementia have been reported among African Americans and Latinos than among non-Latino Whites (Escobar et al., 1986; Heyman et al., 1991; Murden, McRae, Kaner, & Bucknam, 1991; Schoenberg, Anderson, & Haerer, 1985; Weissman et al., 1985). Yet, very little is known about caregivers within various ethnic and cultural groups and whether or not there are differences, for example, in the percentage of caregivers within these various groups. Given that the older adult population is growing ethnically and culturally at a faster rate than the general population (McPherson, 1998) and that different norms and values related to familial responsibility may exist within these groups, there is a growing need to extend our understanding of caregiving in the dementia context to the different ethnoracial and cultural groups.

Changing Demographics of Caregivers

Patterns of family caregiving in North America are undergoing significant change (Gwyther, 1998; Kriseman & Claes, 1997). The social organisation of caregiving in the United States and Canada is based on a model of family and work organisation that is increasingly rare. Men are not the sole sex working outside the home, and women less often remain at home in the "private" realm as homemakers and caregivers. Women are participating to a greater extent in the paid labour force outside the home, which, when coupled with caregiving, can lead to increasing tensions between responsibilities at home and at work (Wimo, Winblad, & Grafström, 1999). The number of family hours spent working outside the home has increased from post-WWII levels of 48 hours per week to 60 to 80 hours per week. In the period from 1980 to 1990, the number of women with children under 3 years of age working outside the home rose from 36.8% to 53.3% (Myles, 1991). Consequently, there is a dramatic decline in the amount of unpaid working time available to women who have traditionally performed caregiving tasks (Myles, 1991). In fact, some couples facing increased personal and professional responsibilities have opted

to provide less direct care, and act instead as care managers.

The aging population is resulting in an increased likelihood that a middle-aged adult will have a surviving parent (Gee, 1991; Rosenthal, 1997). Single parents may face a double financial burden in attempting to care for young children and aging parents on their own (Gwyther, 1998). Individuals, and in particular women, who fall into this category are often referred to as the "sandwich generation" (Dautzenberg, Diederiks, Philipsen, & Stevens, 1998; Gwyther, 1998; Hawkins, 1996; Keating et al., 1999; McKibbon, Genereux, & Seguin-Roberge, 1996; Zal, 1992). Also referred to as "women in the middle" or the "middle generation", these caregivers are confronted with competing demands that contribute to stress and a growing reliance on formal care (Spillman & Pezzin, 2000). Rather than taking away from dementia caregiving time, their responsibility for children most often adds to their total caregiving hours (Keating et al., 1999).

In Canada, a longer lifespan and an increasing elderly population have been accompanied by a declining birthrate (Grunfeld, Glossop, McDowell, & Danbrook, 1997), resulting in an increasing number of elderly persons while the number of caregivers remains constant (McCarty, 1996). Other changes or trends in the family have made caring for an elderly relative even more challenging. For example, couples are marrying later in life, waiting longer to have children, and having fewer children who may be potential caregivers in later life. Rates of divorce and remarriage also are increasing. Multiple marriages may result in a lack of clearly defined family roles and greater conflict over caregiving issues. Blurring of family boundaries mean that caregivers may be providing care to family members as well as to those who are no longer viewed as part of the family, and these circumstances can lead to additional family conflict and uncertainty, and ultimately, to greater caregiver distress (Caron, Boss, & Mortimer, 1999).

Further, there has been an increase in single person households and single parent families (Myles, 1991), as well as an increase in female heads of households. These families are much more likely than other family types to live below the poverty line. Therefore, when caregiving responsibilities are added to the mix, these caregivers face not only increased stress from being the sole parent and the sole caregiver, but also face much greater financial strains associated with caregiving. People also are increasingly mobile and families are more widely distributed geographically. As a result, there is an increasing incidence of long distance care (Gwyther, 1998). Indeed, the primary caregiver may be the only family member near the older adult's place of residence.

In summary, the demographic changes discussed here have implications for caregivers in terms of rising stress levels and time pressure, decreased social support, and heightened social isolation. As these demographic shifts continue, family caregivers in the future will be faced with much more complex caregiving situations and may find it much more difficult to access the resources they need to adequately cope with their own stress and provide quality care for loved ones.

CAREGIVING TASKS AND ROLES

Caring for someone with dementia inevitably means an increase in the workload for the caregiver. Haley (1997) reports that the median length of in-home caregiving before nursing home placement is 6.5 years. Family caregivers of persons with Alzheimer Disease whose relatives live in the community report an average of 60 hours per week spent on caregiving responsibilities (Haley et al., 1995; Max, Webber, & Fox, 1995). Caregivers who live with care receivers provide more hours of help and perform a greater range of caregiving tasks than those who live in separate residences (Boaz & Muller, 1992; Penrod et al., 1995).

Generally, caregivers provide assistance to persons with dementia by being available when needed; supervising prescribed treatment; evaluating significance of changes; providing structure to the care receiver's daily routine; normalising this routine within the bounds of impairment; and assisting in the activities of everyday living, including transportation, grocery shopping, housework, preparing meals, managing finances, arranging and supervising outside services, giving medicine, assisting the individual with getting in or out of bed or a chair, dressing, bathing, toileting, feeding, and help with continence and diapers (Cohen, 2000; Dhooper, 1992; Schulz, 2000).

The 1996 General Social Survey breaks eldercare tasks into the following six categories:

1. *Personal care*, which involves assistance in tasks such as bathing, dressing, walking, eating,

getting in and out of a bed or chair, grooming, taking medication, cutting toenails, and toileting;

2. *Household activities*, which include: (a) *housework*: assistance in making beds, doing laundry, preparing meals, cleaning up after meals, cleaning, washing floors, and vacuuming; and (b) *household maintenance*: washing windows, putting up storm windows, minor repairs, and yard work;

3. *Shopping and transportation*, which includes assistance in shopping and errands;

4. *Financial management*, such as assistance in balancing chequebooks, paying bills, and filing income tax forms;

5. *Emotional support*, which involves assistance in maintaining social interaction, cheering up individuals who are depressed, validating attitudes or perceptions, providing opportunities for socialisation, self-affirmation, and self-actualisation; and

6. *Monitoring care*, which encompasses ensuring that the care recipient's needs are met and quality of services are provided (Keating et al., 1999).

Differences in Caregiving Tasks by Gender

Evidence suggests that men and women may approach the caregiving role differently, and therefore, may place emphasis on different caregiving tasks. Women tend to be more intensely involved in overall assistance to their care receivers than men. They perform a larger number of caregiving tasks and also spend significantly more hours doing these tasks than men (Keating et al., 1999; Walker et al., 1994). Analysis of the data from the 1996 General Social Survey found that women caregivers average 5.0 hours per week in caregiving tasks, while men spend an average of 3.0 hours per week on these tasks (Keating et al., 1999). Both men and women spend the most hours doing meal preparation and personal care, and the fewest paying bills and banking (Keating et al., 1999).

Women are also more likely than men to provide "hands-on" assistance in the areas of domestic and personal care, such as helping with eating, bathing, dressing, and toileting (Allen, 1994; Chang & White-Means, 1991; Ingersoll-Dayton, Starrels, & Dowler, 1996; Stoller, 1990; Tennstedt et al., 1993). Male caregivers, on the other hand, are more likely to engage in home maintenance and repair tasks, and to take on a care management role rather than a care provider role by arranging for transportation, social services, and benefits (Birkel & Jones, 1989; Coward, 1987; Finley, 1989; Finley, Roberts & Banahan, 1988; Globerman, 1996; Horowitz, 1985a; Keating et al., 1999; Kramer & Kipnis, 1995; Matthews & Rosner, 1988; Montgomery & Kamo, 1989; Young & Kahana, 1989).

Nonetheless, a number of studies demonstrate that some husbands and sons also take on primary caregiving responsibilities (Harris, 2002; Keating et al., 1999; Montgomery & Kamo, 1987) and that these men perform a broad spectrum of caregiving functions including personal aspects of care (Kaye & Applegate, 1993). Despite the caregiving work that males do, they often feel that their work is invisible and unappreciated (Russell, 2001). A key limitation associated with the research on male caregivers is that it tends to view them through the lens of women's caregiving roles and experiences. As a consequence, some observers have argued that research on male caregivers needs to take a fresh, unbiased perspective to understanding their caregiving roles (Kramer & Thompson, 2002).

In fact, some researchers suggest that men's involvement in caregiving is increasing and will continue to grow as more and more younger women enter the job market and become less available for caregiving (Mathew, Mattocks, & Slatt, 1990; Stone et al., 1987; Toseland, Smith, & McCallion, 1995). Currently, however, men are more likely to reduce their hours of care in the face of competing familial demands (e.g., married, employed, children living at home). Women, on the other hand, often find ways to accommodate their caregiving responsibilities in addition to their other responsibilities without reducing the hours spent in elder care (Keating et al., 1999). Nevertheless, men's involvement in caregiving is likely to increase dramatically over the next several years. With women more likely than men to be diagnosed with Alzheimer Disease, as the numbers of persons with dementia continue to increase, the caregiving role and its responsibilities is especially likely to fall more and more to husbands (Fitting, Rabins, Lucas, & Eastham, 1986).

Men and women also may define caregiving in different ways. Women, particularly wives, may not

view tasks such as meal preparation, laundry, and housecleaning as caregiving because these activities are part of their traditional domestic role (Walker et al., 1994). Household chores have not been traditional responsibilities for men, so when they perform these tasks, they consider themselves to be providing informal care (Keating et al., 1999). As caregiving activities are more non-normative for siblings than for parents, they tend to provide less help, but often experience stronger perceptions of burden (Reinhard & Horwitz, 1995).

Studies suggest that gender differences in caregiving may be due, in part, to differences in feelings of affection and obligation (Finley, Roberts, & Banahan, 1988). Jansson, Grafström and Winblad (1997), for example, compared daughters and sons caring for elderly persons with and without dementia, and found that daughters reported showing more affection for their care recipients than sons. Feminist theorists (e.g., Baines, Evans, & Neysmith, 1991; Dalley, 1988; Gilligan, 1982; Larrabbe, 1993) argue that women are socialised into an *ethic of care*; that is, women are culturally conditioned to feel a sense of obligation to care for others. More recent studies of male caregivers suggest that some men have just as great a sense of affection, commitment, and family responsibility as women (Russell, 2001). Wells (1999), for instance, found that middle-aged men reported a greater willingness to care than middle-aged women.

Differences in Caregiving Tasks by Relationship to the Care Recipient

Research suggests that the caregiving role also differs by the caregiver's relationship to the care receiver. Spousal caregivers are the most intensely involved in care, while friends provide the least amount of assistance to an older adult (Keating et al., 1999; Tennstedt et al., 1993). Some studies suggest that spouses provide three to five times more care than other family members (Frederick & Fast, 1999). Chang and White-Means (1991) found that spouses spent about 60% more time attending to caregiving responsibilities than did others in their sample as a whole. In addition, spouses and adult daughters provide assistance in a broader range of tasks and are much more likely to provide assistance with hands-on personal aspects of care compared to other caregiver groups. Moreover, spouses continue in the caregiving role for longer periods of time than adult children (Pruchno & Potashnik, 1989).

In comparisons of adult children providing care to parents, Dwyer and Coward (1991; see also Lee, Dwyer, & Coward, 1993) found that daughters were over three times more likely than sons to provide assistance with activities of daily living (ADLs) and over twice as likely as sons to provide assistance with instrumental activities of daily living (IADLs). Further, Laborde Witt (1994) found that adult daughters provided more care than sons in all areas of care measured, including personal care, housework, meal preparation, transportation, and handling bills and money. Daughters also play an important role in providing elderly parents with emotional support (McCarty, 1996). Sons are more likely to assist with tasks that are either gender-neutral or male-oriented, and are more limited in their caregiving in terms of both time and task commitment; that is, sons are less likely to help with housekeeping or personal care (Horowitz, 1985a; Stoller, 1990; Young & Kahana, 1989).

Nevertheless, both spouses and adult children provide more care and more intensive and intimate care than other relatives or friends (Horowitz, 1985a). In fact, other relatives and friends tend to take on a secondary caregiver role, providing financial aid, assisting with shopping, and providing respite services (Penrod et al., 1995; Tennstedt, McKinlay, & Sullivan, 1989) and supporting primary caregivers with transportation, gardening, housework, and cooking (Nocon & Pearson, 2000).

Very little research has been conducted on daughter-in-law and son-in-law caregiver roles. However, the research that does exist suggests that there are differences between sons-in-law and daughters-in-law in the patterns of care they provide. A study conducted by Globerman (1996) found that sons-in-law responded to their partners' requests and marital needs, and not so much to the needs of the parent-in-law with dementia. Similar to daughters in caregiving roles, daughters-in-law tended to be "kin-keepers". However, daughters-in-law indicated their motivation was primarily a relational obligation to their partner in that they acted to take caregiving pressure off of their husbands. In contrast, sons-in-law felt they could not alleviate the pressure placed on their wives.

Caregiver Tasks and the Caregiving Career

In addition to gender and relationship status, research also suggests that caregiving roles and experiences can vary greatly depending on where a

caregiver is in her or his caregiving career. For example, Keating et al. (1999) found that caregiving was most intense for female caregivers early in the community-based caregiving career (i.e., in the first six months of the caregiving career). Men's caregiving responsibilities, on the other hand, were the most intense in later phases of the caregiving career (i.e., between the first and second years of the caregiving career). Therefore, the concept of the caregiving career is an important consideration because it reflects the directions and patterns that the caregiving experience may take over time. As well as distinguishing between the objective and subjective dimensions of career, Hughes (1971, pp. 405-406, p. 125) defined career lines as the "significant phases of careers and the sequences in which they occur…the shifts from weighting or combination of activities or pressures to another…a sort of running adjustment…the phases and turning points of one's whole life."

A career includes the process and sequences of learning the techniques and purposes of the position, the progressive perception of the whole system and of possible places in it, and the accompanying changes in conception of the work and of one's self in relation to it over time. The joining of different life events, different adaptations, different decisions, and different conceptions comprise each person's unique career.

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

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

Other authors also have described the multiple phases and transition of the caregiving career in the community. Given and Given (1991), presenting what they refer to as the "natural course" of caregiving, discuss four stages that family caregivers go through. These stages include selection into the role, acquisition of care-related skills, provision of care, and cessation of care. Similarly, Wilson (1989) offers a three-stage career path, which is comprised of: (1) taking it up, deciding to become a caregiver; (2) getting through it, enduring the unfolding sequence of problems entailed in providing care; and (3) turning it over, relinquishing care and control to an institution.

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

1. *Role acquisition* – the recognition of the need for the role and the assumption of its obligations and responsibilities;

2. *Role enactment* – the performance of role-related tasks within the home and, for some, within the formal setting of a long-term care facility; and

3. *Role disengagement* – the cessation of caregiving and the returning to other venues of life that typically follow the death of one's impaired relative (p. 23).

Aneshensel et al.'s (1995) conceptual model points to the importance of recognising that each stage in a caregiving career represents only one piece of the entire caregiving career path. They further emphasised:

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

Thus, the caregiving role will change over the caregiving career as caregivers adapt to different circumstances, to different pressures, and to ever-changing perceptions or definitions of the caregiving situation. As a caregiver travels through each phase and turning point in her or his career, one set of roles will be constantly created and recreated into another set of roles. Caregivers at different points in their individual caregiving careers may think about their roles differently and, in turn, may have different expectations for themselves and may react differently in terms of their role behaviours.

Ethnicity and Caregiving Tasks

Although recent literature has begun to examine the meaning and experience of caregiving in relationship to caregiver ethnicity, this review found no literature pertaining specifically to ethnicity and caregiving tasks. However, it is quite likely that the caregiving role varies across cultures as well as across different ethnic groups. Certainly, research on caregivers' motivations for caring for a person with dementia suggest important culturally related differences (Kabitsi & Powers, 2002). Such cultural differences in motivation could lead to quite varied approaches to the caregiving role as well as different experiences in those roles. Research is needed to explore differences in caregiving task performance among caregivers of different ethnic and cultural groups and their experiences in caregiving.

Early Onset Dementia and Caregiving Tasks

Few, if any, studies have examined differences in the caregiving role for those caring for adults with early onset dementia versus those caring for older adults with dementia. Given that the needs of younger people with dementia can be very different from the needs of older adults with dementia (Williams et al., 2001) and that their caregivers may have different life situations, particularly the younger spouses of persons with early onset dementia, it is reasonable to assume that the amount of caregiving and/or the types of tasks performed in the caregiving role may differ in important ways. Future research is needed that compares the caregiving tasks of caregivers of persons with early onset dementia with those of caregivers of persons with dementia over the age of 65 years.

SUMMARY OF CHAPTER

- Currently, there are close to 140,000 persons with dementia in Ontario who either now or in the future will require assistance and support – this number will increase significantly over the next two decades.

- Approximately half of the individuals with dementia in Canada live in the community.

- Almost all persons with dementia living in the community (94%) are cared for by family members and friends.

- Caregivers are most often spouses, daughters, or sons, but these caregivers also rely on secondary support from other family members and friends.

- Women make up the majority of caregivers; however, more and more men are taking on the caregiving role.

- Caregivers are often elderly themselves.

- Caregivers often care for more than one person.

- The growth of the older adult population, coupled with changes in family roles and structures, suggests that the caregiving situation will be far more complex in the future, contributing to higher stress levels and time pressures, decreased social support, and heightened social isolation among caregivers.

- Caregivers assist in many tasks, including personal care, household, shopping and transportation, financial, emotional, and monitoring tasks.

- The caregiving role differs by the gender of the caregiver and the relationship to the care receiver with women and spouses being far more intensely involved in caregiving responsibilities than other caregivers.

- Caregiving involves a long career and the tasks associated with caregiving may change over time.

- Little is known about differences in task performance for caregivers of different ethnic and cultural groups, and for caregivers of persons with early onset dementia.

CHAPTER THREE
THE EXPERIENCE OF CAREGIVERS IN THE DEMENTIA CONTEXT

Most of the research on caregiving has focused on the experience of the caregiving role for caregivers. This research suggests that caregiving can have both negative and positive consequences for the caregiver. More specifically, the caregiving role can have an impact on the psychological and physical health of caregivers, family relationships, social and leisure lifestyles of caregivers, work, and also can have significant financial implications. Nonetheless, more recent research suggests that the caregiving role can be very rewarding for some caregivers. This chapter will explore the consequences of the caregiving role on caregivers of persons with dementia.

Given the potential consequences of caregiving on family members and others, the person who is providing care for the individual with dementia has come to be referred to as the "hidden patient" or the "forgotten client" (Pratt, Schmall, & Wright, 1987). Generally, these caregivers experience feelings of fear, guilt, frustration, uncertainty, anger, sadness and loss, chronic fatigue, stress, depression, and a disruption in social participation (George & Gwyther, 1986; Gwyther, 1998; Rabins, Mace, & Lucas, 1982; Schulz & Williamson, 1991). Caregivers of persons with dementia pay 50% more visits to their physicians and take up to 86% more prescribed medications than their non-caregiving contemporaries (Katon, Kleinman, & Rosen, 1982). Although community care is currently being promoted as beneficial for persons with dementia, in many instances, it increases role-related stress for the caregiver. According to the *Alzheimer Caregiver's Stress Model* (Pearlin et al., 1990), a primary task of caregiving centres on responding to and managing the impacts of the caregiving process.

PSYCHOLOGICAL HEALTH AND CAREGIVER BURDEN

Caregiving for someone with dementia has significant implications for caregiver psychological health and burden (Connell, Janevic, & Gallant, 2001). For example, several studies have linked caregiving with depression or depressive symptoms (Haley, LaMonde, Han, Narramore, & Schonwetter, 2001). Dura, Stukenberg, and Kiecolt-Glaser (1990) found that 23% of spousal caregivers met DSM-III-R criteria for depressive disorder, although few had depression prior to caregiving. Another study conducted by Teri (1994) found that 70% of caregivers of Alzheimer Disease patients with co-existing depression had depressive disorders themselves. Further, loneliness has been found to be an important factor in predicting depression in spouses and adult daughters caring for a person wth Alzheimer Disease (Beeson, Horton-Deutsch, Farran, & Neundorfer, 2000). According to the CSHA (1994b), 16% of people caring for someone with mild dementia in the community, 40% of those caring for someone with moderate dementia in the community, and 18.4% of informal caregivers assisting someone with severe dementia in an institution reported symptoms of depression. Overall, depression is nearly twice as common in people caring for someone with dementia as in other caregivers (CSHA, 1994b).

The impact of the caregiving process on the caregiver has most often been described in terms of "caregiver burden", a term which has been subjected to multiple and inconsistent definitions and measurements (DiBartolo, 2000; Harper & Lund, 1990). Some definitions of caregiving burden focus on the experience in the role. George and Gwyther (1986), for example, define burden as the "physical, psychological or emotional, social, and financial problems that can be experienced by family members caring for impaired older adults" (p. 253). Other researchers have introduced definitions that place less emphasis on the experience. Ory et al. (1985), for instance, define the term as the "impact of changes in cognition and behaviour of the Alzheimer patient on the family, and the patient's subsequent need for care and supervision" (p. 623).

Other researchers emphasise that burden may be experienced differently by caregivers living under similar environmental conditions and, therefore, may be more usefully thought of as the interaction between *care receiver characteristics* (e.g., functional disturbances, disturbing behaviour), *caregiver characteristics* (e.g., age, gender, multiple social roles, health status, ethnicity, level of education, relationship to care receiver), and the

caregiving context (e.g., financial situation, informal and formal care resources) (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Duijnstee, 1994). Intervening factors such as coping (i.e., caregiver adaptation to the situation), acceptance of the situation, and motivation might also explain differences in burden (Duijnstee, 1994). Caregiver burden can be subjective (e.g., the caregiver's perceptions or emotional response to a situation) or objective (e.g., amount and type of caregiving, disruption of family life), and has been described both as a stressor and as an outcome of caregiving (George, 1987; O'Rourke, Haverkamp, Tuokko, Hayden, & Beattie, 1996; Vitaliano, Young, & Russo, 1991). Clark and Bond (2000) suggest that attending to subjective burden is most critical because caregivers become depressed when they are unable to perform at the level they believe is necessary to provide adequate care (see also Gallagher-Thompson & Powers, 1997).

Caregivers who experience significant burden often experience a loss of control over the caregiving situation (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken 1991; Morris, Morris, & Britton, 1988b; Pagel, Becker, & Coppel, 1985), depression, increased likelihood of patient institutionalisation (Bedard, Molloy, Pedlar, Lever, & Stones, 1997), diminished communication with the care recipient (Morris, Morris, & Britton 1988a), and heavy workload (Donaldson, Tarrier, & Burns, 1997; Stephens, Kinney, & Ogrocki, 1991). Caregivers also experience a loss of "congruence" or "shared meaning" with the care receiver as her or his capacity for verbal communication diminishes (Wright, 1991). Grief over the immediate caregiving situation and in anticipation of the final loss of the care recipient is also common in the caregiving context (Dempsey & Baago, 1998; Lindgren, Connelly, & Gaspar, 1999; Ponder & Pomeroy, 1996; Walker, Pomeroy, McNeil, & Franklin, 1994). Caregivers must learn to adjust to all the symptoms associated with dementia (e.g., wandering, aggression, decreased ability to communicate, loss of memory) as well as imbalances in family relationships, increasing isolation, fear, fatigue, and overwhelming loss of control if they hope to cope in their caregiving roles (Gwyther, 1998).

Turning the focus on the *process* of caregiving research, some researchers (e.g., Bedard, Pedlar, Martin, Malott, & Stones, 2000) have highlighted a number of methodological issues that have limited our understanding of burden among caregivers of persons with dementia, especially as it changes across their caregiving careers. Two of the more critical issues are the need to make distinctions among subgroups of both caregivers and care receivers rather than treating them as homogeneous groups, and greater rigour and clarity concerning measurement issues, research design, and statistical techniques. Nevertheless, the research that does exist provides substantial insight into those factors that are related to caregiver burden and psychological health.

RISK FACTORS OF CAREGIVER BURDEN AND DECREASED PSYCHOLOGICAL HEALTH

Type of Caregiving Situation

Although some research has found similar experiences among caregivers of persons with dementia when compared to non-dementia caregivers (e.g., Cattanach & Tebes, 1991; Draper, Poulos, Cole, Poulos, & Ehrlich, 1992; Rabins, Fitting, Eastham, & Fetting, 1990), much more research suggests that the dementia caregiving role and the experiences in that role differ significantly from other caregiving roles (Clipp & George, 1993; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Thus, some researchers suggest that although caring for a person with dementia can be extremely rewarding, it can also be one of the most difficult, frustrating, and distressing of all the caregiver roles (Brody, Lawton, & Liebowitz, 1984; Motenko, 1989).

In comparisons with non-dementia caregivers, dementia caregivers report greater emotional burden and stress (Birkel, 1987; George & Gwyther, 1986; Krizek-Karlin & Bell, 1992; Leinonen, Korpisammal, Pulkkinen, & Pukuri, 2001), greater caregiver strain (Ory et al., 1999), higher levels of depressive symptoms (Moritz, Kasl, & Berkman, 1989), increased dysphoric mood (Moritz et al., 1989), and more mental and physical health problems (Ory et al., 1999). They also are much more likely to use psychotropic drugs (George & Gwyther, 1986; Schulz, 2000; Schulz, O'Brien, Bookwala, & Fleissner, 1995), to give up or to experience limitations in selected social and personal leisure activities (Moritz et al., 1989; Ory et al., 1999), to have less time for family (Ory et al., 1999), and to experience greater employment complications and increased family conflict (Ory et

al., 1999) compared to non-dementia caregivers. In addition, Straw et al. (1991) found that caregivers of persons with dementia are more likely to report unmet caregiving needs than caregivers of individuals with other illnesses, and may require additional assistance with household tasks, transportation, and direct care.

The experience of caregiving also may vary with type of dementia. One study found that vascular disease patients impose a greater burden on relatives during early stages of disease, while in severe stages relatives of Alzheimer Disease patients experience burden more adversely (Vetter et al., 1999). In another study, spousal caregivers for patients with dementia from Alzheimer and Parkinson's Disease were both found to be significantly more distressed (Dura, Haywood-Niler, & Kiecolt-Glaser, 1990).

Although most research on the experience in the caregiving role, and more specifically on caregiver burden, has focused on caregivers of older persons with dementia, recent studies suggest that caregivers of persons with early onset dementia experience significant levels of caregiver burden and distress (Baldwin, 1994; Delany & Rosenvinge, 1995; Sperlinger & Furst, 1994). In a study of early onset dementia in Dublin, Freyne et al. (1998) found that caregivers of younger people with dementia exhibited high levels of stress, especially those still actively involved in the caregiving role. Hatada et al. (1999), in fact, suggest that caregiver burden and distress may be even greater among caregivers of persons with early onset dementia compared to those caring for persons with later-onset dementia because these "family members are not psychologically ready for the [care receiver's] early aging disability and are confused by his/her unexpected early changes" (p. 125). Others have suggested that these caregivers may experience higher levels of stress and burden due to delays in establishing community support systems specifically designed for younger people with dementia because the current support systems may not be adequate to meet the needs of this group of care receivers and their partners in care (Williams, 1995). Freyne and colleagues (1998), for example, found that service provision for caregivers of persons with early onset dementia living in Dublin was patchy and did not match their level of dependency and need. Clearly, much more research is needed that examines the experience of caregiving for caregivers of younger people with dementia and how that compares to the experience for those caring for persons with later-onset dementia.

Differences in caregiving associated with the type of caregiving situation are likely explained, in part, by differences in caregiver characteristics as well as differences in the experience of caregiving for dementia and non-dementia caregivers (Ory et al., 1999). When compared to non-dementia caregivers, for example, caregivers of persons with dementia are more often women, spouses, retired, and unemployed (Schulz, 2000). Dementia caregivers are significantly older than other caregivers, spend significantly more time on caregiving than other caregivers, and assist more with both activities of daily living such as dressing and bathing, and with instrumental activities such as using a telephone (Ory et al., 1999). Caregivers of persons with dementia are more likely to be family members than paid professionals (Birkel & Jones, 1989). Further, dementia caregivers may become insular, relying more on other family members than outside help, while ties to other social supports are gradually eroded. Dementia caregiving also entails a unique and particular strain, requiring caregivers to redefine the meaning of their relationship to their care receiver (Gallagher, Wagenfeld, Baro, & Haepers, 1994).

Caregiving Experience and Gender

Although a few studies have found no gender differences in caregiver stress or burden (e.g., Miller & Cafasso, 1992; Montgomery & Kamo, 1989) and no differences in the appraisals of the perceived stressfulness of primary caregiver stressors (Ford, Goode, Barrett, Harrell, & Haley, 1997), much more research suggests that caregiving generally has a greater negative impact on women than on men (Fisher & Lieberman, 1994). Specifically, female caregivers report more negative feelings, more physical symptoms, higher levels of burden and depressive symptoms, greater strain, higher emotional and physical stress, and poorer morale than male caregivers (Adams, Aranda, Kemp, & Takagi, 2002; Barusch & Spaid, 1989; Bedard, Molloy, Pedlar, Lever, & Stones, 1997; Beeson, Horton-Deutsch, Farran, & Neundorfer, 2000; Brody, Hoffman, Kleban, & Schoonover, 1989; Chang & White-Means, 1991; Donaldson & Burns, 1999; Finley, 1989; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Grafström & Winblad, 1995; Kramer & Kipnis, 1995; Morris et al., 1991; Parks & Pilisuk, 1991; Rose-Rego, Strauss, & Smyth, 1998; Zarit & Zarit, 1982). Mantell (2000)

found that female caregivers reported more burden than male caregivers, but they were not significantly different in their levels of depression. Also, Young and Kahana (1989) found that female caregivers were more negatively affected by their caregiving roles than males in multiple areas including greater subjective burden, greater physical health decline, and greater mental health consequences.

Interest in gender differences has generated other studies that further explored the caregiving process for men (e.g., Parsons, 1997). Kramer (2000), for example, conducted a longitudinal study of husbands caring for wives with dementia, and found a high rate of depressive symptoms in her research subjects. In a married couple, the wife may be the main source of friendship and companionship, and the main link to the outer social world for her husband. This can be a particularly critical stressor when the wife has dementia. Men's social ties often come from work, but this potential source of social support is cut off because male caregivers are often retired (Harris, 1993). Nevertheless, male caregivers may be more likely to report reductions in burden over time (Bedard et al., 1997). However, another study found that female caregivers reported both greater feelings of subjective burden and more aspects of caregiving as enjoyable (Gold, Cohen, Schulman, Zucchero, Andres, & Etezadi, 1995).

Several factors may help to explain these gender differences. Men and women may perceive the caregiving process in very different ways. Men, for example, often see caregiving as a new job or a meaningful retirement activity (Kaye & Applegate, 1990a), whereas women may see the responsibility as an unwanted and resented continuation of their life-job. As a result, male caregivers may be able to keep greater emotional distance from their caregiving tasks than women, who experience greater feelings of guilt and inadequacy. Also, differences may exist in the types of coping strategies used and supports available. Women, for instance, may make greater use of emotion-focused coping strategies, which are associated with higher levels of distress (Stoller, 1994). Other researchers have noted that older male caregivers receive more formal and informal supports compared to female caregivers. Differences may also exist in levels of burden and how burden is experienced by male and female caregivers. Male caregivers experience burden, particularly in relation to the daily living and orientation symptoms of the person with dementia, and in relation to conflicting demands on their time. In contrast, women are particularly influenced by "their general outlook on life and the elements of functional dementia pertaining to orientation and affect" (Harper & Lund, 1990, p. 256). Differences in burden may also reflect differences in caregiving tasks, as discussed in the previous chapter

Others have argued that men may not experience less caregiving stress, but that they may express and handle caregiver burden differently (Kaye & Applegate, 1990b). For example, some authors suggest that female caregivers may be more likely to express burden than male caregivers (Miller & Cafasso, 1992). Davies, Priddy and Tinklenberg (1986) found that male caregivers of persons with Alzheimer Disease masked their depression. "Consistent with sex role socialisation that values men's bearing-up under stress, these men took a 'stoic-intellectual' approach to caregiving." (Kaye & Applegate, 1990b, p. 293).

Despite these gender differences, it is important to emphasise that caregiving experiences also vary by gender in relation to other factors such as socio-economic status and ethnicity. For example, Hibbard, Neufeld, and Harrison (1996) report that younger men and men of higher socio-economic status have larger social networks than other men, and these networks could serve as an important coping resource for these men in their caregiving roles.

Recent studies have called for a degendering of caregiving (Neysmith, 1991) because caregivers of both genders experience social isolation, caregiving burden, and the emotional impact of institutionalisation (Siriopoulos, Brown, & Wright, 1999). In their study of male and female primary caregivers of persons with Alzheimer Disease, Ford and associates (1997) report that "gender roles may be less important than the nature of the stressor in determining reaction to primary stressors" (p.158). Hepburn et al. (2002) found that husbands and wives were more similar than not in their caregiving experiences. Based on their findings, they suggest that how caregivers perceive their caregiving roles or what the meanings of their caregiving experiences hold for them, may offer more insights into the differences that exist among caregivers and their caregiving than would gender. Nevertheless, regardless of the caregiver's gender, those individuals who spend the most amount of time in providing care to a person with dementia, experience the highest levels of burden.

Caregiving Experience and Relationship to the Care Receiver

The experience of the caregiver role also varies depending on the relationship to the care receiver. Given the intense involvement in care, it is not surprising most studies find that spouses are at the greatest risk of the negative consequences associated with caregiving. Spouses report the highest levels of both objective and subjective burden, followed by adult children and other relatives (Barnes, Given, & Given, 1992; Frederick & Fast, 1999; George & Gwyther, 1986; Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999). Spouses report more visits to doctors, poorer self-rated health, more stress symptoms, lower levels of affect balance and life satisfaction, and are more likely to use psychotrophic medications than adult children and other relatives (George & Gwyther, 1986). Burden tends to increase for female caregivers throughout the disease process (Winslow & Carter, 1999), and caregiver wives report more negative psychological states than caregiver husbands (Rose-Rego, Strauss, & Smyth, 1998).

Several factors may account for this pattern. First, wives pay more attention to their emotions than husbands, and therefore are more prone to report negative emotions such as depression. Wives also perform more personal care tasks and household chores than male caregivers do, and receive less help from family and other informal sources (Rose-Rego et al., 1998). However, other research has found that husbands caring for their wives with dementia may sustain a heavier burden than other relatives, experiencing anger, worry, weariness, guilt, distress, and isolation (Samuelsson, Annerstedt, Elmstahl, Samuelsson, & Grafström, 2001).

Although spouses have been identified as the highest risk group for burden and distress among all caregivers (Cantor, 1983; George & Gwyther, 1986; Motenko, 1989; Quayhagen & Quayhagen, 1988), adult daughters are also deeply affected by their caregiving responsibilities. In fact, the literature suggests that adult daughters are the second most affected group of all caregivers experiencing significantly more caregiver stress than sons (Ingersoll-Dayton, Starrells, & Dowler, 1996). Daughter caregivers report significantly higher levels of strain, poorer self-rated health, less respite support, higher levels of caregiving role involvement, and more interference in personal and social life compared to sons (Mui, 1995a). Daughters caring for persons with dementia living in long-term care facilities also experience higher emotional stress than caregiving sons. In a study conducted by Grau, Teresi, and Chandler (1993), daughters of care receivers living in long-term care facilities reported the second highest demoralisation scores (i.e., non-specific psychological distress related to anxiety, self-esteem, helplessness/hopelessness, and sadness) after spouses, and had significantly higher scores than sons. Riddick et al. (1992) also found that although spouses showed significantly higher levels of caregiver burden than daughters, spouses and daughters reported similar negative emotions (i.e., guilt, sadness, anger, frustration with lack of control over relative's health, thoughts about own future health, and thoughts about own future living arrangements) surrounding the placement of their loved ones into a long-term care facility. Similarly, Brody, Dempsey and Pruchno (1990) noted significant differences in the effects of parent care when comparing adult daughters and sons of institutionalised older adults. Daughters experienced significantly higher emotional effects (e.g., helpless, frustrated, angry emotionally drained, guilty, worried) and levels of depression than sons.

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

approaches to the caregiving role taken by adult sons and daughters are more important in explaining the greater distress felt by adult daughters than are the competing demands of multiple roles. In fact, combinations of roles may have positive outcomes for a caregiver's well-being and sense of self (Scharlach, 1994; Skaff & Pearlin, 1992; Stoller & Pugliesi, 1989).

Caregiver–Care Receiver Living Situation

Caregivers who live with rather than apart from the care receiver may experience greater burden and diminished psychological well-being (Brodaty & Hadzi-Pavlovic, 1990; Brodaty & Luscombe, 1998; Goodman, 2000; Grafström, Fratiglioni, Sandman, & Winblad, 1992), although there is some evidence to suggest the opposite (Cohen, Luchins, Eisdorfer, Paveza, Ashford, Gorelick, et al., 1990). The greater burden felt by co-resident caregivers again might be related to the fact that they tend to provide a greater number of hours of care, and engage in a greater range of caregiving tasks.

Caregiving Experience and Ethnicity

Most of the research on caregiving and ethnicity has focused on the caregiving experience for different ethnic groups. This research suggests that caregivers of different ethnic groups may experience the caregiving role quite differently. A number of studies have found that Black caregivers experience higher levels of caregiving satisfaction and mastery, and lower levels of burden, depression, and role strain than do Caucasian caregivers (Connell & Gibson, 1997; Farran, Miller, Kaufman, & Davis, 1997; Hinrichsen & Ramirez, 1992; Javenic & Connell, 2001; Lawton, Rajagopal, Brody, & Kleban, 1992). Differences in the caregiving experience across ethnic groups and cultures may reflect different perceptions of family and family obligations as well as differences in the supports and personal coping capacities of caregivers. Several studies, for example, suggest that Black families may have the benefit of extended family and high levels of social support, which may help them cope better in their caregiving roles (e.g., Adams et al. 2002; Dungee-Anderson & Beckett, 1992). African American caregivers also have been found to be more resourceful in their caregiving than Anglo-American caregivers (Gonzalez, 1997).

However, even though Black American caregivers report lower levels of burden, they also report equal levels of depression and anxiety in caregiving when compared to Caucasian caregivers. This may reflect a tendency to use emotion-focused caregiving, which may lead to increased emotional distress (Knight, Silverstein, McCallum, & Fox, 2000). Further, reliance on an extended network of caregivers may also mean that a perceived lack of informal supports may exacerbate stress in Black caregivers more than in a Caucasian sample (Cox, 1995). Cox explained it this way:

> [b]ecause the Black group maintains stronger adherence to norms of filial responsibility, they also have greater expectations of their supportive networks. When these needs are perceived as inadequate regardless of the number of hours of assistance, caregiver well-being may be affected. Thus supports may actually exacerbate stress. (p. 347)

Given the stronger adherence to filial responsibility, Black caregivers may feel increased pressures to meet caregiving responsibilities and a greater sense of incompetency if they are not able to meet the increasing needs of their care receivers. This can magnify stress even further for these caregivers (Cox, 1995). One recent study found that even though Caucasian caregiving families experience increased depression and decreased life satisfaction, caregiving had similar social consequences for both Black and Caucasian families (Haley et al., 1995). A few studies have explored the differences in caregiving experiences among caregivers from a number of different ethnic backgrounds. For example, Adams et al. (2002) examined differences in distress, coping, and social resources among Japanese, Anglo-, African-, and Mexican American spousal caregivers of pesons with dementia and found that Mexican American caregivers had significantly higher rates of depression compared to both Anglo- and African-American caregivers. The findings from their study suggest that ethnic differences in caregiving experiences may be explained in part by differences in the kind of caregiving appraisals (i.e., spiritual, pessimistic, lack of support), coping styles (i.e., escape-avoidance, seeking social support), and amount of social support available to caregivers of different ethnic backgrounds.

Recent research has also explored the experience of caregiving for Hispanic caregivers. This research suggests that the factors that contribute to caregiver depression may differ significantly between white Hispanics and white non-Hispanics. Harwood et al. (1998), for instance, found that the cognitive impairment of the care receiver was a predictor of caregiver depression only among white Hispanic spouses and children, and that patient psychosis was a predictor of caregiver depression only among white non-Hispanic spouses. Similar factors appear to predict burden in Cuban-American caregivers as in Caucasian caregivers. Harwood et al. (2000) found that patient behavioural pathology, caregiver gender (i.e., female caregivers), and lower levels of perceived emotional support were the best predictors of burden in Cuban-American caregivers of persons with Alzheimer Disease. Further, older caregivers and those with higher levels of perceived social support had higher appraised caregiving satisfaction, but length of residence in the United States as a measure of acculturalisation did not appear to be related to positive or negative caregiving appraisals.

In general, minority elders have been identified as subject to a "double jeopardy", combining minority status and stressors related to aging (Belgrave, Wykle, & Choi, 1993). Related to the double jeopardy, ethnic caregivers may also face increased health risks related to poverty, unemployment, crime, and racism (Dilworth-Anderson & Anderson, 1994). In fact, perceptions of some ethnic caregivers, such as African Americans, having less burden than Caucasian caregivers may not account for the embodiment of large-scale socio-political and historical forces including residential, educational and occupational segregation, institutional racism, and economic exploitation over the life course (Fox, Hinton, & Levkoff, 1999). Much more work is needed in order to better understand ethnic and cultural differences in the dementia caregiving context and the nature of these differences.

Strain and burden have also been documented in cross-cultural studies of caregiving. High levels of burden and mental distress have been found in caregivers across the European community (Schneider, Murray, Banerjee, & Mann, 1999). Caregivers from both China and the United States report more depressive symptoms and more physical symptoms when compared to non-caregivers (Patterson et al., 1998). In Guatemala, caregivers of persons with dementia generally have less institutional and more informal supports available than American caregivers, they bring patients to a doctor sooner after the appearance of their first symptoms, they have poorer perceived health than US subjects, and consequently, may experience greater burden than their North American counterparts (Salguero, Kohn, Salguero, & Marotta, 1998).

A number of different factors may lead to higher or lower levels of burden in different cultures. Behavioural disturbance by the person with dementia has been identified as a determinant of caregiver burden in Japan (Arai et al., 1997) and Argentina (Mangone, 1996), and is a primary determinant of stress and caregiver depressive symptoms in Italy (Zanetti et al., 1996). Disturbances in biological function in persons with dementia also contribute to caregiver burden in Manipal, India (Kar, Sharma, & Sengupta, 2001). The number of persons living in the household is also a significant determinant of stress in Italian caregivers (Zanetti et al., 1996). In addition, lower frequency of visits by friends or relatives, caregiver poor health, and higher ages of caregivers also contribute to depressive symptoms in Italian caregivers (Zanetti et al., 1996). Caregivers for persons with dementia in Hong Kong are most stressed by their frustrated social life, negative emotional responses, financial strain, and by the frustration caused by the inability of the person with dementia to cope with daily life (Chu, 1991).

In comparisons across cultures, low caregiver burden is associated with extended family support and high filial responsibility in Korea, whereas low levels of burden for American caregivers are related to the use of formal services and high gratification from caregiving (Lee & Sung, 1998). High burden for Korean caregivers is associated with limited formal services outside the family and low gratification from caregiving for in-laws, whereas high burden for American caregivers is associated with limited extended family support and low filial responsibility (Lee & Sung, 1998).

In a study of adaptation in caregiving period, Arai, Zarit, Sugiura, and Washio (2002) examined the experiences of Japanese caregivers over a one-year period and found support for results of studies conducted in the west. Specifically, they found that different patterns of outcomes, including both adaptation and "wear-and-tear", may exist among caregivers. Japanese caregivers of persons with dementia were more likely to experience

unsuccessful outcomes in their caregiving roles over time when compared to other caregivers. Also, Japanese spousal caregivers appeared to be better able to adapt in their roles over time than could daughters-in-law who were providing care.

Unfortunately, very few cross-cultural studies have compared Canadian caregivers with caregivers from other countries.

Education Level of Caregivers

Research on the relationship between the level of education of and the burden or stress felt by caregivers appears to be inconsistent. Some research has found that greater psychological illness is associated with lower education levels of caregivers (Meshefedjian, McCusker, Bellavance, & Baumgarten, 1998); however, other studies have found little relationship between levels of education and outcomes associated with the caregiving process (Dura, Stukenberg, & Kiecolt-Glaser, 1990; Haley, Levine, Brown, & Bartolucci, 1987). Lower educational levels of caregivers might result in a lack of monetary resources, which in turn may be related to a lack of a variety of supports for caregivers (Kurlowicz, 1993; Meshefedjian et al., 1998).

Self-Rated Health

Caregivers tend to perceive their health to be worse than non-caregivers (Baumgarten et al., 1992). Low self-rated health status has been identified as a significant predictor of caregiver depression for both male and female caregivers (Brodaty & Hadzi-Pavlovic, 1990; Hinrichsen & Niederehe, 1994; Hooker et al., 1992; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Moritz et al., 1997; Morrissey, Becker, & Rubert, 1990; Neundorfer, 1991; Semple, 1992). Further, caregivers experiencing low levels of burden often report significantly better mental and physical health, and relatively low levels of psychopathology (Cairl & Kosberg, 1993). However, the evidence is again inconclusive, as Draper et al. (1992) found no relationship between self-rated health and psychological distress.

Care Receivers with Depression

Recent studies have identified a link between relatively high levels of depression in persons with dementia (Cummings et al., 1995; Brodaty, Gresham, & Luscombe, 1997) and caregiver psychological morbidity (Brodaty & Luscombe, 1998). Caregivers of care receivers with higher rates of depression and anxiety experience greater burden (Magai & Cohen, 1998; Teri, 1997). Some researchers have identified care receiver depression as the most consistent predictor of psychological morbidity in caregivers (Donaldson & Burns, 1999; Jones & Peters, 1992). Similarly, Teri (1994) found that 70% of caregivers of persons with Alzheimer Disease and co-existing depression had depressive disorders themselves.

Functional Status of the Care Receiver

The literature that has focused on the relationship between the care receiver's functional status and caregiver functioning suggests that the relationship is a complex one (Gubrium, 1988). Some researchers have found a lack of a direct connection between care receiver level of impairment or symptoms and caregiver functioning (Boss, Caron, Horbal, & Mortimar, 1990; Deimling & Bass, 1986; Deimling & Poulshock, 1985; Fitting et al., 1986; George & Gwyther, 1986; Mantell, 2000; Morycz, 1985; Poulshock & Deimling 1984; Zarit, Reever, & Bach-Peterson, 1980; Zarit, Todd, & Zarit, 1986), whereas other research suggests that caregiver burden may increase with the severity of illness (Eagles et al., 1987; Leon et al., 2000; Lieberman & Fisher, 1995; O'Connor, Pollitt, Roth, Brook, & Reiss, 1990; Vetter et al., 1998). In particular, increased behavioural, cognitive, and functional problems displayed by persons with dementia have been identified as key predictors of caregiver psychological morbidity by a number of researchers (Baumgarten et al., 1992; Brodaty & Luscombe, 1998; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Gallagher-Thompson, Brooks, Bliwise, Leader, & Yesavage, 1992; Gaugler, Davey & Pearlin, 2000; Goodman, 2000; Meshefedjian, McCusker, Bellavance, & Baumgarten, 1998; Montgomery & Kosloski, 1994; Naimark, Jackson, Rockwell, & Jeste, 1996; O'Donnell, et al., 1992; Pruchno, Michaels, & Potashnik, 1990; O'Rourke & Tuokko, 2000; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Teri et al., 1992; Victoroff, Mack, & Nielsen, 1998; Winogrond, Fisk, Kirsling, & Keyes, 1987; Winslow, 1997). Chappell and Penning (1996), for example, found that specific behaviours, particularly aimlessness, aggressive behaviours, forgetfulness, and restlessness in care

receivers, were strong correlates of caregiver distress. Apathy or lack of interest in daily activities also was strongly correlated with feelings of burden and depression (Chappell & Penning, 1996). Caregivers of care receivers displaying more challenging behaviours and functional limitations also tend to receive less help from family and friends (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000). Similarly, the Manchester Carer's Project identified behavioural disturbance as the strongest predictor of subjective burden in caregivers, followed by depression in the person with dementia (Donaldson & Burns, 1999). Behavioural disturbance in this study included disruptions to walking, depression-related behavioural changes, physical signs such as appetite loss, and mood alterations. Being the care receiver's spouse protected the caregiver from burden to some extent, however, it is unclear why the spousal relationship served to provide this protection (Donaldson & Burns, 1999).

A number of studies also have examined the relationship between care receiver's cognition and caregiver burden, with some researchers suggesting that higher rather than lower cognitive functioning may have a stronger relationship with caregiver distress. However, only a few studies have shown significant associations between these two factors (Gallagher-Thompson et al., 1992; Kinney & Stevens, 1989b; Stuckey et al., 1996). Perhaps when caring for persons with relatively high levels of cognitive functioning, caregivers may misidentify features of dementia in persons with dementia as reflective of the care receiver's personality, believing that the care receiver could control these symptoms if she or he wished (Donaldson & Burns, 1999). Bauer and her associates (2001) found that caregivers of persons with early to moderate stage dementia did not differ significantly in caregiver depression or personal gains. However, greater cognitive impairment did seem to be associated with lower levels of mastery and greater relational deprivation among caregiving wives. The authors concluded that interventions may be needed that help enhance caregivers' sense of mastery in their roles (Bauer et al., 2001).

One limitation of many of these studies is that they tend to define functional status or impairment in objective terms by measuring, for example, the number of problems. Deimling and his associates (Deimling & Bass, 1986; Poulshock & Deimling, 1984), however, suggested that the caregiver's interpretation and appraisal of the impairment might be more important to caregiver functioning than objective impairment. Other more recent studies support this notion that the caregiver's perception of the care receiver's functional status may be more important to the caregiver's experience in the role than functional status itself (Hadjistavropoulos, Taylor, Tuokko, & Beattie, 1994; Pot, Deeg, & van Dyck, 2000; Pushkar Gold, Reis, Markiewicz, & Andres, 1995). Further, caregivers with significant levels of burden are more aware of care recipient deficits (Seltzer, Vasterling, Yoder, & Thompson, 1997). Levesque, Cossette, and Lachance (1998) found that appraisals of disturbance from dysfunctional behaviours are predictive of an increase in psychological distress and of negative feelings about the caregiver role. In fact, caregiver appraisal has been identified as an important mediator between stressors and caregiver distress (Goode, Haley, Roth, & Ford, 1998; Harwood, Ownby, Burnett, Barker, & Duara, 2000; Pot, Deeg, van Dyck, & Jonker, 1998; Rapp & Chao, 2000).

Phase in the Caregiving Career and Ambiguous Loss[1]

The caregiving role, and therefore the experience in that role, can change over the caregiving career (Burns & Rabins, 2000). Symptoms of caregiver stress are prevalent early in caregiving careers among caregivers caring for persons with mild forms of dementia. In a recent study of spouses of 92 persons with mild dementia living at home, Braekhus et al. (1998) found that 25% of their sample reported often or always having problems with the following: being depressed by the situation, having difficulties getting away on holiday, negative impacts on their social life, upsetting of household routines, and having their sleep interrupted.

One of the most challenging and frustrating experiences in the early stages of the disease is the struggle involved in getting a proper diagnosis. Teel and Carson (2003) found that the diagnosis process often can take several years, involves many visits to a variety of physicians, requires considerable diligence on the caregiver's part, and often results in feelings of mistrust toward the medical community.

[1] This section on ambiguous loss is a modified version of the review in the article by Dupuis (2002) entitled, "Understanding ambiguous loss in the context of dementia care: Adult children's perspectives" in the *Journal of Gerontological Social Work*.

These authors emphasise the need for support and education throughout the diagnosis stage to help offset these potential issues for caregivers and their care receivers.

As the caregiving career continues, caregiver burden often increases over time for persons providing care at home (Winslow & Carter, 1999), leading to an increased risk of institutionalisation (Colerick & George, 1986; Potter, 1993; Pruchno, Michaels, & Potashnik, 1990; Zarit, Todd, & Zarit, 1986). This occurs particularly as caregivers perform new activities and take on responsibilities that the patient is no longer able to perform (Clark & Bond, 2000). Research also suggests that caregiver burden, strain, and depression can continue even after the placement of a person with dementia into a long-term care setting (Riddick, Cohen-Mansfield, Fleshner, & Kraft, 1992; Stephens, Kinney, & Ogrocki, 1991; Tornatore & Grant, 2002; Whitlatch et al., 2001). Nonetheless, other evidence suggests that burden may decrease over time, as caregivers adapt to their situation and draw on support from informal networks (Grafström & Winblad, 1995).

Given that most of the caregiving research is cross-sectional in design, comparing those early in their caregiving careers with those in later phases, very little research has examined *changes* in caregiving roles over time. The majority of the research that does exist has focused on changes in the community-based caregiving role over time (Pillemer & Suitor, 1996; Suitor & Pillemer, 1996) or on changes between various stages of the caregiving career. In addition, most of this research has focused on changes in the health and well-being of caregivers over time rather than on changes in how caregivers think about their roles and thus play out those roles over time (e.g., Aneshensel et al., 1995; Goode, Haley, Roth, & Ford, 1998; Lawton, Moss, Hoffman, & Perkinson, 2000; Li, Seltzer, & Greenberg, 1999; Schulz & Williamson, 1991; Seltzer & Li, 1996, 2000; Townsend et al., 1989). This existing research points to the highly dynamic nature of caregiving careers and identifies critical factors to consider in examinations of changes in caregiving roles over time. For example, Seltzer and Li (1996, 2000) conducted a prospective study focusing on three types of caregiving transitions between different stages of the caregiving career. They found that transitions of caregiving are marked by changes in social involvement, family support, and psychological well-being, but that these changes were dependent on the type of relationship between the caregiver and the care receiver and the timing of these transitions in the life course. The results highlighted the fact that different subgroups of caregivers (e.g., men versus women, spouses versus adult children) may experience the transitions between each stage, or even within any given stage differently. For example, Seltzer and Li (1996) found that daughters in later stages of caregiving had more distant relationships with care receivers and experienced more subjective burden than daughters in early stages of caregiving.

Increases in burden often lead to the institutionalisation of the person with dementia. In contrast, wives experienced less burden and closer relationships with their husbands during later stages of caregiving. Nonetheless, the impact of entering the caregiving role and of exiting this role was generally greater for wives than for daughters, particularly in terms of burden and social participation. In general, daughters weathered the effects of the caregiving career well while wives experienced a significant downswing in well-being. Seltzer and Li's (1996) work also points to the importance of considering the subjective dynamics of the caregiving process. They found that self-defined stages of the caregiving career are distinct over the length of time care has been provided and that perceived stages were a function of characteristics of the caregiver, the health of the care recipient, and the duration of caregiving.

One of the most painful experiences for family members in dementia care, which generally increases over time, is watching the gradual deterioration and psychological loss of their loved ones (Dupuis, 1997). As the level of dementia increases over the caregiving career, family caregivers often experience confusion regarding whether their loved ones still exist for them as well as great emotional distress and turmoil related to that confusion. This phenomenon has come to be known as *ambiguous loss*.

The concept of ambiguous loss was introduced by Pauline Boss in the mid-1970s. It refers to a loss situation that remains incomplete, confusing, or uncertain for family members. Boss (1999) identified two types of ambiguous loss. In the first type, a person is perceived by their family members as physically absent, but remains psychologically present because it is unclear whether the person is dead or alive. This type of ambiguous loss can occur in families of men missing-in-action and families with missing children. In the second instance, a

person is perceived by family members as being physically present, but psychologically absent. This type is often associated with families who have a relative with Alzheimer Disease or another related dementia, brain injury, stroke, or other chronic illnesses. In dementia, the loved one is perceived to be physically alive, but gradually loses psychological presence in family members' lives as the level of cognitive impairment increases (Boss, Caron, & Horbal, 1988).

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

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

Although ambiguous loss has typically been conceptualised as a stable, single event or situation, Dupuis (2002) suggests that ambiguous loss can involve a number of phases that family members travel through as they deal with the gradual loss of their loved ones. By examining how the experience changed over time for family members in later stages of their institution-based caregiving careers and comparing those in early stages with those in mid and later stages, Dupuis found that the nature of ambiguity shifted and the experience changed as adult children journeyed through each phase. In dealing with ambiguous loss, family members go through at least three phases that involve: (1) anticipating the loss, (2) living through the progressive psychological loss, and (3) acknowledging the loss.

Although Dupuis' (2002) study focused on adult children caring for a person with dementia living in a long-term care facility, it provides some insight on how the nature of ambiguous loss changes over time as the level of dementia increases. In early phases of the caregiving career, family members may experience uncertainty regarding what the future holds and whether or not they will be able to cope with what lies ahead. As the level of cognitive impairment progresses, family members may then move into the phase of progressive loss. This phase of the process often begins in mid-phases of the caregiving career and involves living through and dealing with the gradual loss of loved ones. Progressive loss is characterised by the pain of watching the deterioration and disintegration of the parent and thus the experience in the role becomes more and more difficult throughout this phase. Caregivers watch their care receivers become more and more psychologically absent in their lives and they increasingly struggle with whether or not the parent still exists for them. At some point in the process and typically during later phases of the caregiving career, family caregivers may come to the realisation that their loved ones no longer exist for them and acknowledge the psychological loss of their parents. Some uncertainty related to the "thereness" of the parent may continue. However, at this later phase, family members may struggle most with ambiguity regarding their role in their loved ones' lives and confusion over the usefulness of their visits. Acknowledged loss can then lead to a loss of the parent or spouse in family events, the loss of a valued relationship, and for some, the loss of role identity. Nonetheless, much more longitudinal research is needed in order to better understand how the experience of caregiving changes over the disease process.

Relationship between the Caregiver and Care Receiver Prior to the Illness

The relationship between the primary caregiver and the person with dementia prior to the illness

also may influence caregiver burden (Duijnstee, 1994; McCarty, 1996). Several studies have found that caregivers who, in the past, have had a close and affectionate relationship with their care receiver that was characterised by mutual responsiveness to one another's needs report less burden and distress (Gilleard, Belford, Gilleard, Whittick, & Gledhill, 1984; Gold, Cohen et al., 1995) and are less depressed and less frequently engaged in potentially harmful behaviours (Williamson & Shaffer, 2001). The closer the relationship between the caregiver and the person with dementia, the less the strain is perceived to be (George & Gwyther, 1986; Harvath, 1994). However, a close relationship with the care receiver may also prevent the caregiver from coping because of an inability to remain removed from the situation (Duijnstee, 1994).

Family Expectations and Other Family Issues

Family relationships may also be a source of stress. Proclamations of the benefits of homecare seldom mention the great potential for intra-family tension. As Gwyther (1998) cautions, not all family dynamics are positive, and the designated caregiver can become stressed by expectations from other family members in addition to the person with dementia. Stress often arises from disagreement between primary and secondary caregivers over caregiver coping efficacy (Bourgeois, Beach, Schulz, & Burgio, 1996). Further, caregivers often face family conflict over caregiving decisions (Davis, 1997; Semple, 1992), disagreement between family members in their appraisal of the care receiver (Pruchno, Burant, & Peters, 1997), problematic communication patterns between family members and between caregiver and care recipient (Speice, Shields, & Bliezner, 1998), and boundary ambiguity as children take on tasks of caregiving that have been traditionally assigned to the role of parent (Boss, 1993).

PHYSICAL HEALTH CONSEQUENCES OF CAREGIVING

Although a majority of the research on caregiving examines the psychological and emotional impacts of caregiving, research also suggests that the caregiving role can have negative implications on the physical health of caregivers. Caregiving on a full-time basis can interfere with the caregiver's preventive health behaviours which, in turn, may impede a caregiver's ability to cope in the caregiving role. For example, Connell (1994) found that caregiving stress can interfere with proper nutrition, can lead to increased rates of smoking and make quitting more difficult, and may trigger excessive drinking in some caregivers. Caregiving, therefore, can have detrimental consequences on caregiver's physical health, often leading to disabling (e.g., arthritis, cardiac and back problems) and stress-related health problems (e.g., migraines, colitis) (Connell, 1994; Gallant & Connell, 1998; Graesel, 2002). Caregiving-related physical ailments include impaired immune system function (Canfield, 2002; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991), which in turn is associated with increased rates of respiratory illness, decreased response to influenza vaccinations, and slower wound healing; elevated blood pressure (King, Oka, & Young, 1994); altered plasma lipid levels (Vitaliano, Russo, & Niaura, 1995); poor self-care due to, for example, lack of exercise and/or lack of sleep (Fuller-Jonap, & Haley 1995); and relatively high use of psychotropic drugs (Schultz, O'Brien, Bookwala, & Fleissner, 1995). A study conducted by Vitaliano and associates (1996) found higher insulin levels in caregivers for persons with dementia as compared to caregivers of persons without dementia. Higher insulin and glucose levels are associated with increased coronary risk and coronary heart disease. Further, these ill effects may persist long after institutionalisation or the death of the person with dementia (Bass & Bowman, 1990; Winslow & Carter, 1999).

Sleep disruption is another common disorder amongst caregivers. Wilcox and King (1999) found that older women caregivers of adults with dementia reported more sleep complaints than similarly aged healthy adults, and over one-third (38%) used sleep medication. Sleep complaints include waking up in the night or early morning, bathroom needs, and sleep onset difficulties. Sixty per cent of those reporting sleep disturbances indicated that these disruptions occurred three or more times per week. Caregiver relationship and care receiver diagnosis appear to be unrelated to sleep complaints; however, lower levels of education, less internalised anger, care receiver disruptions, and psychological distress all contribute to poorer overall sleep quality. O'Rourke and Tuokko (2000) examined the predictors of physical health problems and found that "older adults with closer ties and less education

who care for female care-recipients with typical presentations of Alzheimer disease appear to have the most physical impairment" (p. 399).

CONSEQUENCES OF CAREGIVING ON OTHER LIFE DOMAINS

Impacts of Caregiving on the Family

Caring for the person with Alzheimer Disease or a related dementia can have a significant impact on the caregiver–care receiver relationship and often affects all members of the family as well as friends and neighbours of the care receiver (Gwyther, 1998; Fisher & Lieberman, 1994; Spruyette, Van Audenhove, Lammertyn, & Storms, 2002). Owens (2001), for example, found that dementia caregivers experienced lower levels of marital satisfaction at present and greater decreases in marital satisfaction since the onset of the care receiver's disease than did caregivers of persons with Parkinson's disease. The reduction in shared activities, the loss of emotional support from the person with dementia, and a decrease in the quality of verbal communication between caregivers and their spouses with dementia can have further significant consequences for the spousal relationship (Baikie, 2002).

The quality of the relationship between the caregiver and the person with dementia also appears to be affected by disturbances in behaviour and the caregiver's perceptions of these disturbances (Spruyette, Van Audenhove, Lammertyn, & Storms, 2002). A decrease in the quality of the relationship, especially low marital cohesion and satisfaction, can have significant negative consequences for caregivers' mental health (Owens, 2001; Rankin, Haut, & Keefover, 2001) and lead to increased risk of instutionalisation for the person with dementia (Spruyette, Van Audenhove, & Lammertyn, 2001). Research on these impacts suggests the need for interventions that focus on maintaining the quality of the caregiver–care receiver relationship across the caregiving career.

Strains are often put on other family relationships as well when they have different perceptions of the care receiver's illness or when difficulties arise in negotiating the care that is needed (Dupuis, 1997). Caring for a person with dementia gives rise to family conflict over a number of issues. These issues can include the following:

a. limits of family solidarity;

b. disapproval of other family members' actions or attitudes towards the care receiver; for example, other family members not paying adequate attention to the care receiver;

c. disagreements about the nature and seriousness of impairment and the appropriate care needed; and

d. the perception that less-involved family members fail to appreciate the extent of caregiving demands on primary caregivers or disapprove of the care being given (Aneshensel et al., 1995; Gwyther, 1995).

Conflicts involving family members' attitudes and actions toward the caregiver are associated with increased risk of depression among caregivers, while conflicts stemming from family members' attitudes and behaviours toward the care receiver are most likely to result in anger (Semple, 1992). Family conflict also is associated with caregiver burden and poor personal health (Shields, 1992; Strawbridge & Wallhagen, 1991).

The impacts of changes in the family and in reciprocal exchange in the caregiving situation may vary by relationship to the person with dementia. While spouses may justify caregiving burden in terms of role obligations, adult children often report competing loyalties to their spouse, children, and parents, and they may experience inescapable guilt and sense the caregiving responsibilities to be unfair (Gwyther, 1995). Smith, Smith, and Toseland (1991), in fact, found that sibling conflict is common among community-based family caregivers. One reason for this conflict and the sense of unfairness felt by adult children is the lack of opportunity to have a say in decisions about formal services (Gwyther, 1995). Closer kinship to the community-dwelling care receiver also may impose a greater burden on individual family members (Annerstedt, Elmstahl, Ingvad, & Samuelsson, 2000).

Research also suggests that although elder care may offer positive relationship building opportunities between adolescents and their grandparents, this process is also stressful for young adults, with potential negative impacts on their relationships with their elders and other family members. Caregiving circumstances may alter adolescents' peer relationships and result in interruptions of "normal"

family interaction, as well as frustration, anxiety, and internalisation of anger over the unpredictability of the caregiving situation (Beach, 1994).

Work and Financial Implications of Caregiving

Many caregivers, especially adult children, work outside the home in addition to their in-home caregiving responsibilities. Combining work and elder care responsibilities can have positive benefits as well as negative impacts on caregivers (Brody, Kleban, Johnsen, Hoffman, & Schoonover, 1987; Enright & Friss, 1987; Neal, Chapman, Ingersoll-Dayton, & Emlen, 1993; Scharlach, 1994; Scharlach, Lowe, & Schneider, 1991; Skaff & Pearlin, 1992). Work can be a place of respite or a haven from caregiving. It can provide opportunities to demonstrate personal competencies and to re-establish or maintain feelings of self-efficacy, and can serve as a source of social support for caregivers (Baruch & Barnett, 1986; Brody, 1985, 1990; Goldstein, Regnery, & Wellin, 1981; Poulshock & Deimling 1984; Scharlach, 1994; Scharlach et al., 1991; Skaff & Pearlin, 1992). Work outside the home and the caregiving situation provide caregivers with an opportunity for "normal social exchanges with friends and peers, interaction that is often in short supply in the lives of caregivers" (Aneshensel et al., 1995, p. 87). Paid employment also may be an important indicator of the caregiver's social evaluation because unlike their caregiving roles, caregivers get paid for their work roles (Aneshensel et al., 1995). In addition, the process of caregiving for a person with dementia may impose considerable financial strain on the caregiver and on the family, and the income gained from working outside of the home may help to alleviate this burden (Aneshensel et al., 1995). Employed, community-based caregivers also have shown significantly lower levels of stress than their non-employed counterparts (Giele, Mutschler, & Orodenker, 1987).

However, caregiving also has negative implications for the work roles of some caregivers, and dementia caregivers tend to experience greater negative work complications than other types of caregivers (Ory et al., 1999; Scharlach, 1989). Caregiving responsibilities may negatively affect the productivity of employed caregivers, who could miss out on career moves, and thereby experience negative economic consequences, or who may need to give up employment entirely to meet caregiving demands. Caregivers for persons with dementia may take time off from work more often than other employees (Starrels, Ingersoll-Dayton, Dowler, & Neal, 1997). One study of caregivers for younger persons with dementia (i.e., under 65 years of age) found that out of 61 working caregivers, 59% reduced their hours or stopped working after diagnosis and 89% experienced financial problems after diagnosis (Luscombe, Brodaty, & Freeth, 1998). Aneshensel et al. (1995) found that approximately 25% of caregivers of persons with dementia changed their work situation because of the care receiver's memory problems. Other caregivers reduced the hours they worked by moving from full-time to part-time work (12.7%), while others stopped working full-time (46.3%) or part-time (16.4%) altogether. Aneshensel et al. (1995) concluded, "in all, almost one in five caregivers reduced or eliminated their previous level of employment specifically to accommodate caregiving" (p. 88). Moore, Zhu, and Clipp (2001) estimated that, in 1998, caregivers were faced with an average of over $10,000 (US) in lost earnings as a consequence of their caregiving, which can present even further financial difficulties for caregivers and their families.

Working caregivers may also experience negative impacts on their work performance, and in fact, these impacts may be greater than the impacts on the family. Aneshensel et al. (1995) found that approximately one-third of working caregivers of persons with dementia experienced intense work-related problems. The two most common problems for working caregivers were insufficient energy and worry about the care receiver while at work. Both of these problems were reported by half of employed caregivers. Also, almost 80% of working caregivers reported at least one difficulty at work. Working also means additional labour for the caregiver, which can be taxing on both mind and body. This can then lead to a sense of feeling overloaded by constant responsibility and may also lead to competing demands among different roles. The impact of caregiving on employment, however, varies with caregiver gender. Women caregivers tend to take on new roles rather than replace or alter existing ones (Moen, Robison, & Fields, 1994), and thus are more likely than men to report difficulty combining work and family responsibilities (Anastas, Gibeau, & Larson, 1990; Neal et al., 1990).

The discrepancy between those who gain positive benefits from work and those who experience negative impacts and role overload leads

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

A closer review of the literature, however, reveals that the research that examines the relationship between multiple roles and the experience in the caregiving role have generally failed to consider the *quality* of the experience within various roles. It seems likely that caregivers who perceive the work role as stressful and/or unrewarding will not receive the same positive outcomes of involvement in work as others who perceive positive experiences in the employment role (Dupuis, 1997). Further, if caregivers perceive several roles (e.g., parent, wife, employment) to be unsatisfying and stressful, they reasonably might be more likely to experience the consequences of role overload, to experience more negative impacts in their caregiving, and to find the employment role not to be therapeutic in any way. Aneshensel et al. (1995) emphasise, therefore, that "employment is not inherently positive or negative for caregivers; instead, its impact depends upon the conditions encountered at work and how these conditions intersect with caregiving" (p. 87).

Impacts on Social Life and Role Captivity in Caregiving

Caregivers are often faced with the loss of friends, freedom, privacy, and leisure opportunities (Wimo et al., 1999). The combination of these factors increase the risk that caregivers will feel isolated in their situations, which in turn can lead to increased depression, relational deprivation, and poorer quality of the caregiving relationship (Beeson Horton-Deutsch, Farran, & Neundorfer, 2000). As dementia progresses, caregivers give up activities to provide more time for caregiving, and friends, family, and other associates may withdraw from these caregivers (Meshefedjian, McCusker, Bellavance, & Baumgarten, 1998). Caregivers often watch friends drift away and find it more difficult to socialise with or without the care receiver present. Lack of knowledge about the biophysical effects of Alzheimer Disease, and of the emotional, social, and economic impacts of caregiving, can contribute to the withdrawal by family and friends. Friends and family may not understand the caregiver's situation and experience, and may be frightened by the unpredictable behaviour of and other changes in the person with dementia, leading them to withdraw emotionally and physically from both the caregiver and care receiver (MacRae, 1999). In addition, due to time and task constraints of the caregiving situation, caregivers may perceive little opportunity for developing and maintaining new social relationships. Caregivers, therefore, face the limited availability of peers (Johnson & Troll, 1994) that, if available, could serve as an important social support resource for them.

Male caregivers may be at higher risk of isolation than female caregivers (Russell, 2001). Wives are often the main source of friendship and companionship, and the main link to the outer social world for their husbands. Thus, this social world can often shrink significantly for males when their wives have dementia and are no longer able to plan the social life for the couple (Harris, 1993). Also, men's social ties often come from work, but this potential source of social support may be absent when male caregivers are retired, as they typically are.

Isolation has many dimensions. Caregivers may initially deny symptoms of dementia, isolating the care receiver and themselves from others. When a caregiver acknowledges that a spouse has dementia, fear of the future progression of the disease may inhibit her or him from confiding in others (Wells & Kendig, 1997). Caregiver isolation is heightened by a lack of community resources and/or a lack of knowledge about these resources (Hooker, Monahan, Bowman, Frazier, & Shifren, 1998). In an ecological model of caregiver isolation, Tebb and Jivanjee (2000) identified a lack of early information

and support as leading to caregiver economic, social, and psychological isolation. At the individual level, biophysical isolators include the physical and cognitive decline of the care receiver and the caregiver's lack of understanding of the effects of the disease. "Lacking knowledge about the disease, the caregiver adapts, covers up, and makes excuses for the care receiver. Embarrassed or fearful, she may avoid contact with others, not realising that the disease is isolating them" (Tebb & Jivanjee, 2000, p. 58). Also at the individual level, a lack of economic resources, combined with fear of the future and the prospect of financial difficulties, leads to limited social participation and, consequently, caregiver isolation. Caregiver feelings of guilt, lack of hope, and disruption to future plans also contribute to a sense of isolation. At an environmental level, biophysical isolators include the physician's lack of knowledge of Alzheimer Disease and/or of caregiver needs. These factors can isolate caregivers from much needed support at the time of diagnosis (Tebb & Jivanjee, 2000).

Changes demanded by caregiving can reshape self-concepts and lead to constriction of normal activities and the loss or shrinkage of self, as caregivers give up occupations, social activities, plans, and hopes. They become engulfed in the caregiving role. Engulfment in the caregiver role and loss of self are associated with lower self-esteem and mastery and greater depressive symptomatology for some caregivers (Skaff & Pearlin, 1992). Women (Fitting et al., 1986; Horowitz, 1985a; Pagel & Becker, 1987; Skaff & Pearlin, 1992), spouses (Skaff & Pearlin, 1992), and younger caregivers (Skaff & Pearlin, 1992) are more likely than men, adult children, and older caregivers to report a loss of self. Adult children are at greater risk of *role captivity* (Aneshensel, Pearlin, & Schuler, 1993). Aneshensel et al. (1995) defined role captivity as:

> [t]he sense of being an involuntary incumbent of the caregiver role. This feeling of being trapped exists when a person feels compelled to be and to do one thing, while preferring something else. Role captivity refers less to the demanding responsibilities associated with care … and more to the fact that these responsibilities are experienced as obligatory (p. 80).

Alspaugh et al. (1999) found that the caregiver's subjective experience of role captivity predicted the chronicity of risk for depression. Other studies have shown that feelings of being trapped in the caregiving role and lack of choice and control in taking on this role contribute to negative caregiver health outcomes (Robinson-Whelen & Kiecolt-Glaser, 1997).

Impacts of Caregiving on Leisure Lifestyles[2]

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% likelihood that caregiving would limit family leisure time and an 81% 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

[2] This section is a modified version of the review from the paper entitled, "Bittersweet journeys: Meanings of leisure in the institution-based caregiving context" by Dupuis and Smale (2000) published in the *Journal of Leisure Research.*

leisure participation (Bedini & Guinan, 1996a; Dunn & Strain, 1998; Horowitz, 1985b; Pratt, Schmall, & Wright, 1987; Sneegas, 1988). Dunn and Strain (2001) found that providing assistance with activities of daily living (ADLs) and a lack of time due to work outside the home also were associated with reducing the number of caregiver's leisure by at least one activity. 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, higher levels of caregiver burden, and physical and emotional fatigue are common internal barriers to leisure involvement expressed by caregivers (Bedini & Guinan, 1996a; Dunn & Strain, 1998, 2001). The caregiver's own physical and mental health also has been identified as an important reason for a change in leisure behaviour (Dunn & Strain, 1998, 2001).

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 might 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 care of others, fearing that something might happen while they are away (Bedini & Guinan, 1996a; Weinblatt & Navon, 1995). These feelings of guilt and anxiety and the inability of some caregivers to leave their care receivers in the hands of others also can have significant implications beyond leisure time (e.g., attending medical appointments, running needed errands).

Women in particular 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 (Brattain Rogers, 1997; Pratt, Schmall, & Wright, 1987). 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; Hooyman & 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 *non*-participation 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 might 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 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, Reever, & 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. Concomitantly, 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. Much research supports the notion that participation in leisure activities and exercise can contribute to life satisfaction and psychological well-being (Evans & Haworth, 1991; McTeer & Curtis, 1990; Smale & Dupuis, 1993; Wankel & Berger, 1990), to physical well-being (King, Baumann, O'Sullivan, Wilcox, & Castro, 2002; Nieman, 1998; Paffenbarger, Hyde, & Dow, 1991), and to the development and maintenance of friendships and other 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 recharged 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 and thus experience less of an impact due to their caregiving roles. Brattain 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. They therefore 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 including her or him into their own pursuits or by adapting their leisure to the needs of the care receiver. 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 energising or recharging themselves for the caregiving responsibilities. This research, therefore, seems to suggest that depending on how leisure is viewed by the caregiver will influence whether or not caregivers will continue to access leisure as well as the degree to which leisure can serve as a coping resource for caregivers.

POSITIVE ASPECTS OF CAREGIVING

In contrast to an emphasis in much of the literature on caregiver burden, caregiving is also a potentially positive and growth-enhancing experience (Sherrell, Buckwalter, & Morhardt, 2001). In fact, recent studies have demonstrated that caregivers often have positive as well as negative experiences in their caregiving roles (Butcher, Holkup, & Buckwalter, 2001; Cohen, Gold, Shulman, & Zucchero, 1994; Farran, 1997; Farran et al., 1991; Farran, Miller, Kaufman, Donner, & Fogg, 1999; George & Gwyther, 1986; Hasselkus, 1988; Jivanjee, 1994; Kramer, 1997; Langner, 1995; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Motenko, 1989; Noonan, Tennstedt, & Rebelsky, 1996). This research also points to the strength, resilience, and resourcefulness of caregivers in the dementia context (Dupuis, 1997; Perry, 2002). Positive rewards or experiences in caregiving include: a sense of satisfaction, gratification, and pride in the caregiving role; increased sense of mastery, competence, and accomplishment; a sense of purpose or meaning in life; emotional uplifts experienced in caregiving; a sense of reciprocity of care; personal growth; and improved social relationships including increased quality of the relationship with the care receiver.

Caregiver Satisfaction, Gratification, and Pride

Caregivers report a sense of satisfaction in a job well done and a sense of gratification, confidence, and pride in being able to help in the care of their loved ones (Dupuis, 1997; Farran et al., 1996; Noonan et al., 1996). Kinney and Stephens (1989a) identified four types of caregiver uplifts:

1. *practical/logistical*, such as satisfaction in preparing meals for the care receiver, and in having an understanding family;

2. *cognitive*, such as satisfaction in witnessing the recognition of others by the care receiver, and in the care receiver showing interest in things;

3. *activities of daily living* (ADL) *uplifts*, such as satisfaction in assisting the care receiver with bathing and grooming; and

4. *care receiver behaviour*, such as the care receiver being responsive, showing affection, being co-operative, and smiling and winking.

These uplifts vary with caregiver age, intensity of involvement in the care process, and with the relationship to the care receiver. For example, younger caregivers who spend more time in caregiving activities report more behaviour uplifts. Women caregivers and those caring for persons with mild confusion tend to report more uplifts associated with care receiver's cognitive function. Caregivers

who report greater ADL uplifts are often caring for more physically disabled care receivers and spend more time per day giving care. Interestingly, Kinney and Stephens (1989a) also found that caregivers who are most intensely involved in caregiving activities also most often appraise caregiving events as satisfying. Perhaps more time invested in caregiving activities allows for more opportunities to experience uplifts. On the other hand, caregivers who are intensely involved in the caregiving process may feel that they have little choice but to make the best of things, and may make a greater effort to identify positive aspects of the caregiving experience (Kinney & Stephens, 1989a). Other researchers in the United Kingdom have found that caregivers' overall ratings of the degree of difficulty in their caregiving role, as well as the younger age of caregivers, predicted dissatisfaction with the caregiving role (Mafullul & Morriss, 2000).

Increased Mastery and Accomplishment

Caregivers report an increased sense of mastery in learning new skills. Caregivers may develop feelings of power, advocacy, and a feeling of accomplishment in the responsibility of caring for a loved one at home (Cohen, Pringle, & LeDuc, 2001; Horowitz, 1985a; O'Donnell, 2000; Sheehan & Donorfio, 1999).

Sense of Purpose and Meaning in Life

Caregiving is a process of making meaning for both the caregiver and care receiver. It can provide some caregivers with an important sense of purpose in life, and the caregiving context and role can serve as a meaningful component in support of self-identity for both caregivers and care receivers (MacRae, 1995; Noonan, Tennstedt, & Rebelsky, 1996; Rubinstein, 1989; Sheehan & Donorfio, 1999). MacRae (1995) also found that caregiving can be an important source of self-continuity in later life, particularly for women caregivers, because providing care is a meaningful role for some women that can last a lifetime.

Emotional Uplifts and Benefits Experienced

Through their role, caregivers may satisfy their own emotional needs to provide care (Horowitz, 1985b). Research has shown that caregivers value their care receiver's love and appreciation (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991). Caregiving may be an expression of emotional connection between caregiver and care receiver, allowing caregivers to express intimacy and love. Indeed, love, affection, reciprocity, and commitment are commonly reported motivating factors for providing care (Motenko, 1989). Caregivers and care receivers can develop bonds of friendship and enjoy each other's company (Noonan, Tennstedt, & Rebelsky, 1996). In particular, spousal caregivers who maintain continuity in their marital relationship (i.e., who continue to receive companionship, affection, and continuity from this relationship) have been found to experience greater gratification from caregiving (Motenko, 1989). It appears that caregivers receive greater satisfaction in their role if they act out of love or out of reciprocity, but less satisfaction if they act out of responsibility or duty (Motenko, 1989).

Sense of Reciprocity of Care

Many caregivers describe their caregiving experiences as an opportunity to repay their parents, spouses, or other care receivers for what they have given them all or most of their lives – an opportunity to give something back (Dupuis, 1997; Noonan et al., 1996; Sheehan & Donorfio, 1999). Some adults daughters, for example, describe caregiving as an opportunity to repay their mothers for all the sacrifices they had made in caring for them and their families, helping them with childcare, in times of sickness, and during other times of need (Sheehan & Donorfio, 1999). As one caregiver put it: "It is returning to a loving caring person what she gave me all my life" (Dupuis, 1997).

Personal Growth and Development

Caregiving can be an important "route to self-discovery" (MacRae, 1995) and an important means of personal growth and development (Acton & Wright, 2000; Noonan et al., 1996). Through their caregiving roles, caregivers have the opportunity to learn more about themselves and become aware of strengths they did not know they had by learning how to successfully cope in different situations (Noonan et al., 1996). They also have the opportunity to develop various aspects of themselves, such as learning how to be more patient and how to re-evaluate their priorities (Dupuis, 1997; Noonan et al., 1996). Spending more time

with their care receivers, caregivers also learn more about their care receivers. Through reading materials and other sources of information, caregivers also develop an increased understanding of aging and older adults in general, as well as characteristics of the specific disease that their care receiver has (Dupuis, 1997).

Improvements in Social Relationships

Despite the research on family conflict associated with caregiving, recent research suggests that the caregiving experience may lead to improved relationships between those involved in the caregiving process. Caregivers report improved relationships with their care receivers as well as improved relationships with others in the caregiving context. Indeed, some caregivers describe their relationships with their care receivers as much closer because of the caregiving situation (Noonan et al., 1996). Also, some families in the caregiving context tend toward greater cohesion in order to cope with the demands of caregiving. In Beach's (1997) study of adolescents in caregiving families, most respondents described the caregiving situation as having had a positive influence on family relationships. For example, caregiving in some families led to increased bonding between caregiving parents and their children. Mothers who were caring for their husbands with dementia gave credit to adolescents who helped out with caregiving tasks, and mother–child relationships improved in their level of mutual empathy, trust, and respect. Adolescents in this study felt a sense of accomplishment in taking on some caregiving responsibilities.

Relationships between siblings in caregiving families also may improve. Beach (1997) found that siblings who had moved away from the family home increased the frequency of their visits home as they became involved in the caregiving process. Adolescents still living at home benefited from these visits and formed a closer relationship to their siblings. Also, some adolescents were able to develop networks of empathetic friends who would respect the caregiving situation. Thus, family relationships or changes in these relationships are both outcomes of the caregiving process (i.e., improvements in family relationships due to caregiving) and potential mediators between caregiving and its negative consequences. Indeed, such changes in family relationships may serve as an important coping strategy and buffer some of the negative consequences associated with caregiving.

Factors Contributing to a Positive Caregiving Experience

Elements that appear to contribute to a positive caregiving experience are social support from friends and family, hope that the caring situation will change, and a feeling of being useful and needed (Tebb, 1994). Caregivers with larger social support networks are generally more satisfied with their support which, in turn, leads to a reduction in feelings of impaired health (Gold, Cohen, Shulman, Zucchero, Andres, & Etezadi, 1995).

SUMMARY OF CHAPTER

- In spite of the potential for caregiving as a positive experience, caregiving is most often described in terms of burden.
- Caregiver burden is both subjective (perceptions, emotional response) and objective (amount and type of caregiving, disruption of family life).
- Caregivers often report symptoms of depression, particularly in situations where the care receiver has high levels of depression.
- The caregiving role and the experience in that role for dementia caregivers differ significantly from other caregiving roles, with dementia caregivers reporting more caregiver burden than other caregivers.
- Although both male and female caregivers may suffer from burden and distress, female caregivers are at greater risk.
- In terms of the relationship of the caregiver to the care receiver, spouses are at greatest risk of negative consequences associated with caregiving, reporting the highest levels of both objective and subjective burden.
- Caregivers of different ethnic groups may experience the caregiving role differently, due in part to different perceptions of family and family obligation as well as to differences in

social supports and the personal coping capacities of the caregivers.

- The relationship between the care receiver's functional status and caregiver functioning is a complex one, however, caregiver's interpretations and appraisals of the impairment may be more important to caregiver functioning than objective impairment itself.

- Symptoms of caregiver stress are prevalent early in the caregiving career and caregiver burden often increases over time; however, perceived stage in the caregiving career may be more important to caregivers' experiences in the role than actual length of time providing care.

- As the level of dementia increases, many caregivers experience ambiguous loss; that is, they experience confusion regarding whether the care receiver still has psychological presence in their lives and also experience great emotional distress and turmoil related to that confusion.

- The caregiving role can have negative implications for the physical and mental health of caregivers, leading to disabling conditions, stress-related problems, and disruptions in sleep.

- Caregiving can have negative impacts on other life domains resulting in family strain and conflict, changes in employment status and negative impacts on work performance, and reductions in social life and personal leisure opportunities.

- Caregiving can also be a potentially positive and growth-enhancing experience.

- Positive rewards and experiences in caregiving include: a sense of satisfaction, gratification and pride; increased sense of mastery, competence, and accomplishment; a sense of purpose and meaning in life; emotional uplifts experienced in caregiving; a sense of reciprocity of care; personal growth and development; and improved social relationships and increased quality of the relationship with the care receiver.

CHAPTER FOUR
COPING WITH THE CAREGIVING ROLE IN THE DEMENTIA CONTEXT

In order to manage the pressures of caregiving, primary caregivers for persons with dementia rely on a range of supports and services. Caregivers need information about the diagnosis of dementia and about post-diagnosis assistance. They need to be recognised as important partners in the caregiving process. Caregivers also need help dealing and coping with some of the symptoms associated with dementia (e.g., challenging behaviours) as well as with referrals to social agencies and in mobilising their formal and informal support systems. Services such as emotional and medical support, peer support, respite services including day programmes, education, fiscal support, and legal advice, can all have significant positive impacts on the caregiver and her or his ability to cope in the caregiving role (Ham, 1999). Further, specific needs and patterns of service use vary with the progression of the disease and on the basis of caregiver characteristics, including culture and gender.

A number of good reviews of research on support services and interventions for community-based caregivers have been presented elsewhere (for example, Bourgeois, Beach, Schulz, & Burgio, 1996; Kennet, Burgio, & Schulz, 2000; Schulz et al., 2002; Toseland & Rossiter, 1989). These reviews as well as our own review of the literature suggest that, to date, no single caregiver intervention has been identified as a panacea for all of the stresses and complications of caregiving (Schulz, 2000). Various strategies have met with varying rates of success and failure. In this chapter, we will describe formal and informal caregiver support systems and resources, and discuss their use and effectiveness.

FORMAL INTERVENTIONS AND RESOURCES

Psychosocial Interventions

Support Groups

Support groups are "formal group programs which aim to ease the demands on those persons engaged in the family caregiving enterprise" (Kaye & Applegate, 1993, p. 168). This is the most common type of intervention for caregivers, consisting of small, time-limited, professionally led groups, many of which focus on both support and education (Perkinson, 1995). In these groups, peers provide emotional support and encouragement, as well as insight into successful strategies for dealing with various aspects of the caregiving role. Learning from peers provides a combination of empathy and insight into mutual problems, and encourages the exchange of effective strategies for coping with stresses entailed in the role transition to caregiver (Perkinson, 1995). Support groups are often conducted or sponsored by recognised organisations such as the Alzheimer Society. Hamlet and Read (1990) describe one support group in Canada which included 26 caregivers and focused on emotional support, developing social networks, educating caregivers about normal aging, and problem solving, and used a combination of speakers, films, and handouts. Benefits of support group attendance include opportunities to be with people who were having similar experiences and feelings, to receive emotional support from others, to resolve problems, to acquire information about community supports, and to learn effective caregiving skills (Kaye & Applegate, 1993).

Some of the research on caregiver support groups has examined the predictors of participation in this type of intervention, and they have included similarity to other group members, degree of caregiver burden, and perceived availability of family support (Goodman, 1991). Similarity with other members of the support group in terms of caregiving hassles, self-help, negative focus, and escape coping strategies seems to promote attendance (Gage & Kinney, 1995). With respect to the degree of caregiver burden as a predictor of support group attendance, caregivers who experience greater emotional distress directly attributable to caregiving attend more support group sessions (Karlin, Bell, Noah, Martichuski, & Knight, 1999). In addition, caregivers who have provided care for longer periods of time and who have lower life satisfaction attend more support group meetings and perceive them as helpful more often than other

caregivers (Burks, Lund, & Hill, 1991). However, there appears to be some inconsistency in recent studies with respect to the link between caregiver well-being and attendance at support group meetings. For example, Gage and Kinney (1995) found that the attenders and non-attenders in their study were similar in terms of global well-being (i.e., satisfaction with life, depressive symptoms, positive and negative affect). However, non-attenders in their study who were unable to attend due to logistic barriers had more daily hassles associated with caregiving and lower positive affect than those who simply chose not to attend. Perceived availability of family support also has been found to predict support group attendance, as caregivers with a secondary caregiver regularly involved in care attend more support group sessions (Monahan, Greene, & Coleman, 1992).

Among other predictors of support group attendance, Monahan, Greene, and Coleman (1992) found that age is positively associated with attendance in support groups with older caregivers attending more support groups than younger caregivers. In contrast, gender of the caregiver or of the care receiver does not appear to be significantly related to attendance (Monahan, Greene, & Coleman, 1992). Cultural differences and ethnicity also appear to be associated with support group participation. Monahan and colleagues (1992) found that Hispanic caregivers attended fewer meetings than Caucasian caregivers, but attended more often when groups were conducted in Spanish. Their findings clearly indicate the need for interventions specifically designed to respond to cultural preferences. Although caregivers whose care receiver dies or enters long-term care while they are involved in support groups may attend fewer meetings, other factors such as the care receiver's functional impairment, case management services, and living arrangements seem to exert an independent influence on support group attendance. Finally, the caregiver's relationship to the care receiver and her or his knowledge of support service availability may predict support group attendance and participation. For example, Thompson, Tudiver, and Manson (2000) found low rates of support group participation amongst sons who were caregivers, and attributed this pattern to a lack of information regarding community supports and services.

Although several studies have evaluated the effectiveness of support groups, this literature is somewhat limited and findings are often inconsistent. Nonetheless, some of the research that does exist suggests that time-limited psycho-educational support groups are useful in reducing negative feelings and burnout in caregivers (Zarit & Toseland, 1989), and may be a cost-effective deterrent to nursing home admission (Greene & Monahan, 1987). Toseland, Labrecque, Goebel, and Whitney (1992) found that support groups that combined education, problem-solving, stress reduction techniques, and support may be related to helping caregivers cope better in their roles. Caregivers who participated in support groups for two hours per week over an eight-week period had higher marital satisfaction, used more active behavioural strategies, had more knowledge of community resources, and had fewer pressing problems than those who did not receive the support group intervention.

However, while some studies to date have found that support groups do produce modest but positive effects on caregiver depression, other psychiatric symptomatology, and some other positive outcomes, other studies have suggested that support groups have little effect on caregiver burden. Although caregiver's knowledge about dementia may increase through support group attendance and participation, this type of intervention may have little impact on caregivers' physical or psychological health, and might in fact contribute to their burden (Demers, 1996). For example, Hébert, Leclerc, Baravo, Girouarde, and Lefrancois (1994a) assessed the efficacy of a support group programme for caregivers of persons with dementia in the community. Participants attended eight, weekly sessions of two hours each and were provided with information on the disease, were involved in role-playing on the management of behaviour problems, discussed the emotional impact of caregiving, and learned stress management techniques. Although they benefited from a significant increase in knowledge about the disease, there were no significant differences in the caregivers' physical and psychological health, and there was minimal impact on their morbidity and burden. Combination programmes including support groups, therefore, may not contribute to any change in the caregiver or may result in change only after a considerable period of time (i.e., at least eight months) (Dunkin & Anderson-Hanley, 1998). Indeed, the Canadian Survey of Health and Aging found that support groups received the lowest satisfaction rating by caregivers (CSHA, 1994a).

Although some caregivers may value the opportunities that support groups offer them to share their experiences with other families, to learn about community resources, and to accumulate tips on behaviour management, highly structured group interventions or individual and family treatments that individualise the intervention to the caregiver's needs may be more effective (Haley, 1997). Also, family educational programmes and support groups may not be well suited to those making and living with difficult late stage decisions because such groups are often attended by caregivers for persons with earlier stage Alzheimer Disease, and they may fail to address later-stage issues of multiple losses of ambulation, caregiver recognition, meaningful communication, and progression to a vegetative state (Bonnel, 1996).

Counselling

Conflicts within caregiving families reveal a need for nurses, physicians, and therapists to enhance and support family solidarity work with the family as a potential caregiving unit (Davis, 1997). At every stage of the dementia process, family caregivers need assistance in developing self-care strategies that reduce or manage caregiving stressors and enable family members to provide respite for one another. These are the goals of counselling services. Counselling also may include skill training and stress management techniques.

Several different types of counselling services exist. For example, caregivers may seek out *individual-focused treatment*, including psychiatrist sessions (Dunkin & Anderson-Hanley, 1998). One Canadian study found that individualised problem-solving nurse counselling was helpful for caregivers by decreasing psychological distress and improving psychosocial adjustment (Roberts et al., 1999). *Network therapy* also has been promoted as an intervention for caregivers (Cohen, Blumberger, Zucchero-Sarracini, Lets, & Marshall, 1998). This type of counselling intervention focuses on increasing the availability and adequacy of help to primary caregivers through their informal social network and on facilitating linkages with formal community services.

Family therapy identifies patterns of family interaction in order to implement family-based interventions. Assessment of these patterns can lead to identification of maladaptive family processes which "block the ability of the caregiver to receive support from family members and the ability of family members to offer relief to the caregiver" (Dunkin & Anderson-Hanley, 1998, p. 208). Family therapy identifies family dynamics, with the primary caregiver as the central figure. Family interactional changes that benefit the caregiver also benefit other family members, and "it is only through this mutual satisfaction that interactional changes can be maintained" (Dunkin & Anderson-Hanley, 1998, p 202). Family therapy is often provided by clinics, medical centres, and hospitals to deal with unresolved caregiver family issues. While there is some evidence of its effectiveness as an intervention (Mitrani & Czaja, 2000), the process of engaging more resistant families in therapy can be very challenging. This type of intervention may be more effective and acceptable if framed as educational in nature (Dunkin & Anderson-Hanley, 1998).

There is some evidence that various types of counselling services can assist caregivers in coping with caregiving, improving caregiver morale and knowledge about dementia, helping in planning and managing their daily lives (Brannstrom, Tibblin, & Lowenborg, 2000; Mittelman, 2000; Perkins & Poynton, 1990), and providing long-term positive effects (Whitlatch, Zarit, Goodwin, & von Eye, 1995). For example, Whitlatch and associates (1995) found that caregivers who received individual and family counselling were more likely to show reductions in caregiver stress than caregivers in support groups or on a waiting list. Counselling programmes may also aid caregivers in delaying or forestalling the institutionalisation of the care receiver (Ferris, Steinberg, Shulman, Kahn, & Reisberg, 1987; Whitlatch et al., 1995). In fact, research suggests that programmes of counselling and support can substantially increase the time spousal caregivers are able to care for dementia patients at home, especially during early to middle stages of dementia (Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996).

There is also research that has examined the efficacy of different *types* of counselling services (i.e., individual versus group, professional versus peer). Toseland, Rossiter, Peak, and Smith (1990), for example, examined the effects of individual versus group counselling on daughters and daughters-in-law caring for frail, elderly parents. Both counselling interventions focused on validation and confirmation of caregiving experiences, encouragement and praise for providing care, affirmation of the caregivers' ability to cope, and support and understanding for struggling with

difficult circumstances. Caregivers who received individual counselling showed greater reductions in burden and psychiatric symptoms than did those in the group counselling sessions. However, and not surprisingly, caregivers in the group counselling intervention showed improvements in social support received. Further, caregivers in both interventions reported improvements in their relationships with their care receivers in comparison to caregivers who received no intervention. In another study, Toseland and Smith (1990) looked at the efficacy of individualised counselling sessions conducted by professional counsellors versus peer counsellors. Both counselling interventions focused on problem solving, time management, and stress reduction techniques. Caregivers in both types of counselling showed improvements in psychiatric symptomatology and in their relationships with their care receivers. However, those who received professional counselling also showed significant improvements in their subjective well-being compared to those receiving individual counselling.

In contrast, other studies have questioned the efficacy of counselling for caregivers. Haley, Brown, and Levine (1987), for example, found that small group participation in counselling did not alleviate depression, nor contribute to life satisfaction, social support, or coping for caregivers. Given the differing opinions reflected in the empirical research, our understanding of the effectiveness of counselling and how it contributes to the caregiver experience is clearly still quite limited at present and in need of much further examination.

Knowledge, Education, and Skills Training

Educational interventions for caregivers can come in a number of different forms and focus on a number of different areas. They include: (a) information-sharing sessions with physicians or other experts on dementia on the nature of the illness and its symptoms, causes, and course; (b) sessions identifying resources available for support; (c) sessions which focus on effective management strategies for behaviour problems and agitation, communication skills, and on the creation of structure in daily routine; and (d) sessions on stress management (Teri, Logsdon, Uomoto, & McCurry, 1997). Educating caregivers about dementia can give them a sense of control over their situation and improve their coping abilities (McFarland & Sanders, 1999).

The research on educational interventions generally suggests that these types of programmes may have moderate success in delaying the institutionalisation of the care receiver and improving the psychological well-being of the caregiver (Kennet, Burgio, & Schulz, 2000). For example, Brodaty and associates (Brodaty, McGilchrist, Harris, & Peters, 1993; Brodaty & Peters, 1991) examined an education programme targeted at teaching problem-solving and coping skills, and increasing the caregiver's knowledge. Compared to caregivers receiving institutional respite and 6-month delayed caregiver training, caregivers who received an immediate educational intervention showed reductions in caregiver stress. The intervention also was effective in delaying the institutional placement of the care receivers for those who had received the training. Further, educational interventions have been found to be effective in providing caregivers with knowledge and skills to improve the eating and dressing abilities and to manage behavioural problems of persons with Alzheimer Disease and related dementias (Buckwalter et al., 1999; Chang, 1999). Psychoeducational interventions that teach caregivers how to manage challenging problems, in turn, may be effective in decreasing depression among caregivers (Buckwalter et al., 1999) and have positive impacts on the immune responses of dementia caregivers (Garand et al., 2002). Programmes that provide education and make environmental modifications to the physical and social nature of the home also have been associated with: (1) reduced need for assistance with instrumental activities of daily living by persons with dementia, (2) fewer declines in self-care by persons with dementia, (3) fewer problem behaviours demonstrated by persons with dementia, (4) reduced upset for caregivers, and (5) enhanced self-efficacy for female and minority caregivers (Gitlin, Corcoran, & Winter, 2001).

Courses in stress management can lead to a better awareness and understanding of stress and its management, and to a decrease in caregivers' ratings of the frequency of dementia-related problems, in caregiver burden related to dementia-related problems, and in overall caregiver burden (Mitchell, 2000). One study found that an intervention combining information about dementia diagnosis and prognosis, reinforcement of coping strategies, crisis prevention advice, and memory management programmes led to improvements in care receiver memory scores and to greater caregiver well-being

(Moniz-Cook, Agar, Gibson, Win, & Wang, 1998). Another study based on stress and coping theory that investigated a role-training intervention found that caregivers who received this type of intervention scored significantly better than those caregivers who did not on a number of outcome measures, including beliefs about caregiving, responses to behaviours, depression, and burden (Hepburn, Tornatore, Center, & Ostwald, 2001).

A number of studies have investigated the efficacy of programmes that focus on teaching caregivers communication skills to use with their care receivers. Ripich and Wykle (1997; cited in Kennet et al., 2000), for example, examined the effects of a communication skills training programme where both African American and Caucasian caregivers showed improvements in knowledge and satisfaction with their communications with their care receivers. Bourgeois and colleagues (1990, 1997) examined a programme that taught caregivers specific communication skills (e.g., use of a memory aid) to use with their care receivers. After the intervention, care receivers showed increases in "on topic" speech (i.e., intelligible and unambiguous statements related to the topic of discussion) (see Bourgeois et al., 1997) as well as decreases in repetitive verbalisations (see Bourgeois, 1990). Caregivers reported increased self-efficacy in their roles once programme staff no longer visited the home (Bourgeois et al., 1997).

Ostwald and colleagues (1999) conducted a three-year randomised trial on the effectiveness of an interdisciplinary psycho-educational family group intervention in decreasing caregiver perceptions of the frequency and severity of behavioural problems in persons with dementia and their reactions to those problems, and in decreasing caregiver burden and depression. Participants attended seven weekly, two-hour multimedia training sessions including education, family support, and skills training. The researchers found that this intervention was successful in reducing caregiver negative reactions to disruptive behaviours and in reducing caregiver burden over time. Their study seems to suggest that education alone may not be as effective as a combination of education and support programmes in reducing burden and enhancing caregiver well-being.

Some more recent studies has looked at the impact of a psycho-educational programme (i.e., Empathic Coping) designed to teach caregivers how to be more accepting and empathetic towards the person with dementia as a way to cope with caregiver stress and stress in the relationship (Kasl-Godley, 2002). Although the results varied by kin relationship and ethnicity, Kasl-Godley found that this type of intervention might increase acceptance among caregivers, improve instrumental and intra-psychic coping with stress in the relationship with the person with dementia, increase perceived competence with caregiving, increase stress coping abilities through social activities, and decrease psychological distress among some caregivers, particularly adult children. This type of intervention may therefore be important in helping to maintain the quality of the dyadic relationship over the caregiving career.

However, other studies have questioned the effectiveness of interventions that focus solely on education. For example, Coen and colleagues (1999) evaluated the impact of a Dementia Carer Education Program on caregiver quality of life, burden, and well-being for 32 caregivers aged 35 to 80 years. These caregivers participated in eight weekly, two-hour education and support sessions. In their results, the authors report that the only significant change over time was an increase in the caregivers' knowledge of dementia. There was no significant positive impact on quality of life, burden, or well-being. Further research is required to extensively evaluate the effectiveness of educational programmes.

Respite Interventions

Much of the literature on support services for families has focused on the provision of respite services. Respite interventions focus on the reduction of caregiver distress as well as the reduction of long-term care costs through the prevention or delay of placement in skilled care facilities. These types of services are designed to provide caregivers with relief from the caregiving situation for short or longer periods of time. In 1999, the Ontario Government recognised respite services as a key support for caregivers and thus earmarked a specific amount of each year's long-term care community service expansion budget to be used exclusively to expand adult day programme spaces and create new volunteer respite programmes for caregivers and their care receivers (Government of Ontario, 1999).

Gottlieb and Johnson (2000) identified three different types of respite interventions, and they include:

1. *Centre-based adult day programmes/services*, which include congregate care for a number of hours per week, depending on the needs of the caregiver and the programme characteristics;

2. *In-home or domiciliary respite*, which provide relief in the home by workers with qualifications and training suited to the person with dementia; and

3. *Institutional respite and vacation/emergency respite*, which includes round-the-clock substitute care, usually in a long-term care facility, for a short-term stay.

Centre-Based Adult Day Programmes/Services

Adult Day Services (ADS) refer to "a structured, comprehensive community-based program that provides a variety of health, social, and related support services in a protective setting during any part of the day but provides less than 24-hour care" (Beisecker, Wright, Chrisman, & Ashworth, 1996, p. 431). On average, clients usually attend ADS a couple times a week, with attendance more frequent in the United States than in Canada. For example, use of ADS in the United States is two to three days a week (Zarit, Gaugler, & Jarrott, 1999), whereas Canadian clients typically attend ADS 1.7 days per week in British Columbia (Gutman, Milstein, Killam, Lewis, & Hollander, 1993), one to two days per week in Toronto (Phillips, 1999), and 1.52 days per week in southwestern Ontario (Gottlieb, 1994).

There are two principal models or approaches to adult day programmes: (a) the *health model*, which includes nursing services; and (b) the *social model*, which provides custodial care, social interaction, and exercise, and which aid in the daily management of behavioural problems and depression within a protected environment (Dziegielewski & Ricks, 2000). Programmes based on the health model are utilised by patients who are in greater cognitive and functional decline, have more depressive symptoms, more medical illnesses, and more challenging behaviours (Dziegielewski & Ricks, 2000; Zarit et al., 1998). Patients who are Caucasian and who have a higher levels of formal education and household income are more likely to use adult day programmes based on the health model (Dziegielewski & Ricks, 2000). Also, caregivers of patients in medical day care generally have more caregiver burden and more paid help than other caregivers (Dziegielewski & Ricks, 2000).

Different respite services might be used quite differently by different types of caregivers. For example, some researchers have found that adult day services (ADS) in general may be used more frequently by those caregivers with lower levels of emotional stress and less strain in their relationship with the care receiver (Dziegielewski & Ricks, 2000). However, Zarit et al. (1998) found that caregivers living in the United States who used respite programmes reported greater feelings of worry, strain, overload, anger, and depression. They also found that there might be cultural differences in the use of adult day programmes. For example, African American caregivers, often due to issues of cost, appear to use these services less frequently (Zarit et al., 1998). Other researchers, however, have found that even though African American caregivers are less likely to use respite services in general compared to white caregivers, when they do choose to use respite they show a modest preference for adult day services rather than in-home respite (Deimling & Looman, 1993/1994). Similarly, adult children may be more likely to use adult day programmes than they are to use in-home services. This suggests that adult children may not be using respite services for "relief" from their caregiving role, but rather as an opportunity to continue in their jobs. In addition, evidence from studies conducted in both Canada and the United States consistently finds that women caregivers utilise respite services earlier in the care-giving career and more frequently than male caregivers (Evashwick, Rowe, Diehr, & Branch, 1984; Gottlieb & Johnson, 1995; Shapiro & Tate, 1985).

Some characteristics of the care receiver might also be associated with type of respite used. For example, care receivers with the fewest self-maintenance dependencies and those who are the least cognitively impaired may be more likely to use adult services (Deimling & Looman, 1993/1994). Lawton et al. (1989), however, found no relationship between cognitive symptoms in the care receiver and type of respite used. Much more research is needed in order to understand the relationships between caregiver characteristics, care receiver characteristics, and use of day care services.

Several studies have found adult day services (ADS) effective in caring for the person with dementia (Cox & Reifler, 1994), and have identified high levels of caregiver satisfaction with these

services (Gottlieb, 1994; Henry & Capitman, 1995). Benefits of using ADS include a reduction in family stress (Gori, Vespa, Magherini, & Ubezio, 1998); delayed institutionalisation (Palley, Hanley, & Watson, 1994); partial respite and a break in the caregiver's routine (Curran, 1995; Dziegelewski & Ricks, 2000); and decreased overload, worry and strain, depression, and anger (Gaugler, Zarit, Townsend, Stephens, & Greene, 2003; Zarit et al., 1998). The use of ADS can help to decrease burden, lower levels of caregiving-related stress, and improve psychological well-being (Cox, 1997). Adult day services restructure caregiving activities by reducing the amount of time caregivers spend dealing with behaviour problems, reducing the time care receivers spend alone, and by increasing the amount of time caregivers spend away from their relatives and the caregiving situation (Gaugler, et al., 2003; Jarrott, Zarit, Stephens, Townsend, & Greene, 2000). ADS also can provide caregivers with reassurance that their relative is safe during their absence. Gaugler et al. (2003), however, found that adult day programmes might be most effective for caregivers of persons with dementia when they are used consistently, starting early in the caregiving career and over longer periods of time.

Caregivers may perceive different benefits from ADS depending on their experience of overload. Caregivers with lower levels of depression and higher levels of overload are more likely to report benefits for their care receivers, such as a reduction in agitation, after utilising ADS (Jarrott, Zarit, Parris-Stephens, Townsend, & Greene, 1999). However, benefits for caregivers themselves tend to be inversely related to overload. That is, the higher the sense of overload in the caregiving situation, the less likely the caregiver is to report benefits from using ADS. To benefit from ADS, caregivers also must feel that their relatives are enjoying and benefiting from the programme or service. Nonetheless, caregivers with a heavy load of care-related tasks are more likely to perceive ADS as helping the care receiver and not the caregiver her or himself (Jarrott, Zarit, Parris-Stephens, Townsend, & Greene, 1999).

One American study has suggested that a more comprehensive case managed, adult day care system involving comprehensive health care teams and typically provided by private adult care centres in the United States has a more positive impact on the behavioural functioning of clients with dementia than less comprehensive approaches utilised by public centres in the United States (Palley, Hanley, & Watson, 1994). However, this proposal does not account for the fact that many caregivers may not be able to pay for private ADS.

More recent research has begun to challenge the effectiveness of ADS use. These studies suggest that preparing the care receiver for ADS may actually increase workload rather than decrease it for the caregiver. Problems of transportation and extra preparation work, therefore, may undermine the potential psychological benefits derived from ADS (Gottlieb & Johnson, 1995, 2000). Other research suggests that ADS use does not relieve time spent on activities of daily living (ADLs), nor does it give employed caregivers more free time to pursue other valued activities (Gottlieb & Johnson, 1995, 2000). Also, ADS may not provide significant relief for caregivers who need help with ADLs unless the programme provides services such as bathing and/or transportation (Jarrott et al., 2000). ADS alone, therefore, are unlikely to have a major impact on caregiver stress, and caregivers often need to rely on additional services (Curran, 1995; Palley et al., 1994).

Patterns of ADS use in the province of Ontario reflect these findings. In an extensive investigation of ADS centres in and around southwestern Ontario, Gottlieb and Johnson (1995) found that ADS significantly reduced caregiver stress and anxiety, but did not significantly improve caregiver quality of life. This lack of improvement in quality of life was attributed to the limited number of hours of respite, only 1.52 days per week on average. This limited amount of respite does not allow caregivers to do much more than catch up on necessary tasks. Also, many caregivers do not access formal services until they reach a crisis point and are no longer able to cope successfully in their caregiving roles. At this point, utilitsation of ADS is perceived as a stepping-stone to long-term care placement and a testing ground for institutional care. Few caregivers, therefore, use ADS at this point simply for respite (Gottlieb & Johnson, 1995, 2000).

Despite some of the potential benefits of adult day services, several barriers exist that can inhibit or limit the use of ADS by caregivers. Barriers to ADS use include: a lack of perceived benefits by caregivers; perceptions that ADS are unavailable; lack of information about ADS; inflexibility of services and hours when programmes are provided; problems specific to rural communities such as geographic isolation, transportation issues, and a

heavier reliance on relatives and friends for care; inadequate provision for particular groups such as those with early onset dementia and ethnic minorities; and perceptions that the composition of the programmes do not correspond to caregiver needs with respect to the level of disability of participants, cost, and/or transportation services available (Beisecker, Wright, Chrisman, & Ashworth, 1996; Cohen-Mansfield, Besansky, Watson, & Bernhard, 1994; Furness, Simpson, Chakrabarti, & Dennis, 2000; Gottlieb & Johnson, 2000; Hayslip, Ritter, Oltman, & McDonnell, 1980).

A frequent refrain in the popular media has suggested that long waiting lists and inconsistencies in the availability of adult day services from region to region might be contributing to accessibility barriers experienced by caregivers. However, there currently are no studies available that have examined waiting lists and regional access, so this debate remains largely speculative. According to *Ontario's Strategy for Alzheimer Disease and Related Dementias: Preparing for Our Future*, during 1999 and 2000, there were 57 ADS programmes in Ontario serving 10,000 clients with Alzheimer Disease, and another 85 ADS programmes serving 9,000 persons with Alzheimer Disease and the frail elderly (Government of Ontario, 1999). Caregivers have expressed a need for improvement to existing ADS services in Ontario, calling for more days in day programmes, overnight stays, weekend care, and evening care (Markel-Reid et al., 1998). Caregivers also reported that they would like more culturally appropriate care and improved staff continuity (Markel-Reid et al., 1998). Clearly, a closer examiniation of the provision of adult day services and programmes is needed to clarify these issues.

In-Home Respite Services

There is a range of in-home respite services available to caregivers of persons with dementia. In-home respite workers may provide companionship, help with personal care or housework, and/or provide recreation-focused programmes. Through friendly visitor programmes, care providers visit homebound seniors to provide companionship, stimulation, and emotional support. Matches for friendly visitors are based on shared interests, geographic arrangement, and degree of need (MacIntyre et al., 1999a, 1999b). Recreation-focused programmes aim to enhance the shared and independent recreation behaviours in the daily lives of persons with dementia and their caregivers (Bollin, Voelkl, & Lapidos, 1998; Voelkl, 1998). In-home respite workers may also provide services including homemaking and cleaning, personal care, in-home nursing, and home-delivered meals (Hawranik & Strain, 2001).

In Canada, out-of-home respite services (i.e., ADS, institutional respite) are used by fewer caregivers than are those services that provide help and health care in the home (Hux et al., 1998). This is a finding that is also supported by research from the United States (Zarit, Gaugler, & Jarrott, 1999). Lawton et al. (1989), for example, found that the most popular respite service used by caregivers of persons with Alzheimer Disease living in Philadelphia was in-home respite. Some caregivers view out-of-home respite as too costly and inflexible, and they do not perceive caring for someone with dementia as a long-term problem. However, in-home respite also can be expensive if used for long periods of time (Brody, Saperstein, & Lawton, 1989).

In-home respite might be preferred by caregivers because it is more flexible than other forms of respite in adjusting to the amount of service and specific times services may be needed by caregivers (Brody, Saperstein, & Lawton, 1989; Lawton, Brody, Saperstein, & Grimes, 1989). However, other studies have found that caregivers are concerned about a number of issues related to in-home respite, including a lack of weekend and evening respite, inconvenient timing of respite, lack of responsiveness to emergency situations, high staff turnover and frequent substitution of staff, intrusions into privacy, pressure for the caregiver to leave home during in-home respite, and worker task restrictions (Gottlieb & Johnson, 2000; Markel-Reid et al., 1998; Worcester & Hedrick, 1997). Also, caregivers may be reluctant to allow strangers into their home (Brody et al., 1989). In-home respite workers are often poorly paid, resulting in questions and concerns regarding their reliability and the quality of service that they provide (Brody et al., 1989). Other research, however, has found that in-home respite workers and volunteers are reliable, competent, and nurturant (Harris, 1991).

Few empirical studies have reported on the benefits of community-based services such as in-home respite, and those that have, report the benefits as being rather modest (Zarit, Gaugler, & Jarrott, 1999). At least two studies have found that the use of in-home respite contributes to relief of caregiver

stress and distress (Cohen, 2000; Marks, 1987/1988). Other research suggests that a combination of support services including in-home respite might be necessary for caregivers to experience significant benefits. For example, Mohide et al. (1990) found that a combination of caregiver-focused health care, education about dementia and caregiving, assistance with problem solving, regularly scheduled in-home respite, and a self-help family caregiver support group contributed to an improvement in caregiver quality of life, delays in institutionalisation, the caregiver role being experienced as less problematic, and greater satisfaction with nursing care. On the other hand, Whitlatch, Feinberg, and Sebesta (1997) found that caregivers who experience deterioration in physical health and burden and who use in-home respite on a short-term, sporadic basis might be especially vulnerable to the chronic stress of long-term, in-home care. Consequently, more frequent and regular use of in-home respite may be needed to buffer the effects of caring for a loved one over long periods of time in the home. In fact, Lundervold and Lewin (1987) found that short-term, in-home respite care did not lead to significant clinical changes in caregiver depression, stress, or burden. In their study, only caregiver perceived health showed signs of improvement. Similarly, Theis, Moss, and Pearson (1994) found that in-home respite for up to four hours per week combined with short-term institutional stays over a year was not sufficient to improve the caregiving situation (i.e., mood, quality of life and responses to caregiving) for caregivers.

A number of caregiver and care receiver characteristics appear to be associated with the use of in-home respite. With respect to caregiver characteristics, older caregivers, caregivers with the greatest health decline and activity restriction, and those with higher subjective caregiver burden are more likely to use in-home respite compared to other respite services (Deimling & Looman, 1993/1994; Lawton et al., 1989). Deimling and Looman (1993/1994) also found that spouses were more likely to utilise in-home respite; however, other researchers have reported contrary evidence which suggests no association between relationship to the care receiver and type of respite used (Lawton et al., 1989). Care receiver characteristics associated with the use of in-home respite include higher functional dependence and the demonstration of more inappropriate social and other behaviours (Deimling & Looman, 1993/1994; Lawton et al., 1989). Some researchers have found a relationship between cognitive impairment and the use of in-home respite (Deimling & Looman, 1993/1994), while others have found no such association (Lawton et al., 1989). Furthermore, in-home respite may not be an option for all caregivers. Chumbler and associates (2000) found that caregivers who are African American and who live in small rural communities removed from urban areas had an increased likelihood of being ineligible for in-home respite care. Clearly, much more research is needed before conclusions can be made about the extent of use and effectiveness of in-home respite services.

Institutional Respite and Vacation/Emergency Respite

Compared to other types of respite, institutional respite is typically used for longer, continuous periods of time, and is often used when caregivers need to be away for short periods of time (e.g., when caregivers need a holiday, become temporarily ill, or in emergency situations such as a death in the family). This type of respite is the least frequently used by caregivers (Lawton et al., 1989). Institutional respite care is used most often by caregivers who are older, who are experiencing greater burden, and who are caring for someone who is older and more cognitively and functionally impaired (Adler, Kuskowski, & Mortimer, 1995; Clark & Bond, 2000; Lawton et al., 1989). Caregivers without secondary caregivers are also more likely to seek out and use these services (Kosloski, Montgomery, & Youngbauer, 2001). In addition, those caregivers who provide greater amounts of care are slightly more likely to use respite in general and institutional respite in particular (Lawton et al., 1989).

Brody, Saperstein, and Lawton (1989) suggest that institutional respite offers several advantages over other forms of respite. Institutional respite is often less expensive than in-home respite for long, continuous periods of time. Furthermore, institutional respite provides an environment prepared to handle emergencies and behavioural problems. However, Brody, Saperstein, and Lawton (1989) report that caregivers may be very hesitant to use even short-term placement for fear it may lead to longer-term institutionalisation. Preparation for institutional respite might also be complicated in terms of paperwork, medical information to be collected from doctors, packing of clothing and

personal belongings, and explanation of arrangements to the care receiver. The limited number of days provided in institutional respite also may not always meet caregiver needs. Other problems associated with extended overnight respite include less flexible scheduling (e.g., depends on bed in suitable facility), irregular provision, and cumbersome regulations (Zarit, Gaugler, & Jarrott, 1999).

There have, however, been some benefits of institutional respite reported in the literature. Benefits to caregivers include improved mood (Curran, 1995); reduced physical, emotional, and mental distress and strain (Caradoc-Davies & Harvey, 1995; Harper et al., 1993; Knight, Lutsky, & Macofsky-Urban, 1993; Scharlach & Frenzel, 1986); improved physical health (Caradoc-Davies & Harvey, 1995; Larkin & Hopcroft, 1993), improved sleep (Larkin & Hopcroft, 1993), and delayed nursing home placement (Kosloski & Montgomery, 1995). Residential respite is potentially helpful if it is correctly and selectively prescribed after proper planning and discussion of other forms of respite, particularly in-home respite, domiciliary help, and permanent placement (Brodaty & Gresham, 1992).

However, the available evidence on the impact of institutional respite programmes is inconsistent. While this type of intervention may be effective in some areas such as delaying nursing home placement (Kosloski & Montgomery, 1995; Theis, Moss, & Pearson, 1994), it appears to have little long-term effect on caregiver burden or depression. Benefits of overnight or temporary institutional respite are transitory, providing temporary relief from burden and depression (Grasel, 1997), with levels of burden returning to baseline after the person with dementia returns home (Adler, Ott, Jelinski, Mortimer, & Christensen, 1993; Larkin & Hopcroft, 1993). Evidence also suggests that overnight respite may be harmful to patients, placing them in unfamiliar settings and disrupting usual routines (Zarit, Gaugler, & Jarrott, 1999). In-hospital respite, for example, has been associated with particular risk of patient decline, adverse events, and institutionalisation (Larkin & Hopcroft, 1993).

A Final Note on Respite Services

While respite services in general are the most desired intervention reported by caregivers (Clark & Rakowski, 1983), caregivers use respite too infrequently and too late in the caregiving trajectory for a reduction in personal health risks (Theis, Moss, & Pearson, 1994). Both formal and informal respites are underutilised (Worcester & Hedrick, 1997), most often due to care receiver refusal (Cohen-Mansfield, Besansky, Watson, & Bernhard, 1994). Caregivers may not ask family members for informal respite because they feel it is inappropriate, and for fear of imposing on friendships (Worcester & Hedrick, 1997). Barriers to formal respite use in general include transportation issues, negative caregiver perceptions of respite services, a lack of knowledge of available services, a lack of guidance and education for caregivers in responding to needs of persons with Alzheimer Disease and to their own need for respite, feelings of guilt over leaving a loved one and taking some time off, attitudes and perceptions that caregivers should provide all care themselves, concern about the quality of formal support services, lack of informal community linkages to facilitate entry, and a general lack of resources and complex eligibility requirements (Cohen-Mansfield et al., 1994; Kosloski & Montgomery, 1995; McCabe, Sand, Yeaworth, & Nieveen, 1995). Caregivers may also be concerned that potential helpers will not be aware of the complexities of care, feelings of imposing on helpers or feelings of being imposed upon by helpers, concern over the conservation of resources and energy, anxiety regarding preparation for respite, and concern about what might happen in their absence (Worcester & Hedrick, 1997). Scheduling inflexibility also appears to be a barrier for caregivers to both formal and informal respite (Worcester & Hedrick, 1997).

There is little evidence that formal respite care in general has significant long-term benefits for caregiver well-being, particularly in terms of burden, psychiatric status, or physical health (Lawton et al., 1989). There is also little evidence that formal respite programmes are beneficial for care receivers, particularly in terms of cognition, function, or physical health (Flint, 1995; Haley, 1997). There is some evidence that suggests respite may delay institutionalisation of care receivers (Lawton et al., 1989); however, one study failed to find even transitory improvements in caregiver functioning (Homer & Gilleard, 1994). Some caregivers use respite only in crisis situations (Dunkin & Anderson-Hanley, 1998). Furthermore, despite the positive influence formal respite care may have on family relationships, maintenance of employment, and ability to run errands, it does not allow time for less urgent pursuits such as leisure and socialising

(Berry, Zarit & Rabatin, 1991), even though they can serve as important coping mechanisms for many caregivers. Much more research is needed in order to understand why respite services are underutilised by caregivers, to identify factors that may affect the use and non-use of respite services, to develop a comprehensive understanding of the experiences of caregivers who use respite services, and to demonstrate the potential impacts of these services on both caregivers and care receivers.

Home Care Services

Home care generally includes an array of health care and supportive services which assist persons with disabilities or impairments to live at home, often with the goal of delaying, preventing, or substituting for institutionalisation (Health Canada, 1998). At the present time, no universally accepted definition or model of home care exists in Canada, and therefore, each province has developed its own model and approach to the provision of home care services (Health Canada, 1998; Parent & Anderson, 2001). Nevertheless, home care services typically encompass a multitude of services and can include the following:

- assessment of client needs (medical and social) and determination of the "best setting of care" based on a client's health and social situation;
- development of an in-home care plan, which includes family involvement, teaching, interventions, and community support systems;
- provision of nursing services, therapy services, and home support services (assistance with the activities of daily living);
- co-ordination of medical supplies, equipment, pharmaceuticals, and assistive devices;
- on-going monitoring and evaluation of the client, family, and caregiver's status and needs;
- respite care to assist informal caregivers and support families in their role as caregivers; and
- discharge planning and co-ordination of placement services to long-term care facilities, if required (Canadian Home Care Association, 2001, pp. 3-4).

In delivering comprehensive services to caregivers and their care receivers, home care programmes often work with other programmes and services within the community, such as Meals on Wheels, adult day programmes, respite care services and facilities, volunteer services, and transportation services (Canadian Home Care Association, 2001, p. 4).

Concerned with the "substantial differences in the range and adequacy of services that people can receive in their homes and communities, depending upon where they live in Canada" and the lack of a "minimum definition of comprehensiveness" in the delivery of home care services in this country, the Canadian Association for Community Care and the Canadian Home Care Association (2001, p. 2) argued for a minimum set of service standards in all provinces and territories. These organisations recommended that the following basic set of eleven core services be provided in each province and territory:

1. *Case management* – the assessment of needs, co-ordination of service and management of resources;
2. *Professional care* – the services of nurses, social workers, physiotherapists and other professionals, plus access to geriatric assessment and consulting pharmacists and physicians;
3. *Assistance with the activities of daily living* – often referred to as "personal care";
4. *Assistance with the instrumental activities of daily living* – often referred to as "homemaking" or "home support";
5. *Caregiver support* – respite and advice;
6. *Organised volunteer services* – Meals on Wheels, friendly visiting;
7. *Palliative care* – services to support dying at home;
8. *Necessary medical supplies and equipment*;
9. *Day programmes*;
10. *Self-managed care option*; and

11. *Access to subsidised prescription drugs* (Canadian Association for Community Care and Canadian Home Care Association, 2001, pp. 2-3).

Further, in a recent examination of the status of home care in Canada, it was found that a comprehensive home care system by design was very much needed in Canada, but currently not available (Parent & Anderson, 2001). The study, which was sponsored by Canada's Association for the Fifty-Plus (CARP) – a non-governmental organisation of over 400,000 Canadians over 50 years of age – provided a number of important recommendations including a call for the uniformity of home care in Canada and the need for family caregivers to be acknowledged and supported (Parent & Anderson, 2001). More specifically, *CARP's Report Card on Home Care in Canada, 2001* offered the following recommendations related to these areas of concern:

- A common national definition of home care must be established.

- National standards for reporting home care data are essential for developing nation-wide home care policies, planning, and research.

- Common assessment tools to support standardised reporting within and across the provinces and territories must be instituted in order to provide uniform services across the country.

- Home care programmes must be inclusive, meeting the health, social, and cultural needs of all Canadians, regardless of geographical location.

- A National Forum on Best Practices in Home Care should be held on an annual basis to share and promote innovative and effective service delivery.

- Families are the backbone of home care. Federal, provincial, territorial and local governments, as well as businesses and corporations, can acknowledge and support the contributions of family caregivers in a number of ways such as tax breaks, financial compensation, training, counselling, respite, and job security.

- Family caregivers must be involved in all decisions regarding home care policy and programme development.

- Volunteer organisations must receive sufficient financial and all other forms of support to enable them to play a key role in the delivery of home care (Parent & Anderson, 2001, pp. 42-43).

Consequently, a redirection of funding as well as additional funding are needed before a co-ordinated, uniform, national home care system that meets the needs of all Canadians can be developed and sustained (Parent & Anderson, 2001).

Studies on the predictors of home care use have generated inconsistent results. While some studies have identified cognitive impairment in the care recipient as predictive of home care use (Branch et al., 1988), other studies have found weak or no association between cognitive status and the use of home care (Coulton & Frost, 1982; Grabbe et al., 1995; Hawranik, 1998; Houde, 1998; Worrall, Briffett, & Moulton, 1994). Penning (1995), for example, found that persons with higher levels of impairment were less likely to use homemaking services than those with lower levels of impairment, and Dabelko and Balaswamy (2000) found that adult day service users had greater levels of cognitive impairment than home health care users. In addition, a study conducted by Crowell et al. (1996) found that elderly persons living in Newfoundland using home care services were more likely to have cognitive impairment than non-users. However, this result did not show up among users of home care services in Nova Scotia, despite a higher prevalence of cognitive impairment in that province (Crowell et al., 1996).

One recent study has identified functional status of the person with cognitive impairment as the most consistent characteristic associated with home care use (Hawranik & Strain, 2001). Deterioration in functional status accompanies certain cognitive changes, leading to decreased problem-solving ability and a need for assistance with activities of daily living (ADLs). Individuals who receive personal care are more often experiencing difficulties with incontinence and disruptive behaviour, are refusing to eat, and sleep excessively during the day (Hawranik & Strain, 2001; Soldo, 1985). However, gender of the caregiver does not appear to influence use of home care (Hawranik & Strain, 2001), and caregivers are more likely to use

home care if they live apart from their care recipients (i.e., in a separate residence) (Crowell et al., 1996; Tennstedt, Sullivan, McKinlay, & D'Agostino, 1990).

A recent study on elderly users and non-users of home care services in urban Nova Scotia and Newfoundland has provided further insight into factors that might affect the use or non-use of home care services. Crowell et al. (1996) found that home care users in these provinces tended to be older than non-users, female, and were more likely to be unmarried (i.e., widowed, never married, divorced, or separated) compared to non-users. Interestingly, dependence in instrumental activities of daily living (IADLs) was significantly related to home care use, however, dependence in activities of daily living (ADLs) – a common predictor of institutional placement – did not appear to be associated with the use of home care. Even though many of the subjects were dependent in the area of activities of daily living (i.e., personal care tasks), most of these older adults did not use home care services and most home care users were not ADL dependent. These findings question the utility or effectiveness of a model of home care that focuses on home care as a substitute for institutional long-term care because most of the subjects who were at greatest risk of institutionalisation were, in fact, not using home care services in these provinces (Crowell et al., 1996).

Home care has been found to be beneficial in terms of improving caregiver quality of life and there is some evidence suggesting that home care may delay institutionalisation (Mohide et al., 1990). However, other studies have indicated some limitations of home care. For example, preventive home visits by a nurse may have little impact on institutionalisation or the functional status of the care recipient (Dalby et al., 2000). Schwarz and Blixen (1997) compared caregivers receiving home health care and caregivers not receiving home health care, and found that, when services were provided by home health care agencies, caregiver strain and depression were not significantly improved. This result may reflect the limited amount of time that home health care workers spent with the caregivers and care receivers, and the fact that families receiving home care did not receive respite from providing ongoing care (Schwarz & Blixen, 1997).

Similar to patterns of respite use, caregivers view formal home care supports as a last resort, and are generally reluctant to use home care until the care receiver's health is so limited that it can no longer be handled by the informal support system alone (Chappell & Guse, 1989; Soldo & Manton, 1985; Stone, Cafferata, & Sangl, 1987). Barriers to home care use include a perception that caregiving is a familial responsibility, lack of available trained personnel, social embarrassment felt by caregivers, and lack of knowledge about services and how to access them (Hawranik, 1998).

Case Management

Although case management can have "multiple definitions depending on the profession, client group, context, and organisational structure" (Smith, 1998, p. 95), case management generally refers to "a service coordination mechanism designed to provide multiple services to individuals with complex needs" (Seltzer, Ivry, & Litchfield, 1987, p. 722). Case management has also been referred to as a "linkage mechanism" between informal and formal service systems. The *Provincial Case Management Standards, Guidelines and Indicators Project* (OCMA, OCSA, & MOHLTC, 2000) outlined the goals of case management as follows:

- to identify individuals at risk and in need of community resources;
- to provide timely access to: (a) information about community resources, and (b) the delivery of community services;
- to enable clients to direct their own care and make decisions to the degree possible;
- to facilitate the integration and co-ordination of services; and
- to promote the optimal allocation of finite resources (p. 3).

While tasks of caregiving may be taken up by caregiving families or by elderly persons themselves, increased severity of dementia may necessitate reliance on formal case management agencies (Seltzer et al., 1987). Case managers who are trained professionals and who have specialised knowledge of community resources are more able to link caregivers with community services, and can act as resources for education and training about effective caregiving strategies (Noelker & Bass, 1995).

Even though numerous definitions and approaches to case management exist, common core functions or activities associated with case management have been identified (Smith, 1998). The activities of case management include case finding, screening, establishment of eligibility, assessment, development of the care plan, co-ordination of services, supervision of direct care providers, and follow-up. The case management process also includes reassessment and evaluation, including possible revision of the care plan, and discharge (Arnsberger, 1997; OCMA, OCSA, & MOHLTC, 2000; Smith, 1998). Case management can maximise scarce resources to provide needed support services to clients and their caregivers over the duration of an illness or disability (Smith & Smith, 1997).

A number of different models or approaches to case management have been identified, most of which have similar approaches within each model. For example, Applebaum and Austin (1990) presented three classifications of case management models: the broker model, the service management model, and the managed care model. Robinson and Toff-Bergman (1989) examined case management models in the United States and Canada and developed a typology of four case management approaches: the expanded broker or generalist model, the rehabilitation model, the personal strengths model, and the full support model or assertive community treatment model (ACT). Desimone (1988) identified seven approaches or models of case management: the social model, the primary care model, the medical/social model, the health maintenance organisation model, the independent (private) services model, the insurance model, and the in-house case management model. Case management models also have been adapted by a number of agencies and organisations so that they better meet the needs of those settings.

Research comparing different approaches to case management suggests that different styles of case management may be associated with different outcomes. For example, Arnsberger (1997) outlined six styles of case management being employed by the Medicare Alzheimer's Disease Demonstration project sites in the United States and then used these models of care to examine differences in service use, healthcare utilisation, and caregiver outcomes:

1. *Routine Service Monitoring* includes routine assessment, care plan revision, ongoing contact with service providers, and monitoring of problems with service providers. This style is associated with increased use of nursing services, personal care services, companion use, homemaker chore services, home modification and medical supplies, less nursing home use, lower levels of caregiver burden, and more hours of informal caregiving.

2. *Caregiving Education and Training* includes the provision of disease information to the caregiver, caregiver training on behavioural management, and caregiver training to meet ADL and IADL needs. This style appears to be related to increased use of caregiver education and training groups, adult day care, and increased use of adaptive and assistive medical equipment.

3. *Crisis Intervention Model* includes crisis assessment, obtaining health services assistance, intervening therapeutically with clients, and referrals to adult protective services. Arnsberger (1997) relates this style to lower use of caregiver support groups, lower caregiver burden, and reduced levels of depression.

4. *Clinical Nursing/Caregiver Support Factor* includes registered nurse consultations, ongoing service adjustment, provision of general caregiver support, and assistance for the caregiver to get to support groups. This style has been related to increased use of support groups, nursing services, personal care services, mental health services, congregate meals and adult day care, and has been associated with reduced nursing home and emergency medical services use.

5. *Mental Health and Advocacy Activities* include access to funded social services and referral to support groups that are not part of the US demonstration project sites, and the use of public guardian services. Arnsberger (1997) associates this style with greater use of client and caregiver mental health services, Meals on Wheels, and legal and financial services.

6. *Focus on Client Safety and Placement* includes client mental health and medication monitoring, discharge planning, and placement assistance. This style is associated with the use of

> supportive housing and out-of-home respite, is inversely related to companion use and homemaker chore services use, and predicts higher levels of hospital and nursing care use.

Arnsberger (1997) promotes a case management approach which emphasises routine service monitoring and/or nursing and caregiver support, as both of these approaches lead to reduced use of nursing homes and hospitals, and are cost-effective (see also Arnsberger, Fox, & Zhang, 1999).

Other research supports the idea that the different styles of case management may be associated with different outcomes (Jerrell, 1995; Lafave et al., 1996; Rapp, 1995). For example, in a Canadian study of persons receiving an assertive community rehabilitation programme (modelled on assertive community treatment) or a hospital-based case management programme, Lafave et al. (1996) found that those receiving the assertive community rehabilitation programme spent much less time in hospital and scored higher on an indicator of quality of life related to their living situation. These clients also reported feeling more in control of their living environment.

Research on different models of case management suggests that case management may be most effective when it follows a "clinical" or nursing model, characterised by a therapeutic client–worker relationship, ongoing monitoring and assessment of psychosocial and practical service needs, and emotional support (Arnsberger, Fox, & Zhang, 1999; Chu, Edwards, Levin, & Thomson, 2000; Morrow-Howell, 1992). An approach to case management that is clinical, but also emphasises maintaining the client in a familiar environment, advocacy, and behavioural management has shown significant reductions in caregiver burden, slight improvements in depression scores, and improvements in behavioural problems (Arnsberger, Fox, & Zhang, 1999).

Recent studies have identified similar benefits associated with case management; however, our understanding of the impacts or potential benefits of case management is still quite limited. Our understanding of the outcomes associated with case management specific to the dementia context is even less developed. However, research does suggest that caregivers value case management for the provision of information and for the development of a special relationship with someone in the service system such as the case manager. Case management promotes the use of other community services and resources (Noelker & Bass, 1995) and may be effective in bringing about temporary reductions in caregiver stress and institutionalisation (Chu, Edwards, Levin, & Thomson, 2000). Chu and colleagues (2000) found that a comprehensive home care programme provided to persons with early stage Alzheimer Disease and their primary caregivers over a period of 18 months led to decreased caregiver burden and delayed institutionalisation for patients with mild to moderate impairment. The authors attribute the results to the case management service provided to persons in the treatment group, which featured supportive counselling, referral, skill training, and education.

However, other studies have identified problems with case management, including unreliability of providers of in-home care and overly bureaucratic procedures. Some caregivers have expressed a lack of understanding with respect to how benefits and the level of service delivery are determined, or how they had originally been identified to receive help. These caregivers had been excluded from the planning process of case management, but did not want to ask questions and risk the disruption of service provision (Malone Beach, Zarit, & Spore, 1992). Case management is most effective in meeting caregiver needs when caregivers make themselves accessible to their care receiver's case manager. It is more difficult for case managers to reach and assist caregivers who live apart from their care receiver or who have only infrequent or less intense contact with their care receiver (Malone Beach, Zarit, & Spore, 1992). As with other formal support services, much more research is needed before an assessment of the utility and impact of case management is completely understood.

Multi-Component Programmes

Integrated services aimed at factors that determine health and which offer a psychosocial and mental health focus together with a physical care approach, have been found to be more effective in addressing caregiver needs than are individual, fragmented, disease-oriented, focused approaches to care. Proactive community health services are equally or more effective and equally or less expensive than are focused, on-demand, piecemeal services (Browne et al., 1999). In a Canadian review of caregiving interventions, Cohen (2000) identified limitations to both respite and psychosocial interventions, and

suggested that the most effective interventions are comprehensive support programmes that combine a range of intervention strategies. Indeed, Acton and Kang (2001) suggest that multi-component programmes might be the only type of intervention to significantly reduce caregiver burden.

Several studies have illustrated the benefits for caregivers of combining psychological support, education about dementia, and support for the caregiver from other family members and formal service providers. For example, a number of studies have demonstrated that combinations of adult day programmes with other respite services are beneficial for caregivers, resulting in decreased subjective burden, increased caregiver morale, and a reduction in tension and family relationship strain (Deimling, 1991; Kosloski & Montgomery, 1993)

Similarly, combining education-focused and emotion-focused interventions (e.g., support groups) may be more effective than an emphasis on only one of these strategies. Gauthier (1999) argues that:

> Early efforts emphasised education and information, support groups and respite services as sources of support and relief for caregivers. Although both education- and emotion-focused interventions alone are more effective than no intervention at all in reducing caregiver stress, a combination of both appears to be most effective (p. 36).

Several examples of effective multi-component programmes exist in the literature. In Ontario, for example, Mohide and associates (1990) described a programme of family caregiver support consisting of caregiver-focused health care, education about dementia and caregiving, assistance with problem solving, regularly scheduled in-home respite, and a self-help family caregiver support group. Participation in this programme led to improvements in quality of life and a delay in institutionalisation. Caregivers experienced their roles as less problematic and reported greater satisfaction with nursing care.

Brodaty, Gresham, and Luscombe (1997) described a 10-day residential programme, including sessions with a variety of professionals to learn how to deal with stress, social isolation, and guilt. Participants were taught how to use community services, how to use new coping skills in dealing with dementia daily, how to begin planning for the future, and were provided with information about medical aspects of dementia. Telephone conferences also were arranged at regular intervals between the programme co-ordinator and cohorts of caregivers. The intervention resulted in a delay in the institutionalisation of dementia patients.

Hinchliffe and colleagues (1992) examined a multi-component intervention including training on the development of cognitive and behavioural skills to target behaviours in care receivers, respite, training in coping skills, psychological support, education on dementia, training in time management, and drug therapy for caregivers with depression. Caregivers receiving the intervention showed improvements in mental health compared to those on a waiting list for treatment.

Mittelman, Ferris, Shulman, Steinberg, and Levin (1996) described an intervention that combined individual and family counselling sessions, and focused on increasing support for spouse-caregivers from other family members. The intervention included education about behavioural problems and how to deal with them, as well as an emphasis on caregiver self-care. Programme participants attended weekly support groups and could request ad hoc consultation by telephone at any time. Continuous support for primary caregivers was provided for as long as was needed. This intervention strategy resulted in delays in the institutionalisation of dementia patients and a reduced prevalence of depression among spousal caregivers.

Finally, Donaldson and Burns (1999) reported on a dementia caregiver programme aimed to address isolation, lack of support, and coping difficulties. Caregiver interventions included group therapy, didactic education, management skills training, assertiveness training and principles of behaviour modification, extended family therapy, and training in techniques for managing specific problems. Interventions for patients included memory retraining, reminiscence therapy, environmental reality orientation, and general ward activities. Caregiver interventions resulted in less psychological morbidity for study subjects than caregivers on a waiting list or caregivers of patients assigned to memory retraining. Caregiver training also extended patient survival times until death.

These studies appear to suggest that no single programme is effective in meeting all the needs of caregivers and their care receivers. Instead, caregivers need a range of integrated services that address both the emotional and mental stresses of

caregiving and the hassles associated with the physical day-to-day tasks associated with the caregiving role. Kennet et al. (2000) summarised this view in this way:

> Multicomponent interventions that blanket caregivers with a diversity of services and supports in the hopes that a combination of components will impact on a caregiver's unique needs tend to generate larger effects than narrowly focused interventions (p. 63).

In addition, the combination of support services needed by the caregiver may change over the caregiving career, particularly as the level of dementia increases and the experience in the caregiving role changes.

Other Formal Interventions

A number of other interventions to support caregivers and care receivers with dementia also have been identified in the literature including family compensation programmes, pharmaco-therapy, behavioural interventions, communication, and memory clinics. However, these interventions have received much less attention by researchers than other support services.

Family Compensation Programmes

Indirect Payment Programmes. Financial compensation programmes for family caregivers can be either direct or indirect systems of payment. Indirect financial assistance typically includes some form of tax relief or credit (Pijl, 1994). The purpose of this type of programme is to compensate the caregiver for the costs of providing care (Keefe & Fancey, 1998).

The website for the Canada Customs and Revenue Agency (CCRA) provides information on non-refundable tax credits available to Canadian caregivers [http://www.ccra-adrc.gc.ca]. Caregivers who have sustained significant medical expenses for themselves or their dependents are eligible for the *Medical Expense Tax Credit*. This tax credit can help offset the cost of specific supports (e.g., attendant care, nursing home care, ambulance services) and medical devices (e.g., wheelchairs, braces, special eyeglasses). Individuals with "severe and prolonged mental or physical impairment" and their caregivers are eligible for the *Disability Tax Credit*. Eligibility is based on the effects of the disability rather than its presence, and it must be a severe and prolonged mental or physical impairment that markedly restricts ability to perform activities of daily living before a Disability Tax Credit is provided. The Disability Tax Credit provides relief for some of the hidden and indirect costs of disability, including special or additional transportation services (Torjman, 1998). The *Caregiver Tax Credit* is a non-refundable credit available to caregivers of dependent relatives, including in-laws. This credit helps caregivers of elderly parents, grandparents, and infirm dependent relatives.

As a form of compensation, tax relief costs little extra to administer and can be universally applied (Keefe & Fancey, 1997, 1998). However, Trojman (1998) points out that some caregivers and care receivers may not have access to technical aids and equipment through one of the existing programmes, and therefore, they must purchase these supports and services on their own. Further, most programmes require that the care receivers or the caregivers pay for supports and services up-front and then apply for the tax credit; however, some caregivers and care receivers may not be able to afford the up-front payments. These individuals must rely on the special needs provisions of the welfare programme and there is no guarantee of what expenses the programme will actually cover. Torjman (1998) writes, "if a province has exceeded its special needs budget before the end of the fiscal year, it may decide to stop paying for special assistance until the next fiscal year. Or the required item may not be included in the list of permissible costs" (p. 4). Assistance from welfare is most often considered a measure of last resort (Torjman, 1998).

Direct Payment Programmes or Client-Directed Services. Essentially, direct payment programmes or client-directed services provide financial resources to clients so they can purchase needed services on their own. The concept of client-directed services has evolved from the independent living movement. This movement has emphasised the empowerment of people with disabilities, through enhanced independence and increased autonomy (Eustis & Fisher, 1992; Sabatino & Litvak, 1992). By being able to purchase their own services, client-directed services allow consumers of community-based services greater control over the decisions related to their care needs. There are, however, important

assumptions underpinning this concept, including that individuals prefer to take a more active role in their care needs and that they are capable of doing so (Feinberg & Whitlach, 1998).

For some adults with disabilities, client-directed services have meant the ability to independently hire their own Personal Care Attendant (PCA). For many, this has been a crucial expression of their autonomy. It has allowed them greater flexibility with the worker hired, more hours of care, and greater satisfaction with the care received (Doty, Kasper & Litvak, 1996). While this model has been applied to other areas of care for older adults, no evidence of its application to dementia care was found in the literature. Nevertheless, Keigher (1999) has outlined a number of advantages of client-directed services for older adults, including the delay or reduction of institutionalisation, recognition of the contribution of family members, provision of older adults with greater control over services selected, and greater freedom to hire a worker of their choice. Moreover, the elimination of administration costs leads to a greater amount of money available to spend on services. Coupled with the generally lower wages received by independent workers, client-directed services can potentially lead to more hours of service for older adults.

Despite these advantages, older caregivers are more likely to use agency or community services (Eustis & Fisher, 1992). This is probably due to the fact that client-directed delivery confers greater responsibility on the caregiver. They must actively find and hire workers and therefore become a *de facto* employer with all the resulting responsibilities. Payrolls must be met, government deductions prepared, and most importantly, back-up workers found. It is also the responsibility of the caregiver or care receiver to train and supervise the worker (Eustis & Fisher, 1992; Keigher, 1999). The independent nature of the worker hired in a client-directed service system can also be cause for some concern. There is no mechanism in place to assure quality care or the safety of either the client or worker (Keigher, 1999). Furthermore, workers in this system receive lower wages and fewer benefits than agency employees (Doty, et al., 1996; Keigher, 1999).

While the literature includes examples where client-directed services have proven to be beneficial, most of these instances involve their use by younger adults with physical or intellectual disabilities and family caregivers of children with disabilities (Feinberg & Whitlach, 1998; Pedlar, Haworth, Hutchison, Taylor, & Dunn, 1999). Services that are effective for a younger population with physical or intellectual disabilities may not be as effective for older adults with dementia, and in reality, become a greater burden for caregivers of people with dementia. Persons with early onset dementia and their caregivers may prefer to decide on their own what services are most needed and then purchase those services themselves. Adaptation of client-directed services as policy would necessitate high levels of caregiver education and support in the beginning if these services were to be effective (Sabatino & Litvak, 1992). Nonetheless, with very little use of client-directed services in the dementia context, there is little evidence to date that has explored their impacts for persons with dementia and their caregivers.

Direct Financial Compensation for Caregivers. Research into the issue of financial compensation for caregivers is quite limited. The breadth and depth of financial compensation programmes, as well as the policy reasons for implementing and maintaining the programmes, vary not only between countries, but also within them (Evers & Pijl, 1994; Glendinning & McLaughlin, 1993; Keefe & Fancey, 1998). Many of these programmes are offered only when the government perceives them as a cost saving measure. Their *raison d'être* is not to compensate caregivers, but rather to maximise longevity of care and delay institutionalisation.

In Norway, the provision of wages to caregivers is part of the larger social welfare framework of the country (Lingsom, 1994). As well, it has been seen by the women's movement as a way to compensate female caregivers for the work they do and to close the wage gap between men and women. It has not been seen as a way to reduce costs.

In Sweden, payment to family caregivers was originally implemented to substitute for scarce public services (Glendinning & McLaughlin, 1993). Although family members are reimbursed at the same hourly rate as agency workers, public policy emphasis is placed on developing the necessary support services, rather than on payment. These programmes are administered by municipalities and vary from jurisdiction to jurisdiction. Overall involvement in these programmes has been dropping because caregivers prefer to remain in their own jobs and receive services.

In the United States, there is a confusing mix of programmes for caregivers and most appear to be motivated by a cost savings agenda. Payments are minimal and serve only low-income individuals (Keigher & Murphy, 1992). In the Michigan Adult Home Help programme, for example, the maximum payment of $333 (US) per month only amounts to half the minimum wage. Further, in some instances if payment is received, other support services are restricted or denied (Keigher & Stone, 1994).

In Canada, payment to caregivers has primarily been developed as a cost-saving measure. According to Styckman and Nahamiash (1994), the movement toward the development of payment for care has been rationalised, but also criticised from a number of different perspectives, including:

- a well deserved compensation,
- a means of putting control over services back in the hands of clients,
- a thinly disguised form of welfare,
- a job creation scheme,
- a policy to get women out of the workforce and back into the home in a period of high unemployment and backlash to feminism,
- a step towards privatisation (i.e., the public sector contracting out services to non-unionised workers at low costs with no benefits), and
- an effort on the part of the public sector to cope with scarce resources and still meet the needs of frail seniors.

The only programme to have undergone any analysis of its effects on caregivers in Canada is the Home Life Support programme in Nova Scotia. This programme financially compensates family caregivers of frail elderly. The elderly person, the caregiver, and the caregiver's household all must meet restrictive eligibility requirements. Keefe and Fancey (1994, 1997) examined both caregivers who received this monthly stipend and caregivers who received services. They determined that paid caregivers were more likely to be younger, female, to reside with the care receiver, and to reside in a rural area than were caregivers who received services. Caregivers who received payments also provided more assistance and averaged more hours of total care. Although these paid caregivers reported less financial worry than caregivers receiving services, they were more tired, anxious, and experienced higher levels of time dependence burden. Positive change in the caregiving dynamic occurred only for those caregivers who received services (Keefe & Fancey, 1994, 1997, 1998).

The effect of financial compensation programmes on caregivers and care receivers needs further investigation. The available research suggests that compensation programmes substitute for services and that caregivers may not benefit from compensation (Glendinning & McLaughlin, 1993). The exception to this may be rural caregivers, where direct financial compensation may allow for provision of services where the agencies are unavailable. However, payments do not appear to alleviate isolation, time constraints, or burden (Keefe & Fancey, 1998). The debate continues on whether or not it is necessary to compensate for lost time at work, lack of income, or expenses that come about as a result of caregiving. Further, it is unclear what is of the greatest benefit to caregivers related to compensation: services, payment, or a combination of both. Equally, the effect of any financial compensation programme on the care receiver has yet to be investigated in the dementia context and needs to be given consideration.

Pharmacotherapy

Pharmacotherapy refers to the direct treatment of illness or its manifestations (e.g., agitation, aggression) through cognition-enhancing medications (Dunkin & Anderson-Hanley, 1998; Hollister & Gruber, 1996). Most of the existing research on the effects of pharmacotherapy has focused on the impacts of medications on persons with dementia. Thus, very little research has examined the *outcomes* of pharmacotherapy on caregivers, although preliminary evidence suggests that some caregivers experience positive outcomes from the use of certain medications. For example, Fillit, Gutterman, and Brooks (2000) found that caregivers of care receivers who were taking donepezil (i.e., Aricept) reported lower scores on difficulty of caregiving (see also Gauthier, Panisset, Nalbantoglu, & Poirier, 1997). Further, a Canadian economic evaluation of propentofylline therapy versus standard care suggests that the use of propentofylline is associated with the reduction of both home care costs and direct

costs incurred by caregivers themselves (Bachynsky, McCracken, Lier, Alloul, & Jacobs, 2000).

Communication Interventions

Recent developments in interventions for caregivers include a move towards reaching caregivers through multiple channels of communication, including telephone, regular newsletters, and computer-mediated communication in the form of discussion groups and websites. Several websites for caregivers of persons with dementia have been developed to provide caregivers with information about dementia and caregiving, some even providing on-line chat lines for caregivers to share experiences and strategies for coping in the caregiving role. For example, the Dementia Advocacy Support Network (DASN) runs regular chat rooms for persons with dementia and their caregivers (the DASN chat rooms can be accessed through the Alzheimer Society of Canada website at www.alzheimer.ca).

Little research has examined the use and efficacy of communication interventions in improving the caregiving experience of caregivers. A study conducted in Ontario by Colantonio, Cohen, and Pon (2001) found significant interest among dementia caregivers in telephone support, especially among caregivers taking care of someone who did not require constant direct supervision and fewer hours of caregiving per week. Persons interested in newsletters were those with the most flexibility in terms of caregiving demands on time where direct supervision was not required, who scored higher in depressive symptomatology, and had care receivers who exhibited the greatest number of behavioural problems. Younger caregivers were most interested in computer support.

Strawn, Hester, and Brown (1998) examined the utility of a telephone intervention to provide support and assistance to 14 caregivers. Weekly telephone contacts were provided over a 12-week period to discuss caregiver's current experience of stress, anxiety, mood, and general health; to serve as a source of social support and caring human interaction; and to provide information regarding social service agencies. In comparison to before the intervention period, caregivers in this study experienced less general distress, hostility, and obsessive thoughts, and found caregiving somewhat less burdensome. They also showed significant reductions in overall stress and stress-related responses during the intervention. Nonetheless, much more research is needed to assess the outcomes related to communication strategies, to identify those communication interventions that are most effective, and to determine who is most likely to use these types of interventions.

Memory Clinics

Memory Clinics draw on insights from neuroscience to enhance the memory of persons with cognitive impairment. Much of this research examines changes in cognitive functioning throughout the dementia process and the impacts of various strategies on the cognitive functioning of persons with dementia. For example, in a recent study at the Memory Clinic Program at the Institut universitaire de gériatrie in Sherbrooke, individuals with a diagnosis of probable Alzheimer Disease underwent a series of assessments for calculation and numerical processing impairments, in order to further understand changes in the brain during the early stage of dementia.

Much less research has been conducted on the impacts of memory clinics on caregivers. Some of the research conducted thus far, however, suggests that participation in memory clinics may be beneficial for both caregivers and their care receivers. Logiudice and colleagues (1999), for instance, found that caregivers of persons with dementia in memory clinics reported improved psychosocial health-related quality of life. This was particularly due to the "package" of cognitive assessment, counselling, education, and discharge planning provided by the clinic. The clinics also provided caregivers with a forum for social interaction to help combat the effects of social isolation. However, preliminary research suggests that interventions provided by memory clinics may be more beneficial in the early stages of the dementia process, especially for those with mild dementia and their caregivers (Hill et al., 1995; Moniz-Cook & Woods, 1997).

General Patterns of Formal Support Service Use and Effectiveness

While research has investigated the use of and outcomes associated with *specific* formal support services and interventions, other research has examined the use and effectiveness of formal community support services *in general*. All of this research suggests that caregivers underutilise these

services, in spite of their promotion (e.g., Wenger, 1990) and availability (Montgomery & Borgatta, 1989). The Canadian Study of Health and Aging (1994a) found that, although caregivers were generally satisfied with the services they used, 44% of dementia caregivers used none of the nine types of services (e.g., homemaker, home nurse, physiotherapist, in-home personal care, Meals on Wheels, day centre, respite care, counselling services, support group) and only 18% of dementia caregivers surveyed utilised three or more services. In Ontario, 60% of caregivers used no formal services. The CSHA (1994a) also found that service use increased with level of disability and that adult child caregivers used more services than spousal caregivers.

Ten per cent of all caregivers who responded to the Canadian Study of Health and Aging reported needing additional services, with the greatest demand for day programmes and caregiver relief (CSHA, 1994a). Those using existing services were the most likely to request additional services, as were those who were caring for persons with more severe disabilities. Other studies have reported much higher percentages of caregivers requiring additional services. For example, in a study conducted by Toseland et al. (1999), a large percentage of study participants who were already at relatively high levels of service use (73%) indicated a need for at least one additional service, and many (72%) indicated that additional services would reduce the likelihood of institutionalisation of the care recipient.

Caregivers tend to use formal community support services only as a last resort. However, part of the problem with service use could be attributable to difficulties in accessing services. Several studies conducted in various countries around the world have identified a number of barriers to service access. In Australia, Bruce and Paterson (2000) found that patients were often referred late for community care, or were not referred when patients needed services, despite the fact that caregivers were having difficulties for considerable time periods. Lack of services when needed can lead to premature institutional placement. Caregivers also were seldom given adequate information about the diagnosis of dementia, how to deal with problem behaviours, and how to access support services before and after assessment. Similarly, in a study conducted in Ireland by O'Shea and O'Reilly (2000), patients were referred to community services late, leading to institutional placement. Dello Buono and colleagues (1999) identified barriers to medical and social services in Italy, including a lack of information and caregiver preference for a service with more specifically trained operators or more tailored interventions. Caregivers may also experience profound subjective barriers (e.g., denial, feelings of responsibility) to service utilisation, or to utilising sufficient services (Brody, 1990).

At this time, evidence of the effectiveness of formal interventions in general for dementia caregivers is promising, but still inconclusive. For example, Thompson and Briggs (2000) recently conducted a Cochrane database review of the caregiving literature and found little or no evidence that interventions to support caregivers of people with Alzheimer Disease are measurably beneficial. O'Rourke and Tuokko (2000) also found that the use of support services was not directly related to either affective or physical health outcomes among caregivers. Zarit and Teri (1992), however, suggest that the effects of some support services or interventions may be underestimated because of the methodological limitations of caregiver intervention studies. Nevertheless, more recent studies have identified some factors that may increase the effectiveness of support services or interventions. As stated earlier, caregiver services appear to be most effective when they are multi-faceted in nature and target a range of caregiver needs (Kennet et al., 2000). Also, caregiver services and supports are most supportive when they are tailored to the unique challenges of dementia caregivers, recognising that the experience can be very different for dementia caregivers compared with other caregivers (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999).

Thus, caregiver characteristics and the unique circumstances of caregivers need to be systematically assessed and considered in tailoring a "package" of supports to individual caregiver needs (Bourgeois et al., 1996). Services also must meet unmet needs. Single component interventions have greater positive impacts on caregivers when they are more intense; that is, when they are offered more frequently and are of greater duration (Kennet et al., 2000). Services and supports are more effective when they enhance family feelings of control and self-efficacy. Further, interventions that allow the caregiver to identify the problems to be addressed, the methods to be used to address them, and the timing and frequency of the interventions are more likely to achieve desired outcomes than inter-

ventions that are fixed in terms of what, how, and when they are delivered (Schulz, 2001).

Services are also most supportive when they address needs of caregivers and families as well as frail elderly people – that is, when they enable families to function as a caregiving unit (Davis, 1996; Jones & Peters, 1992; Kennet et al., 2000; Robinson, 1994). Interventions aimed at individual caregivers *and* their families can significantly relieve stress (Burns & Rabins, 2000; Knight, Lutzky, & Macofsky-Urban, 1993). Integrated family support programmes, in which patients and caregivers are both supported by one professional staff, are more effective in influencing the total number of behaviour problems and the degree of inactivity and non-social behaviour, than psychogeriatric day care alone (Droes, Breebaart, Ettema, van Tilburg, & Mellenbergh, 2000). Also, caregivers who perceive respite services as benefiting both themselves and their care receivers are more likely to continue using these services. Perceptions of mutual benefit can help to relieve caregiver guilt and, in turn, influence acceptance of respite. A perceived lack of mutual benefit is a determinant of caregiver refusal of respite and Adult Day Services (Beisecker et al., 1996; McGrath, Mueller, Brown, Teitelmen & Watts, 2000). Further, Pedlar and Biegel (1999) have associated trust in service providers as a key predictor of community service use.

Services are also most effective when they are available throughout the caregiving career and targeted to the specific needs of each stage in the disease process. There is a need for high-quality educational material throughout the caregiving career and for former caregivers to act as resources of knowledge about Alzheimer Disease and other illnesses causing dementia (Fortinsky & Hathaway, 1990). Caregiving is often a solitary journey, characterised by burden, responsibility, isolation, and commitment (Boland & Sims, 1996). Caregivers often must struggle alone through early stages of dementia, as community resources are primarily geared for middle and late stages (Kuhn, 1998).

Early in the caregiving career, families receiving news of a diagnosis of dementia need support and comfort, but particularly information about the disease, about the caregiving role, and about resources and support services that might be helpful to them (Davis, 1996; Kennet et al., 2000; Lindgren, 1993). "Once information needs have been met, the caregiver may additionally benefit from interventions that train the caregiver in general problem solving skills as well as more specific skills in areas such as managing patient behaviours or their own affect" (Kennet et al., 2000, p. 79) and developing good time management (Lindgren, 1993).

Later in the disease process, Lindgren (1993) suggests that caregivers may need help with an overwhelming sense of frustration and loss as they struggle with significant changes in their relationship with the care receiver. At this stage in the caregiving career, support groups may offer a sense of belonging and identity with others who have the same issues or problems, and counselling services may help caregivers deal with the emotional impacts of caregiving. Caregivers at this stage may also need help in accessing and receiving the supports they want, and in learning more effective interactive skills such as interpersonal problem-solving (Lindgren, 1993). Caregivers also may need information and assessment for burnout and education on effective coping strategies to help them adjust in their caregiving roles (Lindgren, 1993).

As the disease progresses and the intensity of caregiving increases, caregivers often need assistance with specific issues, such as ensuring adequate sleep at night (Pollak, Stokes, & Wagner, 1997). They also may need relief from the caregiving role through appropriate respite services. In much later stages of the disease, care-givers may need information on institutional care options, how to judge the quality of care in a facility, and how to address financial issues related to the move to a long-term care facility (Lindgren, 1993). Caregivers also might need support at the end their caregiving careers to deal with the emotional reactions and life changes they experience after the death of their care receiver (Eloniemi-Sulkava et al., 2002).

Czaja, Eisdorfer, and Schulz (2000) presented a summary of interventions and strategies that may be helpful to caregivers at different stages of the disease course. They emphasised, "when considering the effectiveness of an intervention strategy, it is important to take into account the changing nature of the disease" (p. 295). Their intervention suggestions at each stage of Alzheimer Disease are outlined in Table 1. In the Table, they list specific interventions for the person with dementia, the caregiver, the social environment (e.g., the family), and the physical environment, and highlight the importance of considering all aspects of the social and physical milieu of the person with dementia when assessing appropriate interventions.

Table 1

Summary of Potential Interventions and Strategies According to Stage of Alzheimer Disease
(adapted from Czaja, Eisdorfer, & Schulz, 2000)

Primary Target of Intervention	Stage of Disease/Diability				
	Pre-symptomatic	Early Stages	Middle to Late Stages	Institutionalisation	Death
Patient	• Patient education • Life planning (e.g., long term care insurance, • Drug therapies (e.g., AD)	• Education (e.g, coping strategies, using assistive devices) • Counselling • Drug therapies • In-home services • Support groups	• Education • Psychological therapies (e.g., counselling) • Drug therapies • Behavioural management • In-home respite services • Cognitive training • Respite care • Music therapy • Support groups	• Drug therapies • Cognitive training • Behaviour manage-ment • Psychological therapies (e.g., counselling, music therapy)	
Caregiver	• Education • Life planning	• Education • In-home respite services • Assistive devices • Support groups	• In-home services • Counselling • Support groups • Education • Technology	• Support services (e.g., transportation) • Education • Support groups • Counselling	• Drug therapies (e.g., depression) • Post-bereavement counselling
Social Environment	• Family education • Life planning • Professional caregiver training	• Family education • Professional caregiver training	• Family therapy • Professional caregiver training	• Family therapy • Professional caregiver training	• Family therapy
Physical Environment	• Environmental modifications	• Environmental modifications	• Environmental modifications	• Environmental modifications	

Service use, needs, and preferences may vary by gender and by relationship to the person with dementia. Although some research suggests that gender does not play a role in the use of community support services (Mockler, Riordan, & Murphy, 1998), other research suggests that female caregivers typically utilise formal supports less than male caregivers (Biegel et al., 1993; Hibbard, Neufeld, & Harrison, 1996). This finding has been attributed to several related factors, including men's greater economic resources (e.g., higher salaries) which allow them to purchase more services (Hibbard, Neufeld, & Harrison, 1996); a greater feeling of obligation by female caregivers to take on the responsibilities of care without outside assistance (Office of Technology Assessment, 1990); and a perception by female caregivers that formal services are not helpful and may indeed heighten caregiver stress (Zarit & Zarit, 1982). Further, Corcoran (1992) found that:

> despite their need for mental health services, elderly women experience considerable difficulty in accessing and using the mental health system ... caregiving wives are not only at risk for mental health problems, but are also unlikely to receive the intervention they need. For the same reasons, female caregivers are unlikely to access preventative support that may assist them in the emotional preparation needed for their role (p. 1009).

Research also suggests that male and female caregivers may respond differently to, and therefore, benefit differently from different types of community support services. Men, for example, might respond best to educational programming, such as a time-limited educational group, led jointly by a male caregiver and a nurse clinician (Harris, 1993), but many men refuse to attend such support groups. Men may also rely to a greater extent on clergy for social support, and might feel that formal in-home respite services are too expensive and too low in quality (Harris, 1993). Husband caregivers frequently regard in-home family help as the best, form of support, regardless of the level of need (Kasper, Shore, & Penninx, 2000). A study that focused on adult sons found that those who use community support services most often requested greater flexibility in support services to meet the needs of their parents and greater accessibility to information about services (Thompson, Tudiver, & Manson, 2000).

Studies linking gender and relationship to the care receiver to preferences for care options have been generally inconsistent. While one study found that younger caregivers in general are more likely to place persons with dementia in nursing homes (Mittleman et al., 1993), a more recent study found that nursing homes were preferred by older women and daughter caregivers as the best option for people with dementia and substantial care needs (Kasper et al., 2000). Other studies have found that spousal caregivers are more likely to utilise in-home services and that adult child caregivers are the greatest users of day care (Cotrell, 1996; Deimling & Looman, 1993/1994). For adult children with multiple responsibilities, weekend respite was identified as an important need in order to give caregivers opportunities to meet other demands. Globerman (1996) writes that interventions for primary family caregivers may not be appropriate for in-laws, who need a focus on relationship and marital issues. Deimling and Looman (1993/1994) found that respite use was predicted by fee subsidy and relationship strain.

Support programmes and services must also be culturally sensitive. However, in assessing the effectiveness of support services, instruments used for caregiver research may not be useful or appropriate for all cultural groups (Trockman et al., 1997). How the outcomes of interventions for caregivers are assessed, therefore, need special consideration. Cross-cultural variations in service utilisation (Kosloski, Montgomery, & Karner, 1999) also suggest that intervention strategies need to vary with cultural group (Chow, Ross, Fox, Cummings, & Lin, 2000). Cox (1999), for example, found that Caucasian caregivers were more interested in obtaining information on the illness or support groups, whereas African American caregivers were more interested in day programmes and home health care and more often reported needs for referrals, respite, and identification bracelets. Deimling and Looman (1993/1994) found that Black families used respite less than white families, and that attrition between assessment and use of services occurred especially for minority families. Ho, Weitzman, and Cui (2000) also found ethnicity to be an important factor in explaining unmet service needs.

Caregiver services also need to address issues pertaining to rural and urban populations, however, our understanding of the particular service needs and

effectiveness of interventions for rural caregivers is in very early stages of development and in need of much further research. Preliminary research suggests that the support services available to rural caregivers are particularly inadequate to meet their needs. Buckwalter (1996) writes, "in many rural areas, the service delivery system is impoverished and fragmented and has insufficient health, mental health, and social services to be supportive of the AD caregiver" (p. 122). Caregiving issues characterising rural communities include geographic isolation, travel time and costs, access to only very limited formal services, and lack of knowledge about formal services (Hayslip, Ritter, Oltman, & McDonnell, 1980). Further, Keefover et al. (1996) suggest that rural caregivers may face different and unique challenges compared to caregivers living in urban settings, and because of these different circumstances and experiences, they also may develop different attitudes and coping strategies which may allow them to delay or avoid institutionalisation. Evidence also suggests that rural caregivers rely extensively on family and friends for caregiving support, although they are no more likely to benefit from informal mutual support (Coward & Jackson, 1983). The reliance on informal support, in part, is likely related to the lack of formal services available to rural caregivers. Coward and Jackson (1983, p. 197) write, "rural health and human services are less abundant, less accessible, and more expensive per unit to deliver than in urban areas." At the same time, caregivers in some rural areas do not necessarily have any more informal support than caregivers in urban areas. Rural caregivers whose incomes fall below the poverty threshold are particularly prone to utilising only informal support until a crisis occurs (Scott & Roberto, 1985).

INFORMAL SUPPORTS FOR CAREGIVERS

Defining Informal Support

Caregivers not only receive support from formal services, but also from informal sources such as other family members, friends, and neighbours. The presence of informal support can be critical in helping caregivers cope in their roles. Research suggests that caregivers in North America generally rely primarily on family support and utilise few formal services (Mogey, 1988). In many situations, formal support is negligible, unavailable, or unused (Mogey, 1988; Stoller & Pugliesi, 1988; Stone et al., 1987). Even when services are available and encouraged, some families still avoid using formal sources of support (Montgomery & Borgatta, 1989). Nonetheless, even when formal support systems are used, kin system assistance does not decrease, and families continue to shoulder the burden of caregiving (Straw, O'Bryant, & Meddaugh, 1991). The reliance on informal support resources often reflects a strong sense of familial responsibility related to guilt, devotion, or affection, and a rejection of outside help (Hooyman & Lustbader, 1986). Spousal caregivers may see caregiving as part of the marital relationship and refuse to accept formal or informal assistance (Barusch, 1988). Significant reliance on informal social support in the caregiving context is also found in other countries and cultures (Heok & Li, 1997).

Informal support may be *instrumental* or *socioemotional*. Instrumental informal support is defined as "informal hands-on assistance with the patient [and] informal assistance with household chores and logistics" (Aneshensel et al., 1995, p. 153). Essentially, instrumental support refers to help with the physical tasks of providing care to a relative with dementia. Socioemotional support generally refers to the emotional support and encouragement that caregivers receive from others, and can include the availability of individuals to talk to who are understanding, caring, and trustworthy (Aneshensel et al., 1995). Caregivers typically receive less instrumental assistance than required, but generally feel cared for by family and friends (Aneshensel et al., 1995). Caregivers also tend to rely more on formal support and assistance over time, particularly as the caregiving role becomes more demanding. At the same time, they experience a decrease in access to and use of informal sources of support over time (Aneshensel et al., 1995).

Not surprisingly, family members, especially adult children, are most often identified as the primary sources of informal support by older caregivers (Bourgeois, Beach, Schulz, & Burgio, 1996; Stoller, Forster, & Duniho, 1992; Stone et al., 1987). However, the generation of the caregiver (e.g., spouse versus adult daughter) appears to be important in terms of the amount of informal support provided to caregivers. Aneshensel et al. (1995) report that, "spousal caregivers receive more help from family and friends than do adult-child caregivers. On the other hand, wives and husbands

report less socioemotional support … than daughters and sons" (p. 179). Siblings provide the greatest source of instrumental support, but also interpersonal stress for daughter caregivers (Suitor & Pillemer, 1996).

The nature of how families share caregiving responsibilities and support the primary caregiver can take many forms. Davis (1997), for example, identified several family caregiving styles (see also Keith, 1995). In *substitutive caregiving*, other family members perform limited caregiving activities, usually those that the primary caregiver is unable or unavailable to perform. Caregivers, however, are often reluctant to use substitute caregivers, believing that one family member must have the primary care responsibility or that no one else could or would provide the desired quality of care (Stommel, Given, Given, & Collins, 1995).

Complementary caregiving includes parallel caregiving activity by more than one caregiver, with different persons performing different caregiving tasks. This approach results in relatively low family conflict. Other family members perform tasks independently and generally have less involvement with the care receiver and the caregiver, who acts as a case manager or service broker (Davis, 1997).

In *conjoint caregiving*, other family members are expected to collaborate with the primary caregiver in performing caregiving tasks. This approach is often conflicted and entails considerable ambiguity and uncertainty in family caregiving roles. The family must function effectively as a problem-solving entity if this style of caregiving is to work. However, the ongoing stress of caregiving on the primary caregiver can lead caregivers to increase demands on other family members in the caregiving system (Davis, 1997).

Friends also play important support roles for caregivers. In fact, rural caregivers tend to rely extensively on friends and neighbours for support (Hayslip, Glamser, Oltman, & Ritter, 1980; Keefover et al., 1996; Scott & Roberto, 1985). Further, research suggests that friends provide the most prominent source of emotional support for married caregiving daughters during the first two years of caring for parents with dementia (Suitor & Pillemer, 1996). Friends and neighbours may also provide direct support to frail elders and become valuable sources of instrumental support for caregivers. Bamford et al. (1998), for example, found that friends and neighbours represented 8% of main supporters of frail older people.

Friends and neighbours, however, most often limit their support to being company or helping with shopping or transportation, and rarely provide intimate or physical care (Bamford et al., 1998). According to Bamford and associates (1998), they also frequently serve as back up to caregivers by helping with tasks such as heavy shopping, heavy housework, preparing and cooking hot meals, and gardening. Although not a substitute for formal services, help provided by friends and neighbours is preferable and considered of better quality by some older people. Also, emotional support in the form of encouragement, personal attention, and conversation can help re-enforce the caregiver's sense of identity and worth (Bamford et al., 1998).

Friends and neighbours are less likely to take on care responsibilities when they conflict with other roles, and as a consequence, they are less likely than family caregivers to report social costs from caregiving, experience less disruption to social activities and holiday arrangements, and are more likely to feel appreciated (Himes & Reidy, 2000). However, they are just as likely as spouses and other relatives to say they felt angry about the caregiving situation (Nocon & Pearson, 2000). Nocon and Pearson caution against the regulation or formalisation of these informal networks of support, as this would inevitably override the flexibility integral to these relationships.

Secondary caregivers, whether other family members, friends, or neighbours, can provide psychoemotional, instrumental, and financial assistance in addition to helping the primary caregiver with direct physical care (Franks & Stephens, 1992; Thompson et al., 1993). Secondary caregivers are especially important because of their intimate knowledge of both the caregiver and care receiver, and may provide new perspectives on the caregiving situation.

However, it is important to recognise that primary and secondary caregivers may have very different perceptions of the caregiving situation. For example, Robinson and Austin (1998) studied the perceptions of both wife caregivers and supportive others of the caregivers' health and social support. They found that supportive others rated the physical help received by wife caregivers to be significantly higher than did the caregivers. Non-depressed caregivers perceived themselves to be significantly healthier than their supportive others perceived them to be. Depressed caregivers reported larger social networks than did their supportive others. The

authors concluded that it is important to gain the perspectives of both primary and secondary caregivers in order to understand the totality of the caregiving situation, especially because primary caregivers may put on a false front of "everything's fine" (Collins et al., 1995). Primary caregivers also may not be fully aware of the impact of caregiving on their life and health, or depression may heighten how negative their self-reports are.

Predictors of Informal Support

Recent studies have examined a variety of factors that might influence or be related to the use of informal support. Most of these studies focus on the relationships between various caregiver and care receiver characteristics and the nature of informal social support. For example, Davis (1997) found that individuals caring for family members who present more behaviour problems were less likely to receive adequate levels of overall social support. These caregivers experienced stronger social support when the care receiver had been institutionalised. The authors suggest that members of their support networks might have felt less apprehension and more security when professionals were providing care. Cohen, Teresi, and Blum (1994) found that caregiver network dimensions were associated with the severity, but not duration, of the patient's illness. However, increased severity of illness was not related to increased network size, but did result in changes in the roles played by existing caregiving network members. That is, members in each network sector assumed new roles not customarily associated with them. With increased disease severity, caregiver informal networks provided more practical support to the caregiver in addition to advice, intimacy, and friendship.

A number of other factors such as race, gender, and age of the caregiver or care receiver can also influence the use of informal support. One recent study, for example, found that greater reliance on family by caregivers was associated with being 80 years of age or older, Black, and living with others (Kasper, Shore, & Penninx, 2000). Women with poorer functioning also were more likely to be cared for by family (Kasper, Shore, & Penninx, 2000). Hibbard, Neufeld, and Harrison (1996) compared the social networks (i.e., network composition and size) of men and women caregivers in Canada and found the social networks of women were larger and included more family members than men. Younger men and men of higher socioeconomic status reported significantly larger available social networks than other men. Women, however, had more sources of conflict, especially from family members. Older men and those of lower socioeconomic status reported fewer sources of support.

Although most research focuses separately either on the use of formal support or on informal support systems, a few studies have explored the relationship between caregiver use of both formal and informal support. Preliminary research suggests that elders of low socioeconomoic status are more likely to rely on a combination of formal and informal support (Scott & Roberto, 1985). Other research suggests that caregivers who are female and restricted in social activity and male caregivers who experience high levels of stress are more likely to receive supplementary formal support services (Noelker & Bass, 1989). The process of moving from informal to formal care is associated with care-related stress and with moving the person with dementia into an institution (Lyons, Zarit, & Townsend, 2000).

In general, much of the research on predictors of informal support use suggests that use, especially of instrumental informal support, is "driven more by the characteristics of the caregiver than by the circumstances of care" (Aneshensel et al., 1995, p. 179) such as the functional status of the care receiver. Consequently, those who are most in need of support because of more intense caregiving situations may not be receiving the support they require to cope effectively in their roles.

Benefits of Informal Support

Several studies have explored the benefits of informal support for caregivers and two general conclusions can be drawn from a review of this literature. First, caregivers' level of satisfaction with informal social support appears to be related to increased psychological well-being of caregivers. In other words, caregivers who are more satisfied with the support they receive are less depressed, have fewer negative psychological symptoms, have higher self-perceived physical health and psychological well-being, and report lower caregiver burden (Fiore et al., 1986; George & Gwyther, 1986; Stuckey & Smyth, 1997; Zarit et al., 1986). Second, conflict or stress experienced by caregivers as a result of interactions with support network members can have a detrimental impact on the psychological

well-being of caregivers. "Negative support" or "interpersonal stress" has been found to predict depression and burden in caregivers (Creasey et al., 1990; Fiore et al., 1986) and can also have a negative impact on marital satisfaction (Suitor & Pillemer, 1996).

Other research has looked at the outcomes of specific types of informal support. This research suggests that informal instrumental assistance tends to offset the effects of the stresses of caregiving roles. Caregivers who receive sufficient informal instrumental assistance in the tasks of caregiving, experience, on average, a decline in depression levels over time (Aneshensel et al., 1995). However, instrumental support does not appear to play a major role in the containment of care-related stressors or in delaying institutionalisation (Aneshensel et al., 1995). Aneshensel and her colleagues, however, emphasise that the average amount of informal support provided to caregivers may be inadequate to show positive outcomes such as the containment of care-related stressors. Gaugler and his associates (2000) found that caregivers of persons with dementia were much less likely to institutionalise their care receivers when family members provided overnight help and assisted with activities of daily living.

A number of studies, however, have commented on the benefits of informal socioemotional assistance. Caregivers who continue to receive companionship, affection, and continuity in their social relationships derive greater gratification and less stress from caregiving than those who experience discontinuity in social relationships (Motenko, 1989). Zanetti et al. (1996) identify visits of friends or relatives as a predictor of caregiver mood. Contact with friends serves a protective function against self-loss among spouses and unmarried adult children. Indeed, contact with friends may be more crucial to well-being in caregivers than contact with family (Norris, Stephens, & Kinney, 1990). Thompson and colleagues (1993) identify social support that engages the caregiver in social interaction for fun and recreation as most important in diminishing the burden of caregiving.

Research on informal social support in general suggests that these support networks can have an impact on a variety of caregiver and patient outcomes, including perceived stress, burden, depression, self-efficacy, and patient institution-alisation (Chang, Brecht, & Carter, 2001; Schulz & Williamson, 1991; Vaux & Harrison, 1985). The presence of individuals in the caregivers' social networks who share similar experiences is strongly associated with lower levels of depression, especially for persons in more meaningful caregiving situations (Pillemer & Suitor, 1996). Zanetti et al. (1996) note that informal support can be a buffer to caregiver distress and can be a resource protecting against stress, and that "the primary caregiver's ability to effectively cope with patient care is significantly associated with the presence of someone with whom the burden of caring can be shared" (p. 24). Another study reported that caregivers with larger social support networks were more satisfied with their support and experienced reduced feelings of impaired health (Pushkar Gold et al., 1995). However, levels of satisfaction with support may decrease as caregiving becomes more difficult (Pushkar Gold et al., 1995). Caregivers with weak social networks may be at risk of negative outcomes when faced with over-whelming caregiving responsibilities (Pagel, Erdly, & Becker, 1987), or when they perceive social support to be low (Baillie, Norbeck, & Barnes, 1988). In fact, for the subjects in the Zanetti et al. (1996) study, breakdown of family assistance was the strongest predictor of institutionalisation.

It is important to emphasise here that caregiver *perceptions* of support and the quality of that support are more important in predicting caregiver health outcomes than the objective number of resources or social ties available (Stuckey & Smyth, 1997). Caregiver perceptions of the adequacy of help from family and friends, quality of prior relationships, and the family's organisation and functioning are mediators of caregiver burden (Cohen, 2000; George & Gwyther, 1986; Price & Levy, 1990; Zarit, Reever, & Bach-Peterson, 1980). Neufeld and Harrison (1995) compared mothers caring for premature infants and women caring for older persons with cognitive impairment on the degree of reciprocity in relationships of friends and family as well as with care receivers. The authors found a negative relationship between perceived satisfaction with support and the women's depression and psychopathology. In other words, women in this study who perceived their relationships to be reciprocal expressed more satisfaction with their ability to care, higher self-esteem, and enhanced ability to ask for support. Atienza, Collins and King (2001) found that caregivers with greater perceived support were less

emotionally reactive to stress occurring in their natural environments because of, in part, a sustained or increased sense of control over the situation.

A Canadian study by Wuest and colleagues (2001) emphasises further the importance of caregiver perceptions of and satisfactions with both formal and informal support to caregiver burden. They distinguished between *connected* and *disconnected* support, based on caregiver perceptions of the helpfulness of support in meeting needs. Connected support is "interaction that [is] perceived by the caregiver to be helpful in addressing his or her needs", whereas disconnected support is "interaction that intensifie[s] caregiver alienation because it [is] not congruent with the caregiver's perceived needs" (Wuest et al., 2001, p. 118). For example, during the dawning stage when the caregiver is beginning to understand the nature of dementia, connected informal support may be given through confirmation of caregiver observations. Examples of disconnected informal support are the denial of dementia or the avoidance of the person with dementia by other family members. Connected professional support includes recognition of family-specific patterns of communication and respect for the primary caregiver. An important finding of this study was that satisfaction with social support is significantly related to psychological adjustment in spousal Alzheimer Disease caregivers, whereas frequency of contact was not. Caregivers need stable and continuous support, rather than simply a larger number of supports. The authors write, "availability of resources does not reflect the support that family caregivers receive. What is more important is the match between service and need" (Wuest et al., 2001, p. 127).

Caregivers' perceptions of satisfaction with informal support, however, may vary according to the type of social network to which they are connected. For example, Fudge, Neufeld, and Harrison (1997), in a qualitative study of 20 women caregivers of persons with dementia, identified three different types of social networks. *Diverse networks* were large in size and consisted of many different types of members including relatives, friends, professionals, support groups and social group members, church members, and colleagues. *Semi-diverse networks* were smaller in size and not as varied in the membership within the network in comparison to diverse networks. *Kin-focused networks* were the smallest type of support network and were dominated primarily by relatives and a small number of friends. Fudge and her colleagues (1997) found that those caregivers who belonged to diverse networks received the most frequent and broadest range of social support, reported high satisfaction with the support they received, and experienced very little or no conflict in the network. On the other hand, caregivers who described their social support network as kin-focused received fewer kinds of support on a less frequent basis, reported low satisfaction with the support they received, and experienced a high degree of conflict as a result of belonging to that type of network. Their research suggests that support from a number of different sources may be more beneficial to caregivers than relying predominantly on family and friends. Similarly, Majerovitz (2001) found that both formal and informal supports are important for the psychological well-being of dementia caregivers.

Limitations of Informal Support

Some research has identified the limits to the benefits of informal social support. Cohen, Teresi, and Blum (1994) note that social networks may have *indirect* effects on caregiver psychological distress, but that they appear to have little, if any, *direct* or *stress-buffering* effects. In contrast, borderline social network/coping variables such as religious attendance appear to have both direct and indirect effects on psychological distress. Stoller and Pugliesi (1991) explored the impact on social networks of older people's health and functional capacity and found that social networks respond to the diminishing health of the elderly person by maintaining their size and increasing their scope of assistance. However, declines in care receiver functioning can produce needs that exceed the capacity of informal networks.

Also, as mentioned earlier, not all relationships between caregivers and members of their social networks are positive and supportive. Relationships between primary and secondary caregivers can be quite stressful at times, and the negative effects of these relationships may outweigh any support provided by secondary caregivers (Pagel, Erdly, & Becker, 1987). Caregivers can experience conflict with informal support systems due to perceptions of lack of concern for them or the care receiver and disagreements about the nature of care being provided (Fudge et al., 1997).

The sources of conflict and resulting consequences of this conflict on caregivers appear to

be quite complicated. Bourgeois, Beach, Schulz, and Burgio (1996), for example, examined disagreement between primary and secondary caregivers about specific caregiving issues, as well as the antecedents and consequences of these disagreements. The authors found that primary caregivers with relatively pessimistic secondary caregivers experienced less psychosocial distress than primary caregivers with more optimistic helpers. The authors suggest several reasons for this. First, secondary caregivers who appear relatively pessimistic about the caring environment may also express more support for the primary caregiver. Primary caregivers may also become more determined in the face of secondary caregiver pessimism. Finally, caregivers may simply perceive themselves as doing better than the secondary caregiver perceives.

Furthermore, the mere presence of informal support does not guarantee relief for caregivers. In a study of Korean and Korean American caregivers, for example, a strong emphasis on the value of familism was identified (Youn, Jeong, Knight, & Benton, 1999). However, even though familism suggests the presence of informal support for the caregiver, it does not necessarily protect against caregiver stress. In fact, higher levels of burden, depression, and anxiety were reported for these populations. The authors concluded that, "familism that emphasises obligation over reciprocal affective ties does not protect against distress and may increase it" (p. 363).

PERSONAL COPING STRATEGIES

Stress and Coping in the Caregiving Context

Pearlin and Schooler (1978) describe coping as those responses to the external strains on life that can prevent, avoid, or control emotional distress. Coping manages stressful situations, stress symptoms, and the meaning of situations, and acts to prevent such situations. Although coping is a concept that has been subjected to multiple and inconsistent definition, the term usually refers to the ways in which caregivers negotiate and mitigate the pressures and strain of caregiving. Attention to coping is critical in understanding caregiver outcomes, as coping strategies may be more important than the condition of the person with dementia in understanding the effects of burden (Matsuda, 1995).

The stress model most often referred to in the stress-coping literature is based on the stress and coping theory of Lazarus and Folkman (Folkman, Lazarus, Pimley, & Novacek, 1987; Lazarus & Folkman, 1984). According to their model, relationships between stressors and caregiver distress are influenced by such factors as the caregiver's gender, age, health, and relationship to the patient; the demands on the caregiver including the care receiver's behaviour problems and functional disability; and the caregiver's appraisal of demands as stressful or satisfying. Coping in this model refers to cognitive and behavioural efforts to manage stressful encounters (Gonzalez, 1997). Outcomes of stressful situations vary primarily because of differences in appraisals and coping strategies. According to Lazarus and Folkman (1984), the individual appraises a situation or event as irrelevant, benign-positive, or stressful, and then mediates the situation or event by drawing on personal characteristics and/or resources, initiating coping activities, and mobilising social support systems. Caregiver characteristics and resources that mediate stressors include such factors as health and energy, material resources, and beliefs. Caregiver outcomes are related to the effectiveness or ineffectiveness of coping mediators, and can include somatic health, morale, and social functioning. Individuals facing a stressful situation use a combination of coping strategies to deal with various stressors.

The predominant model specific to caregiving and stress has been proposed by Pearlin and colleagues (1990). According to their *Alzheimer's Caregiver Stress Model,* the caregiving career is defined by caregiving tasks and relationships between caregivers and care receivers. Caregiving responsibilities are associated with a range of stress-related outcomes. Caregiver adjustment occurs at the interface between environmental and individual characteristics, including primary stressors (e.g., role overload or burden) and secondary stressors (e.g., loss of self in the caregiving role), coping strategies (e.g., problem-solving skills, management of meaning), and social support (Pearlin, Mullan, Semple, & Skaff, 1990). Stress levels increase when the caregiver has difficulty meeting the demands of caregiving or lacks the resources and coping strategies to deal with the specific stresses associated with the caregiving role. Stress and its outcomes are mediated by social support and by the coping strategies available to and utilised by both the

caregiver and care receiver (Aneshensel et al., 1995; Pearlin, Aneshensel, Mullan, & Whitlatch, 1996). Quite simply, in order to cope effectively in the caregiving role and adapt to the role, caregivers must be able to balance the demands and stresses associated with caregiving with the capabilities and resources available to them, including personal resources and coping behaviours (Patterson, 1988). The inability of the caregiver to balance those demands with the resources and thereby cope with the responsibilities of caregiving may jeopardise the health and well-being of not only the caregiver, but also the care receiver.

Types of Personal Coping Strategies

Coping is most often discussed in terms of *emotion-focused* and *problem-focused* strategies. Emotion-focused coping strategies refer to the steps taken to regulate the emotional distress produced by the person-environment relationship. Emotion-focused strategies include wishful thinking, avoidance, regression, and emotional discharge. Problem-focused coping refers taking direct action in order to change a threatening or damaging relationship between the person and environment. Problem-focused strategies include logical analysis of the situation and taking direct action to solve a problem or acquire additional resources (Kramer & Vitaliano, 1994). Problem-focused coping strategies may be adaptational if they are flexible, facilitate interpersonal communication, secure social support, secure relevant information, increase feelings of personal control, preserve social functioning, and help facilitate positive feelings (Lazarus & Folkman, 1984). Emotion-focused strategies are maladaptive if they contribute to passive withdrawal and avoidance behaviours, facilitate feelings of self-blame, reduce emotional ventilation, maintain excessive dependency, and contribute to negative feelings.

Although coping is most often categorised as either problem-focused or emotion-focused, other types of coping have also been identified in the literature. These other types include:

- *instrumental coping* – performing specific tasks (Zarit, Todd, & Zarit, 1986);
- *appraisal-focused coping* – identification of the cause of the problem, attending to one aspect of the problem at a time, drawing on relevant past experiences, and rehearsing responses to the situation (Moos & Billings, 1982);
- *relationship-focused coping* – maintaining and regulating social relationships (Kramer, 1993);
- *cognitive-focused coping* – reframing the situation in more positive terms (Haley et al., 1987) and acceptance of the situation (Kiyak & Borson, 1992).

Jivanjee (1994) encourages the use of cognitive coping strategies including, "staying calm, keeping a positive attitude, taking one day at a time, accepting the situation, treating caregiving as a job, positive comparisons, and the use of humor" (p. 43). Gwyther (1998) suggested that "Type A" behaviours including time pressure, perfectionism, or rigidity in care are detrimental to the caregiver. Instead, it is important that caregivers be able to adopt a "good enough for now" attitude towards problem solving (Gwyther, 1998, p. 19S).

The diversity of stressors encountered by caregivers requires a wide array of coping strategies and techniques (Barusch, 1988). However, the literature on specific coping techniques used by caregivers of persons with dementia is still a relatively new area of study, and consequently, our understanding of the coping strategies that are most effective in dealing with specific stresses in the dementia caregiving context is still in development. However, Williamson and Schulz (1993) have identified a number of specific coping strategies utilised by caregivers of persons with dementia including redefining the situation, direct action, expression of emotions to reduce tension, acceptance of the situation, relaxation, spiritual and religious support, distraction, seeking social support, wishing that the problem would go away, and control over emotions so that others would not know the extent of the situation. Other coping strategies identified in the literature include caregiver recognition of rights and responsibilities to seek help and to not become a second "patient" (Schiff & Kociol, 1989) and refusal to take the care receiver's behaviour personally (Gruetzner, 1988).

Benefits and Effectiveness of Coping Strategies

Some studies have identified the benefits of particular coping strategies for caregivers, especially in terms of maintaining or improving

mental health and overall well-being. This area of research suggests that the way in which the caregiver *appraises* the caregiving situation is related to the experience of caregiver burden. Caregivers who cope with the caregiving situation by defining it in negative terms are more likely to experience reduced well-being. In contrast, caregivers who define the caregiving situation in positive terms more often experience greater well-being and less distress (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Giganc & Gottlieb, 1996).

Furthermore, those caregivers who define the caregiving role in positive terms and those who are able to find meaning in their caregiving roles cope better in those roles than those who do not. Caregivers may define the caregiving situation positively by focusing on caregiving rewards (Noonan, Tennstedt, & Rebelsky, 1996), on personal gain and management of meaning (Pearlin, Mullan, Semple, & Skaff, 1990), and on finding meaning through caregiving (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991). Humans have the capacity to make choices in how they see or respond to difficult situations, and individual personal and philosophical values shape their response to caregiving. Humans have the capacity to find provisional (day-to-day) and ultimate meaning (greater meaning, power); consequently, finding provisional meaning in the immediate, observable effects of the daily caregiving situation is a better predictor of depression and global role strain than is the quest for ultimate meaning (Farran, Miller, Kaufman, & Davis, 1997). In other words, higher levels of provisional meaning are related to lower levels of depression and lower levels of role strain. Farran and associates (1997) suggest that finding provisional meaning, rather than ultimate meaning, may serve as an important coping strategy that has a more immediate and direct effect on caregiver distress. More specifically, "as a method of appraisal, finding provisional meaning may enable caregivers to cognitively appraise the pain and/or distress associated with caregiving and at the same time reappraise the experiences by seeking out experiences that assist in making sense out of and dealing positively with the experience" (Farran et al., 1997, p. 329).

A number of studies have examined the use of specific types of coping strategies and the relationship to caregiver well-being, and generated mixed results. Borden and Berlin (1990), for example, found no relationship between problem-focused coping and mental health of spouse caregivers, and Brashares and Catanzaro (1994) found that the greater use of problem solving coping strategies was related to more depressive symptoms among family caregivers of persons with Alzheimer Disease. Also, Winslow (1997) found no evidence that the combination of formal support and the management of meaning contributed to a change in caregiver anxiety or self-reported physical health. Further, Pot, Deeg, and van Dyck (2000) examined problem-focused and emotion-focused coping, neurotism, and emotional and instrumental support received, and found that none of these caregiver resources had a moderating affect on caregiver stress.

Other researchers, however, have found that the use of problem-focused coping strategies is related to fewer symptoms of depression (Haley et al., 1987; Vitaliano et al., 1987). This research suggests that "strategies geared toward actively addressing problematic situations are related to less psychological distress" (Williamson & Schulz, 1993, p. 748). Haley et al. (1987), for instance, found that appraisal, problem-focused coping, and social support were significant predictors of positive caregiver outcomes. Vitaliano et al. (1985, 1987, 1990, 1991) suggest that coping and other resource variables may interact with vulnerability variables (e.g., anger, health) to predict burden over time. Their research also gives attention to appraisal and resources, citing them as key factors as well. Therefore, the caregiver's appraisal of the situation as well as other caregiver characteristics might explain differences in the results.

Emotion-focused strategies are typically described as ineffective. Caregivers who utilise emotion-focused coping, especially younger women, report less positive affect, greater depression, more interpersonal conflict (Stephens, Norris, Kinney, Ritchie, & Grotz, 1988), and more emotional distress outcomes (Knight, Silverstein, McCallum, & Fox, 2000). Similarly, Dunkin and Anderson-Hanley (1998) found that caregiver behaviours in the category of expressed emotion (EE) are related to poor caregiver outcomes. They define expressed emotion as extreme over-involvement with the patient, critical attitudes, and hostile attitudes. Caregivers high in EE reported more stress, more impairment in mental health, less social support, less effective coping strategies, greater suppressed anger, greater depression, and greater caregiver burden than low-EE caregivers.

Rose and colleagues (1999) found that caregivers experiencing high levels of distress were more often using the emotion-focused coping strategy of wishfulness. Low distress caregivers were more likely to use acceptance and the problem-focused strategy of instrumental coping. Other researchers have found a relationship between emotion-focused coping strategies, such as the use of more emotional discharge (Haley et al., 1987), wishfulness (McCrae & Costa, 1986; Pruchno & Kleban, 1993; Pruchno & Resch, 1989; Vitaliano et al., 1985; Williamson & Schulz, 1993) and avoidance (Vitaliano et al., 1985), and higher levels of depression in caregivers. In fact, the research consistently finds that that the use of avoidance techniques is associated with a number of negative outcomes such as higher levels of burden, lower levels of overall life satisfaction, greater depression, negative affect, and the decreased ability to adapt in the caregiving role (Dupuis, 1997; Felton et al., 1984; Stephens et al., 1988; Wright et al., 1987). Stoicism (e.g., keeping feelings to oneself and avoiding letting others know how distressed you are) also appears to be related to more depressive symptoms in caregivers, especially when used to cope with the decline of a loved one (Williamson & Schulz, 1993).

Nevertheless, a number of other positive and more effective coping strategies have been identified in the literature. For example, research suggests that the ability to develop social resources is an important coping strategy for caregivers. Rapp, Shumaker, Schmidt, Naughton, and Anderson (1998) studied relationships between social resourcefulness, social support, and the well-being of caregivers. They define social resourcefulness as a class of overt and covert behaviours employed by a person to request, direct, and maintain helpful behaviour by another person. In their results, the researchers state that social resourcefulness is significantly related to social support and social network size. Social resourcefulness is also robustly related with indicators of caregiver well-being (i.e., better health status, higher quality of life, more perceived benefits from caregiving, less depressed). In sum, social resourcefulness leads to support, which in turn enhances well-being.

Religion and spiritual beliefs may also serve as important coping resources for caregivers, which may ultimately contribute to caregiver well-being. Religious families find their faith helpful in coping with caregiving (Kaye & Robinson, 1994). Church or community groups can often provide support similar to that offered in formal support groups. In addition, faith can provide family members with explanations of the unknown and offer a promise of hope for the future (Gwyther, 1998). Stolley, Buckwalter, and Koenig (1999) studied the use of prayer and religious coping among caregivers of persons with Alzheimer Disease. They concluded that perceived prayer and trusting in God, when used frequently, were effective coping mechanisms because internal religious activities helped caregivers get through the caregiving situation (Farran, Miller, Kaufman, & Davis, 1997; Kaye & Robinson, 1994). Nonetheless, some research suggests that aspects of spirituality, such as having a greater spiritual perspective, a realistic acceptance in one's relationship with God, and a greater awareness of God, might be linked to higher caregiver burden and increased caregiving hassles (Dyer, 2001). Clearly, much more research is needed on the role that religion and spirituality can play in coping with caregiving.

Mastery or the sense of a control a caregiver feels in the caregiving situation may also be important to the coping of caregivers in the dementia context. Drawing on the work of Pearlin and associates (Pearlin et al., 1981, 1990; Pearlin & Schooler, 1978), Aneshensel et al. (1995) defined mastery as a personal resource involving "the control individuals feel they are able to exercise over forces importantly affecting their lives" (p. 154). Based on the results of a large caregiving study in the United States, Aneshensel and her colleagues (1995) suggest that a sense of mastery may help "contain the proliferation of care-related stressors as time passes" (p. 177) and appears to be related to improvements in emotional well-being for caregivers of persons with Alzheimer Disease. Clair, Fitzpatrick, and la Gory (1995), for example, found that life events have the single greatest effect on caregiver depression, followed by mastery and degree of social support. Miller et al. (1995) compared African American and white spousal caregivers of persons with dementia, and found that caregivers with a greater sense of control experienced less depression, and that caregiver mastery moderated the effects of stressors and depression. They concluded that caregiver mastery was the only significant psychological resource predicting role strain, and that African American caregivers were less likely to report depression and role strain.

Coping may also involve emphasising positive aspects of the caregiving situation and relationship. Kinney and Stephens (1989a), for example, describe appraisal of events as "uplifts", which as a form of coping, emphasise the good feelings coming from being helpful, and downplaying the physical exhaustion. Conversely, negative appraisals of the care recipient can lead to increased negative caregiver outcomes (Almberg, Grafström, & Winblad, 1997; Reis, Gold, Gauthier, Andres & Markiewicz, 1994). In a Canadian study, O'Rourke and Wenaus (1998) found that *marital aggrandizement* – that is, idealising the marital relationship and spouse – was a mediator of burden among spouses of persons with suspected dementia. In other words, those caregivers who tended to have idealised perceptions of their spouse and marriage have lower levels of caregiver burden. The authors concluded that, "marital aggrandizement may function to reduce perceived strain. More precisely, marital aggrandizement may mediate appraisal such that stressors are deemed less severe. Idealised perceptions of one's spouse and marriage may thus reduce the degree to which neurodegenerative illness is perceived as taxing one's resources" (O'Rourke & Wenaus, 1998, p. 395). In addition, caregiver perceptions of family cohesion and of security in the relationship with the care receiver appear to be mediators for caregiving strain and stress (Crispi, Schiaffino, & Berman, 1997; Torossian & Rufins, 1999).

Whatever the coping strategy used, there is some evidence that those strategies that "fit" more closely with the stressor will be more effective. For example, relaxation may be more beneficial when employed as a means for coping with some of the practical aspects of caring for a person with dementia. However, relaxation may not be an effective technique in coping with the caregiver's own emotional responses to losing a loved one (Williamson & Schulz, 1993). Instead, seeking social support may be more beneficial in dealing with emotional distress, particularly when dealing with the decline of a loved one (Williamson & Schulz, 1993). Also, using direct action strategies such as thinking about solutions to the problem, gathering information about it, and doing something to try to solve it, in order to deal with memory deficits appears to be related to higher levels of depression (Williamson & Schulz, 1993). Williamson and Schulz suggest that continued problem-solving in situations where the stressor is not malleable can prove to be futile and exhausting for caregivers, leading to higher levels of depressive symptomology. They also found that relaxation might be a more effective strategy when coping with memory deficits in the care receiver. In situations where the stressor is not changeable, such as dealing with the loss of communication or the physical decline of a loved one, acceptance of the situation may be the most effective means of coping (Williamson & Schulz, 1993). Consistent with Carver et al. (1992), Williamson and Schulz (1993) state:

> …acceptance may be beneficial when nothing can be done to alleviate the stressful situation – for example, prior levels of communication with the patient that are lost and cannot be regained. Similarly, accepting that a loved one is gradually declining and that nothing can be done to change the situation may be highly adaptive, particularly in later stages of AD. Our results seem to confirm the idea that accepting an intractable situation may indicate not that the individual under stress is giving up but instead has chosen to make the best of the situation and move forward (p. 753).

Realistic appraisals of the situation and moves towards acceptance and growth, particularly in later stages of the dementia process, allow caregivers to better accommodate the needs of their care receivers as well as their own needs (Dupuis, 1997; Pruchno & Resch, 1989).

Differences in the Use of and Effectiveness of Coping Strategies

Our understanding of the differences in the use of and effectiveness of coping strategies by caregivers with different characteristics is quite limited. Nonetheless, the research that does exist suggests that coping strategies vary among persons of different genders, different relationships to the care receiver, and different ethnicities. For example, wives are more likely than husbands to perceive themselves as high in distress and they may be more sensitive to negative aspects of caregiving (Folkman & Lazarus, 1980). Wives tend to acknowledge being dissatisfied with themselves and are more likely than husbands to suppress their own needs and desires. Wives are also more likely than husbands to use

wishfulness coping, which is associated with negative mental health outcomes (Folkman & Lazarus, 1980). Women do, however, tend to use a wider range of coping strategies than men, although they do not differ from men in terms of their frequency of use of most strategies or the perceived helpfulness of various coping strategies (Barusch & Spaid, 1989; deVries, Hamilton, Lovett, Gallagher-Thompson, 1997).

Active cognitive strategies that women appear to use more frequently than men include those that focus on perspective-taking and self-affirmation such as praying for guidance and strength, going over the situation in one's mind, telling oneself things to feel better, and making a promise to oneself that things would be better next time (deVries et al., 1997). Active behavioural strategies used more frequently by women focus on seeking out social and recreational support and include talking with a friend, getting busy with other things to keep mind off the problem, and getting away from things for a while (deVries et al., 1997). In the deVries et al. study, both men and women rated getting away from things for a while as the most helpful coping strategy that they employed.

Differences in coping strategies also have been found between adult daughters and wives. Daughters are more likely than wives to blame others and to blame themselves (Wilcox, O'Sullivan, & King, 2001). At the same time, daughters are more likely to use problem-focused coping than wives (Wilcox, O'Sullivan, & King, 2001). The three most common coping strategies used by both groups of caregivers are counting one's blessings, problem-focused coping, and seeking social support. Wilcox and her colleagues, however, also noted different patterns between adult daughters and wives in the relationships between coping strategies and caregiver outcomes. Generally, the relationships between use of coping strategies and psychological distress were more consistent and stronger for wives in comparison to adult daughters. Avoidance of the situation, blaming others, and wishful thinking were related to higher levels of caregiver burden, stress, and depression among wives, but not for daughters. Also, wives who avoided the situation and blamed others were more likely to both internalise their anger and/or express anger in negative or unproductive ways. Finally, wives who used more problem-focused coping strategies reported greater caregiver burden. For daughters, only two relationships emerged between coping strategies and psychological outcomes: daughters who used more problem-focused coping also demonstrated greater control of their anger, and daughters who tended to cope by using self-blame also tended to internalise their anger. More research is needed, however, before a comprehensive understanding of differences in coping styles and the effectiveness of those styles by relationship to the care receiver and gender can be developed.

With respect to ethnic differences in coping strategies, the literature suggests that cultural differences may directly affect the appraisal of caregiving as stressful, and consequently, influence coping skills. African American caregivers, for example, have been found to have higher scores in resourcefulness than Anglo-American caregivers, and report lower levels of burden and benign appraisal of disruptive behaviour in the impaired elders (Aranda & Knight, 1997; Gonzalez, 1997). Haley et al. (1996) compared Caucasian and African American caregivers and found that Caucasian caregivers perceived caregiving as unexpected and disruptive, while African American caregivers perceived it as expected and natural. However, African American caregivers also rely on emotion-focused coping, which increases emotional stress (Aranda & Knight, 1997). Much more research is needed on the cultural difference in the use of coping strategies and the effectiveness of those strategies on caregiver outcomes. In addition, very little research has examined the use of different coping strategies for rural versus urban caregivers, and therefore, more work is needed in this area as well.

Research also suggests that personality characteristics may be related to the use of specific coping behaviours (Fleishman, 1984; McCrae & Costa, 1986). For example, Hooker, Frazier, and Monahan (1994) examined the link between personality factors and coping strategies among a sample of spousal caregivers caring for a partner with Alzheimer Disease or a related dementia. They found that caregivers who scored high on neuroticism (i.e., an individual's proneness to experience negative affect) were less likely to use problem-focused coping strategies, but were more likely to use emotion-focused coping. Those caregivers who scored high on extraversion (i.e., propensity of the individual to seek out social interactions and activities) were more likely to seek out social support in an attempt to cope in their caregiving roles and were less likely to use emotion-

focused coping strategies. The authors point out that caregivers with certain personality characteristics might need help in developing more appropriate coping behaviours so that they are better able to adapt to their caregiving roles.

Limitations of Personal Coping Strategies and Coping Research

Recent research has begun to identify the limitations of individual coping strategies. Pot, Deeg, and van Dyck (2000) suggest that the use of personal coping strategies alone may be insufficient to relieve burden (see Quayhagen & Quayhagen, 1988). Caregivers of persons with dementia may need attention and support when they perceive pressure, regardless of their personal resources. Pot and associates (2000) sampled spouses and non-spouses as well as male and female caregivers of persons with minimal and mild dementia, and caregivers of persons with moderate and severe dementia to test whether personal, psychological, social, and health resources were moderators between the appraisal of the caregiving situation and psychological distress. Resources that were evaluated included problem-focused and emotion-focused coping, neuroticism, received emotional and instrumental support, and physical functioning. The authors found insubstantial evidence for the effectiveness of any of these resources in moderating the relationship between appraisal and distress.

Further complicating our understanding of coping with stress is that current methods for measuring coping are quite limited (Kramer & Vitaliano, 1994). In their response to stressors, people are not behaviourally, attitudinally, and cognitively consistent across situations. The coping process is multidimensional and shifting, with different responses called upon at different times. The ways in which individuals cope with a situation will depend on the character of the stressors they encounter in that specific situation. Research is needed that is able to examine coping styles at the time specific stressful situations are occurring and that is able to follow caregivers from situation to situation.

SUMMARY OF CHAPTER

- Very little research has examined caregiver interventions or resources in Ontario. Thus, our understanding of the utilisation and satisfaction with these supports is limited.

- A number of formal services exist for caregivers including support groups; counselling services; programmes that focus on knowledge-building, education, and skills training; respite interventions, home care services, and case management.

- Other formal support services appear to be less available and not widely used in Canada, including family compensation programmes, pharmacotherapy, communication interventions, and memory clinics.

- Formal intervention services are underused, or used as a last resort by caregivers.

- No single formal support programme is effective in meeting all the needs of caregivers and their care receivers. Instead, caregivers need a range of integrated services that address both the emotional and mental stresses of caregiving and the hassles associated with the physical day-to-day tasks associated with the caregiving role.

- Multi-component interventions are more effective in relieving stress and burden than interventions that are more restricted in their strategies and goals.

- Caregiver formal services and supports are most supportive when they are tailored to the unique challenges of dementia caregivers, recognising that the experience can be very different for dementia caregivers compared with other caregivers.

- Single component interventions have greater positive impacts on caregivers when they are more intense; that is, when they are offered more frequently and are of greater duration.

- Interventions that allow the caregiver to identify the problems to be addressed, the methods to be used to address them, and the timing and frequency of the interventions are more likely to achieve desired outcomes than interventions that are fixed in terms of what, how, and when they are delivered.

- Interventions aimed at individual caregivers *and* their families, including the care receiver, are more likely to relieve caregiver stress than those targeted just at caregivers.

- Caregivers not only receive support from formal services, but also receive both instrumental and socioemotional support from informal sources such as other family members, friends, and neighbours.

- Primary and secondary caregivers may have very different perceptions of the caregiving situation, which can, therefore, lead to quite different impacts on primary and secondary caregivers.

- The use of informal support, especially instrumental informal support, is more related to the characteristics of the caregiver than by the circumstances of care such as the functional status of the care receiver. Thus, those who need informal support the most may not be receiving it.

- The diversity of stressors encountered by caregivers requires a wide array of personal coping strategies and techniques.

- Those coping strategies that "fit" more closely with the stressor will be more effective and it is important to consider the "changeablility" of the stressor when choosing appropriate coping strategies.

- There is some evidence that problem-focused coping strategies and acceptance of the situation mediate stress and burden more so than emotion-focused coping strategies that tend to be maladaptive.

- Personal coping resources alone are often inadequate in the prevention of caregiver stress and burden.

CHAPTER FIVE
FINAL THOUGHTS AND RECOMMENDATIONS

The growth of the older adult population over the next several decades will bring with it incredible challenges for families, communities, and society as a whole (Czaja, Eisdorfer, & Schulz, 2000). The aging population is a particular concern given that the risk of dementia increases significantly with age, with those 75 years of age and older being the fastest growing segment of our population and at the greatest risk of developing an illness causing dementia. As Czaja and colleagues emphasise, "The implications of the increased prevalence of AD are vast and of significant magnitude" (p. 284). This is particularly true for family members of persons with dementia as they continue to provide the majority of care for older adults with dementia living in the community.

Much of our understanding of caregivers of persons with dementia comes from research conducted in the United States. Although the body of knowledge on caregiving in the Canadian context continues to grow, our understanding of Canadian caregivers of person with dementia is still in development. Further, our understanding of dementia caregivers in Ontario is even more limited. Much more research on both Canadian caregivers and caregivers living in Ontario is needed in order for us to develop a comprehensive understanding of the caregiving role in the dementia context in both Canada and Ontario.

Our review of the caregiving literature also uncovered a number of gaps and limitations of existing research on caregiving in the dementia context. Some of these gaps and limitations have also been identified by Czaja and her associates (2000) in a book chapter entitled, "Future Directions in Caregiving". It became clear that although our understanding of caregiving has expanded greatly over the last several decades, much more research is needed in order to have a broad and comprehensive understanding of caregivers of persons with dementia. Drawing on the reflections of Czaja and her associates (2000) as well as are own observations from our review of the caregiving literature, we identify here some of the gaps or limitations in the caregiving literature and provide recommendations for future research in the remainder of this Chapter.

Research consistently demonstrates that the caregiving role is extremely stressful for caregivers of persons with dementia – perhaps more stressful than other caregiving roles. However, the specific causes of this stress remain unclear. Much more research is needed that explores aspects of the caregiving experience that are most stressful for caregivers, and that helps to identify and explain specific factors that are associated with caregiver stress and burden. It is important to identify the causes of stress for caregivers because "different causes of distress require different prevention or treatment approaches" (Czaja et al., 2000, p. 286). In order to provide and recommend appropriate interventions for caregivers, we must first be able to identify the specific causes of the stress they are experiencing. Further, future research needs to be directed at examining the relationship between caregiver stress, coping, and overall caregiver well-being. Coping styles and strategies can be taught and changed. Evidence and information on coping strategies that are most effective in addressing specific stressors or problems and that are associated with improvements in caregiver well-being can be used to develop training sessions for caregivers focused on developing appropriate coping styles.

There have been numerous articles that have discussed the development of specific formal support services and interventions for caregivers of persons with dementia. There have also been a number of studies focused on the use of informal supports by caregivers. Nonetheless, few studies to date have examined the effectiveness of these formal and informal interventions in improving the caregiving experience and caregivers' health and overall well-being. Therefore, our understanding of the interventions and supports that are most effective for caregivers as well as at what stage of the process over the caregiving career they are most needed and effective continues to be quite limited. Larger, experimental design studies are needed in order to understand the impacts of different formal and informal supports and interventions on caregivers. Czaja and her colleagues (2000) emphasised the urgency in finding effective interventions for caregivers of persons with dementia. Given the focus and preference for community care by older

adults and their families as well as by government and health care and social support policy makers, "there is a need to develop innovative interventions for AD patients and family care providers. This need is underscored by the fact that family caregiving is likely to become more prevalent as formal health care services become more constrained. Furthermore, despite our advances in knowledge regarding the pathophysiology and symptoms of the disease, a prevention or cure for AD still appears to be in the distant future" (Czaja et al., 2000, p. 286).

Related to research on community support services, the evidence suggests that many caregivers do not use formal support services to help them cope in their caregiving roles. Much research is needed that focuses on broadening our understanding of why caregivers are often unwilling to use community support programmes and services. Research is also needed that provides us with a better understanding of the barriers and challenges that caregivers experience in trying to access these services.

Much of the research on caregiving tends to regard caregivers as a fairly homogeneous group assuming that all caregivers define their roles, play out their roles, and experience caregiving in much the same way. Much more research is needed that looks not only at differences *between* various groups of caregivers (males versus females, adult daughters versus spouses, and so forth), but also research that examines differences in caregiving *within* specific groups of caregivers (e.g., male caregivers). In addition, information on differences between specific types of caregivers such as rural versus urban caregivers, and caregivers living at a distance versus caregivers living close to the care receiver, as well as differences within these groups of caregivers, is minimal at best. Future research is needed that explores whether differences exist in the experience of caregiving between rural and urban caregivers and long-distant caregivers versus those who are geographically close to the care receiver. Research is also needed that examines the differences between these groups in: (a) the experience of arranging for community support services; (b) the availability and accessibility of community support services; (c) the use of available services and programmes; and (d) the effectiveness of these interventions for caregivers.

Further to the point raised above, it became very evident from our review of the literature that our understanding of the cultural distinctions among caregivers of persons with dementia is extremely limited. Very little research has been conducted on minority caregivers (e.g., Aboriginal, Black, Hispanic, Asian) and on caregivers from different cultural backgrounds (e.g., Mennonite families). Future research needs to be directed towards understanding differences among different ethnic and cultural groups in how the caregiving role is defined and played out. Also, there is a need for research that examines the effectiveness of different interventions for caregivers from different ethnic groups and cultures and whether or not "the efficacy of intervention strategies varies as a function of ethnicity [or cultural background] of the caregiver" (Czaja et al., 2000, p. 290).

A majority of the research on caregiving is cross-sectional in nature, examining caregivers at one point in time during their caregiving careers. Very little longitudinal research that follows caregivers across their caregiving careers exists and yet the caregiving role, the experience within the role, and consequently, the supports needed to cope in that role, likely change over time as the disease progresses. Future research needs to follow caregivers of persons with dementia over time and examine *changes* across time in: (a) the caregiving role and experience; (b) the causes of stress and burden, (c) the support needs of caregivers; (d) the impacts of caregiving on health and well-being; and (d) the effectiveness of various interventions.

Although researchers have begun to recognise that caregiving is often shared among a number of primary and secondary caregivers, very little research has examined the nature of caregiving systems, including family caregiving systems and caregiving systems that include a number of different family and non-family members, and the differing impacts of caregiving on members of the caregiving system. Future research is needed that examines the caregiving system as a whole. More specifically, research on the caregiving system is needed that provides further insight into: (a) the varying caregiving roles that different members of the system play in providing care to a relative with dementia and how members of these systems can work more effectively together; (b) the impacts of caregiving on different members of the caregiving system; and (c) the different support needs of members of the caregiving system.

Research on caregiving has focused almost exclusively on family caregivers although a few, more recent studies have focused on examining the

roles of caregivers who are not part of the immediate family such as friends, neighbours, and in-laws. Our understanding of the experience of caregiving for non-family caregivers is quite limited. There is a need for further research that examines the roles of non-family caregivers, especially research that investigates: (a) how non-family caregivers define their caregiving roles, and thus play out those roles; (b) the causes of stress for these caregivers and the impacts of caregiving on various aspects of the caregivers' lives; (c) the use of interventions and supports, both formal and informal, by these caregivers; and (d) whether or not these caregivers have different needs compared to family caregivers.

Positive aspects of caregiving can serve as important coping resources for caregivers and yet our understanding of the rewards of caregiving for caregivers and other positive aspects associated with caregiving in the dementia context are in the very early stages of development. Research is needed that explores how caregivers find meaning in their caregiving roles and that identifies the rewards and positive aspects associated with caregiving. By focusing research on the positive outcomes of the caregiving experience, innovative strategies may emerge that could help caregivers cope with their role. To that end, further research is needed on the relationship between the positive aspects of caregiving, coping, and caregiver health and well-being.

Finally, few studies have compared the caregiving experience in Canada with the experience for caregivers living in other countries. Information from cross-cultural studies that compare Canadian caregivers with caregivers from other countries might uncover important insights into the uniqueness and similariaties of the caregiving experience in Canada. Also, if caregivers appear to be coping more effectively in different countries, we may be able to learn much about improving the caregiving situation in Canada by understanding why and by identifying effective interventions and strategies employed successfully elsewhere.

In summary, a comprehensive portrait of caregivers of persons with dementia in Canada, and more specifically in Ontario, is notably lacking in the research. In particular, their needs and experiences as the demands of their caregiving involvement increases with the progression of the care receiver's disease are not well understood at all. If caregivers are increasingly expected to maintain their relative at home in the community as long as reasonably possible, then every effort must be made to understand their experiences, articulate their needs for community support services, and enable them to overcome whatever constraints may be present to gaining access to those services. Indeed, learning directly from caregivers about their experiences as well as how community support services should be structured, how and when they should be offered, and if new types of services are needed is a necessary first step towards developing appropriate strategies to address their needs. We must be willing to change existing policy and practices, and to develop innovative approaches to the provision of community support services that are truly sustainable, flexible, portable, and responsive to individual caregivers' needs.

RECOMMENDATIONS FOR FUTURE RESEARCH

In order to further the understanding of the dementia caregiving experience in Canada, and more specifically in Ontario, therefore, we would like to end this review by identifying some specific areas for further research. We recommend that future research focus on the development of:

- a comprehensive profile of caregivers in the dementia context, including information on the demographics of caregivers and the characteristics of the caregiving system;
- a comprehensive understanding of the length and intensity of caregiver roles, including the types of activities in which the caregivers are engaged, the duration of involvement by caregivers in these activities, and the nature and extent to which secondary caregivers provide support;
- an understanding of the types and extent of impacts from caregiving on the caregivers themselves, as well as their families, including impacts on financial circumstances, work, leisure and social lifestyles, and physical and psychological well-being;
- an understanding of the degree of burden that caregivers are under and their abilities to cope with the caregiving role, including an understanding of the demands of the role, the sources and degrees of stress related to caregiving, and

the relationship between caregiver stress, coping, and the well-being of caregivers;

- an understanding of the types and use of coping strategies and personal resources on which caregivers draw to deal with the demands of caregiving and the association between these coping strategies and caregiver well-being;

- an understanding of the extent to which caregivers are aware of, make use of, and are satisfied with both community support services and resources and informal support, and the extent to which they feel these resources are accessible to them;

- an understanding of perceived constraints, barriers, and challenges that caregivers experience in their attempts to access formal community support services;

- an understanding of the effectiveness of various formal support services in improving the caregiving experience for caregivers through the use of experimental research designs;

- a more comprehensive understanding of how the caregiving role and the experience in the role changes over time as the disease progresses using longitudinal research;

- an understanding of how changing demographics (e.g., changing family structures, migratory patterns) are affecting caregivers and their abilities to care;

- an understanding of the needs of minority caregivers and how best to meet their needs, as well as an understanding of whether or not efficacy of interventions varies as a function of ethnicity or cultural background of the caregiver;

- a more comprehensive understanding of differences between different caregivers, particularly rural versus urban caregivers and long-distance caregivers versus those who are geographically close to the care receiver; and

- a better understanding of the positive aspects of caregiving for caregivers of persons with dementia and the relationship between positive aspects of caregiving, coping, and caregiver well-being.

APPENDIX A
TYPES OF DEMENTIA

Dementia is used to describe a group of symptoms that generally include: loss of memory, poor judgement and reasoning as well as changes in an individual's mood or behaviour. There are a number of diseases and conditions that cause dementia. The following is a brief description of the most common.

Alzheimer Disease

Alzheimer Disease is the leading cause of dementia. It is a disease that is progressive and irreversible, causing changes in the brain. "Plaques" and "tangles" develop in the brain, leading to the death of brain cells. Persons with Alzheimer Disease also lack chemicals in the brain that are necessary for the transmission of messages within the brain. There is no known cure for Alzheimer Disease; however, there are drug treatments that may assist individuals in stabilizing some of the symptoms of the disease. At present, age continues to be the greatest risk factor for dementia; however, other risk factors are also being explored, including family history, education level, head injury, estrogen, and environmental factors. People in the early stages of the disease may have difficulty with their memory and may have problems finding the right words. As the disease progresses, individuals may become confused and disoriented, they may experience mood swings and they may become more withdrawn, losing confidence and having problems communicating.

Vascular disease

Vascular disease is caused by many factors. People with high blood pressure, a high level of fats in their blood, and diabetes are at risk of developing vascular disease. Vascular dementia occurs when brain cells are deprived of oxygen. Blood flow to the brain is interrupted, thereby causing brain cells to die and symptoms of dementia to occur. Stroke is one of the most common causes of vascular dementia. Individuals may experience a series of small strokes, which can build up damage in the brain, causing dementia – this is often referred to as *multi-infarct dementia*. Vascular dementia can affect very specific areas of the brain, allowing particular abilities to remain unaffected whereas Alzheimer Disease affects the entire brain. It is difficult to diagnose whether a person has Alzheimer Disease or vascular dementia and there are individuals who have both forms of dementia.

Dementia with Lewy bodies (DLB)

Lewy bodies are tiny spherical protein deposits that are found in nerve cells. When they are in the brain, Lewy bodies interrupt the action of important chemical messengers, including acetylcholine and dopamine. Lewy bodies are also found in the brains of people with Parkinson's disease. Researchers do not know why Lewy bodies develop in the brain. DLB is a progressive disease, typically over several years. People with DLB will usually have some symptoms of Alzheimer and Parkinson's diseases. With DLB, individuals generally experience a progressive loss of memory, language, reasoning ability, and higher mental functions. They may also experience depression and anxiety. There may be hallucinations and with DLB, people experience fluctuations in their abilities. These fluctuations may be daily and even hourly. Diagnosis of Dementia with Lewy bodies is crucial to ensure that appropriate drug treatments are utilised.

Fronto-temporal dementia (including Pick's disease)

Fronto-temporal dementia occurs when there is damage to the frontal lobe and/or the temporal parts of the brain. These areas of the brain are responsible for our behaviour, our emotional responses, and our language skills. People under the age of 65 are more likely to be affected. With fronto-temporal dementia, the early signs will involve changes to personality and behaviour with little impact on memory. There is a family history in about half of all cases of fronto-temporal dementia. It is believed that abnormalities in chromosomes 3 and 17 are linked to some of the inherited forms. Causes for non-inherited fronto-temporal dementia are unknown.

Rarer Causes of Dementia

Creutzfeldt-Jakob disease (CJD)

Creutzfeldt-Jakob (CJD) is a form of progressive dementia identified by brain cells that have died creating a spongy appearance. Persons affected by CJD usually have a rapid onset and decline. Early symptoms include minor lapses in memory, mood changes and lack of interest or social withdrawal. The person may become unsteady on her or his feet. The age of onset is between 45 and 75 years of age.

Binswanger's Disease

Binswanger's disease is a rare form of vascular dementia that is caused by damage to blood vessels deep in the brain's "white matter". It is primarily a result of high blood pressure.

For more information on these diseases, visit www.alzheimer.ca and www.alzheimer.org.uk.

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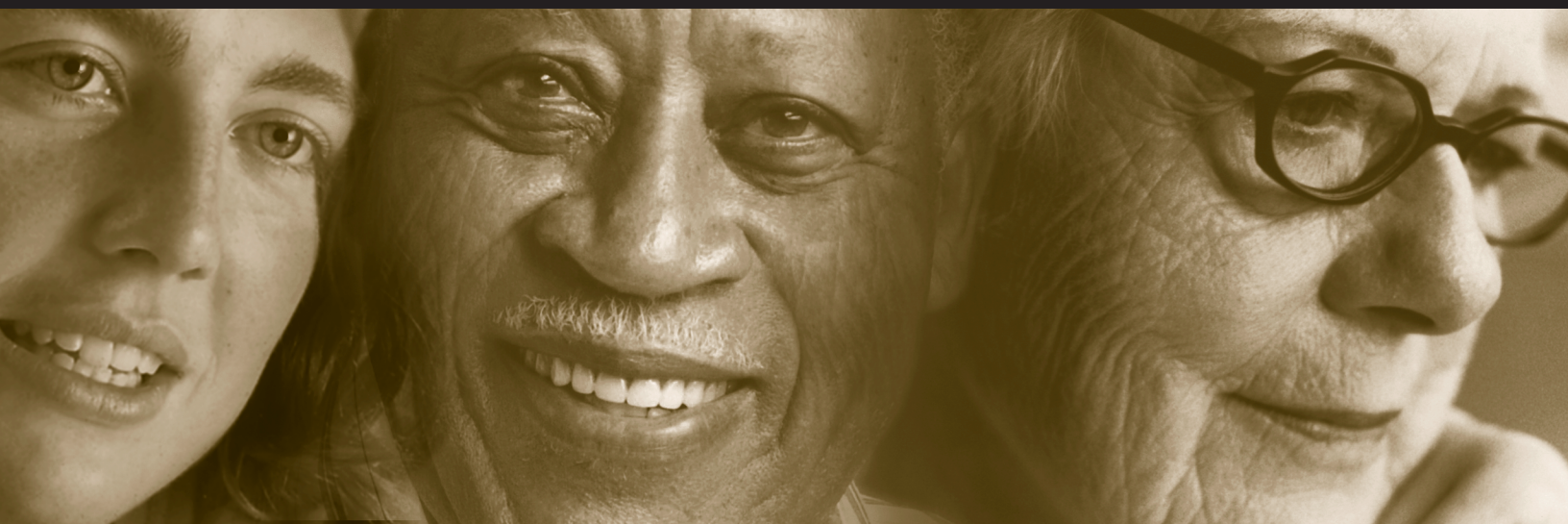
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