

Evaluating the Effectiveness of National Policies Supporting Family Caregivers of Old Adults

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(ABSTRACT)

Caregivers of family elders have diverse needs, many of which are not being met sufficiently.

The purpose of this study was to analyze the congruency between family policy and the needs of family caregivers. Based on the rational policy model, a normative policy analysis of the economics of family caregiving, both its costs and benefits to individual families, corporations, and to society, was provided. A dynamic theoretical framework incorporating the social ecological perspective, role theory, and life course approach, was used to critique the effectiveness of Family and Medical Leave Act (FMLA) of 1993 (P.L. 103-3) and the National Family Caregiver Support Program (NFCSP) of 2000 (Title III-E and Title VI-C). Combined, FMLA and NFCSP are effective in meeting the wide range of informal caregivers' financial, training, and support needs. The workplace-related policies of FMLA speak more to the financial assistance – albeit minimal – and work environment-structural components of caregiver support, while NFCSP pertains more to the training and supportive aspects of family caregiving support. However, workplace policies in support of family caregivers should be more individualized and current caregiver support programs should be expanded to align more closely with the needs of employees and citizens.

Dedication

To my mother, a 17-year caregiver to my grandmother, Dorcas Clisty Barrus. I dedicate this master's thesis to you, Mom, in reverence to all of your hard work, dedication, patience, and faith in God throughout the years of providing "Gram" with the best care anyone could ever receive. I have learned so much from you and your caregiving experience. You are, indeed, an inspiration to all and a model caregiver.

First and foremost, I thank Jesus Christ, my Lord and Savior, for guiding me and providing me with strength and determination during the past two years as a graduate student. Without Him in my life, none of my successes would be possible. Praise be to God!

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I made it!

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Chapter I

Introduction

The Nature and Prevalence of Informal Family Caregiving

The precise numbers of informal caregivers (i.e., uncompensated caregivers both within and outside the family), and the incidence of informal care vary greatly. Estimates of informal caregivers vary, because there is no universal definition of caregiving manifested in the literature, and many caregivers subsume this activity as part of their responsibility to their old adult relatives, rather than viewing it as a separate role (Gaugler, Kane, & Kane, 2002; Mahoney, 2003; Schulz & Martire, 2004). Moreover, one's caregiving experience varies among caregivers, with many providing direct care and others maintaining a more indirect role (National Alliance for Caregiving [NAFC]/American Association for Retired Persons [AARP], 2004).

Current estimates report 44.4 million unpaid informal caregivers in the U.S. – 21% of the adult population – aged 18 and older, with 22.9 million households including informal caregivers. Additionally, most informal caregivers are related to the care recipient in some manner, such as a spouse, sibling, niece, nephew, cousin, or other family member, allowing for a great deal of familiarity regarding the care recipient's needs and preferences in care (NAFC/AARP, 2004). Arno, Levine, and Memmott (1999) estimated 9.4 million caregivers in 1996 provided assistance to individuals of any age, and in 1994, 5.9 million informal caregivers provided assistance to individuals over the age of 65 due to disability or chronic illness such as Parkinson's or cancer (Alexih, Zeruld, & Olearczyk, 2001). Caregiving to an adult aged 65 or older with or without dementia or a related illness, however, is estimated to include 5 to 7

million caregivers in the U.S. (Health & Human Services, 1998; NAFC/AARP, 1997; Spector, Fleishman, Pezzin, & Spillman, 2000), with 25% providing care to an old adult with dementia or a dementia-related illness (NAFC/AARP, 2004). Prospective estimates on the prevalence of informal caregiving to adults aged 50 or older suggest that the number of caregivers could reach 39 million by 2007 (NAFC/AARP, 1997).

Statement of the Problem

A major concern of aging policy is the modifications an aging society may warrant for the formal and informal caregiving system and the financial outlet of the U.S. Often termed the *2030 problem* (Knickman & Snell, 2002), the challenge is to make certain that sufficient financial resources and an effective service delivery system are in place in thirty years, when the aging population doubles in magnitude. The aging baby boomers will be aged 66 to 84, termed the “young-old,” in the year 2030 (Knickman & Snell, 2002).

With the increasing number of old adults in need of care, family elder caregiving has advanced to the forefront of policymakers’ agendas, and has become a prominent issue over the past thirty years (Allen, Blieszner, & Roberto, 2000; Rosenthal & Stone, 1999). Family elder caregiving is most commonly defined as the care provided to an adult aged 65 or older, with or without a dementing illness, by an adult child, sibling, niece, nephew, or other relative, who is most often female (Brody, 2004). For the purposes of this analysis, family elder caregiving will be defined as the care provided to an adult aged 65 or older without a dementing illness, and with at least one activity of daily living (ADL) need (e.g., assistance with bathing, feeding, dressing, transferring from bed or chair, walking, toilet use, grooming). This definition is most appropriate in that old adults with a form of dementia have very specific caregiving needs that will not be addressed in this analysis.

Contributing to the emerging importance of informal caregiving, in addition to the aging of the Baby Boom cohort, is the increasing need for policies in support of low-income caregiving families (Dentinger & Clarkberg, 2000; Marosy, 1997; Piktialis & Morgan, 2003). Many social support-type programs require government funding at some level, and without supportive policies, low-income caregivers are left to rely on their own limited resources. Consequently, the caregiver's and care-recipient's well-being may be at risk, as may be the quality of care provided by the caregiver. For instance, the quality of care may be poor if the caregiver is experiencing a sense of burden while providing care over an extended period of time, as well as if he or she is experiencing poor mental or physical health while caregiving and does not seek appropriate medical attention (Bass, Noelker, & McCarthy, 1999; Lawrence, Tennstedt, & Assmann, 1998; Kellett, 1999; Lee, 2002; Phillips, Morrison, Steffl, Chae, Cromwell, & Russell, 1995; Williamson & Shaffer, 2001). A more comprehensive, family-friendly policy reform with local and national government involvement would provide financially disadvantaged informal family caregivers with necessary services (e.g., training, respite), paid and unpaid leave from the workplace, and financial assistance (e.g., vouchers), all of which would contribute to assisting the caregiver in providing the best quality care possible (Brubaker & Brubaker, 1995; Family Caregiver Alliance/National Center on Caregiving, 2002; Knickman & Snell, 2002; Laditka & Laditka, 2001; Marks & Lambert, 1997; Wisensale, 2003). Furthermore, supporting caregivers in providing care in the home setting, as opposed to institutionalization, may save taxpayers money and prevent or delay reliance upon institutions such as nursing homes (Arno, Levine, & Memmott, 1999; Leon, Cheng, & Neumann, 1998; Weissert, 1991).

Applying a theoretical framework to evaluate caregiving policies will provide a better understanding of the caregiving role in the context of the caregiver-care recipient dyad, and

specify how services and programs currently available can be modified to meet caregivers' multiple needs in fulfilling that role more effectively. Estes (1984) and Marks and Lambert (1997) have attempted to analyze caregiving policies from an explicit theoretical perspective using critical political theory and social ecological and life course theories, respectively, and may serve to further exemplify the importance for the present analysis. However, the present analysis differs from previous analyses (e.g., Estes, 1984; Marks & Lambert, 1997) in that the current theoretical framework is applied to two recent caregiving policies – the Family and Medical Leave Act (FMLA) and the National Family Caregiver Support Program (NFCSP). A lack of rigorous policy analysis in previous years, particularly the use of rational policy model to analyze informal caregiving, also justifies the present analysis. Policies designed to support both working and unemployed informal family caregivers are important in that they provide the foundation for program development and service implementation, as evidenced by FMLA and NFCSP. Without such policies, caregivers would lack the necessary supportive services, such as in-home care options, education and training, and paid leave from work, which would further increase individual stress levels and negatively affect the quality of care provided.

In order to provide a sound theoretical framework to the current policy analysis, the rational policy model is used (Dye, 2005). In the area of policy studies, numerous models have been developed to aid in understanding the various components associated with social policy. The rational model, for example, is based on a comprehensive assessment of all relevant alternatives to reveal the one option that will attain the desired goals and outcomes, meet articulated or anticipated needs, and is most efficient in implementation, as compared to other policy model alternatives (Dunn, 2004; Haas & Springer, 1998; Koff & Park, 1993; Munger, 2000). Additionally, the rational model is often primarily used as a tool to reveal the barriers to

rational planning and problem solving within the existing policy process, which is helpful in determining specifically how to restructure the policy in question (Koff & Park, 1993). Haas and Springer (1998) purport that it is the actual *structuring of the problem* in question that determines policymakers' analysis techniques, with a clear definition of a problem and its alternatives being more amenable to a rational analysis. Serving as the basis of the current analysis technique is the discrepancy between caregivers' resources and their needs, addressed in later sections of this paper, which is evident in the lack of workplace policies to support necessary leave from work for employed caregivers, for example, as well as in a lack of community-based services (e.g., long-term respite) to support family caregivers. Consequently, the rational model was chosen over other models because its components make it a useful and appropriate tool for studying family elder caregiving as an entity that is influenced by public policy and can influence the policy system itself.

Purpose of the Study

The purpose of this study is to investigate within a theoretical framework the effectiveness of FMLA and NFCSP in supporting the various needs (e.g., finances, education, access, social support) of informal caregivers of old adults. Utilizing the rational policy model as a tool and basis for the present analysis, contemporary family caregiving will be analyzed in three important ways: (a) to develop a comprehensive conceptual framework based on theories of caregiving from various fields, including gerontology, psychology, and political science, (b) to use the conceptual framework to evaluate the costs and benefits of current policies related to caregiving (i.e., FMLA and NFCSP), and (c) to make future recommendations for improvement in selected workplace and family policies. Analyzing informal family caregiving on the basis of the rational policy model is useful for promoting advocacy, providing informative policy briefs,

and organizing discussions, such as taskforces and interdisciplinary groups. The lack of supportive workplace policies entails numerous costs to caregivers and corporations, including caregivers' need for extended periods of leave from and subsequent unproductiveness in the workplace. Additionally, a lack of supportive community programs will cost caregivers financially if these services need to be compensated for through out-of-pocket money. Benefits of workplace policies and supportive community-based programs for caregivers include the ability to remain in the workforce, which also benefits employers through a productive workforce, and a higher quality of care provided to old adults through supportive community-based services. Additionally, with care increasingly provided in the home, there is less reliance on formal institutions such as nursing homes, saving national government billions of dollars per year.

The rational policy model is a sound resolution for the problem of limited supportive policies and programs for family caregivers in that rational policy speaks to problem-solving through action that will best meet pre-established goals and expected outcomes, such as maintaining informal caregivers' participation in the workforce and supporting caregivers in the community by providing a range of services. Rational policy model also attempts to ensure that the costs (e.g., paid leave from work, funding for community-based caregiver support programs) of a particular policy to overall society are outweighed by the benefits of the policy (e.g., more productive workforce with leave from work, range of caregiver support services). Consequently, the implementation of more comprehensive workplace policies and supportive community-based services will provide a feasible solution to meeting the various needs of informal caregivers in the workplace and home setting.

The usefulness of the current analysis for practitioners is for FMLA to target employers in restructuring comprehensive workplace leave policies. Likewise, the goal of NFCSP is to target social and aging services agencies, such as Area Agencies on Aging, when structuring supportive community programs for caregivers and their families in order to meet their entire range of needs within and outside the workplace environment. Additionally, while idealistic and perhaps challenging to fully achieve, community meetings with caregivers, employers, and legislators will be useful in providing a team approach to workplace leave policy and caregiver support program development, encompassing the lay, professional, and political points of view.

Personal Perspectives and Biases

In order to provide the reader with an explanation of what prompted the current policy analysis and influenced the manner in which the analysis was approached, the discussion will now turn to my personal experience in being raised in a multigenerational household. This personal experience has acted as a catalyst for the current analysis in that my mother faced numerous challenges in being the sole care provider to my grandmother, such as leaving the workforce to provide extended care, being unaware of available community services, and not having access to select community services based on my grandmother's income level. My mother's caregiving experience is not entirely unique, as there are numerous other caregivers who have faced similar challenges and continue to do so today. However, it is the caregiving situation of which I have the most personal understanding and vested interest.

While both of my parents worked, I spent a great deal of time under the caregiving of my maternal grandparents, who lived five miles from my parents' home. The time spent with my grandparents is probably my fondest memories, in that they owned a 120-acre farm and raised a variety of livestock: cows, sheep, pigs, chickens, turkey, ducks, and a constantly replenishing

litter of wild cats in the hay upstairs in the barn. I was continuously exposed to a variety of real-life experiences, such as the birth of lambs, hosting educational farm tours by the local Girl Scout troop from the nearby camp, and the death of the beloved family farm dog, “Jumper.” In that my maternal grandmother had a total of 12 children, I was always surrounded by cousins of all ages with whom I would play games and sports on the farm. However, the majority of my time on the farm, when I was not in school for the day, was spent in the presence of my grandparents and their old adult visitors. I have always had a natural inclination toward spending time with old adults due to my personal experiences with my grandparents, and this sentiment has continued throughout my young adulthood.

Following the death of my maternal grandfather in October 1988, my grandmother, who is now 95 years of age, sold the farm and moved into my parents’ home, where she has lived for the past sixteen years. Despite the fact that my mother is the youngest of 11 other siblings, she is the sole (and only willing) caregiver to my grandmother. My mother held a full-time office manager position for 15 years before my grandmother moved in with my family, but resigned from her high-paying position to become a 24-hour caregiver. Cognitively, my grandmother functions remarkably well for her age; however, she has other special needs, such as irritable bowel syndrome (IBS), low blood pressure, and sometimes fatally low potassium levels, for all of which she takes medication daily. We lived in a suburb of Worcester, Massachusetts, the supposed “Hub of Healthcare” in New England, offering a plethora of healthcare services to people of all ages.

Over the years, I witnessed my mother’s numerous challenges in accessing various in-home care services, such as visiting nurses, particularly because my grandmother’s income level with Social Security benefits was a few hundred dollars over the minimum threshold. In-home

care services are expensive when one is forced to pay out-of-pocket, so my mother would recruit family friends to help her bathe and dress my grandmother on a daily basis. Money, however, was not the only issue, as my mother had limited knowledge of the types of services that were available in the community, such as short-term respite and local caregiver support groups, both of which would have benefited her greatly during her caregiving tenure.

Given that my mother was the sole care provider to my grandmother, and had no assistance from any of her six brothers and very minimal help from my father, my caregiving experience highlights my sensitivity to gender. I understand that the caregiving role is often assumed by a female family member, typically a daughter, and that the majority of the caregiving duties are performed by women. However, I also realize that men provide care to family members and warrant further attention from policymakers. It should also be noted that I was raised in a white, middle-class family, and as such, my mother was able to leave the workforce in order to provide full-time, extended care to my grandmother, although community resources were limited. Consequently, my caregiving experience will differ drastically from that of a lower-income African-American family that must remain in the workforce, or a higher-income Chinese-American family that is better able to access community services.

My personal experiences may shape my research perspective in that I witnessed firsthand, through my mother's experience, the struggles and challenges that are faced by informal caregivers of old adults, particularly when the community resources are available but remain inaccessible to those with limited financial or informational resources. It is through these experiences with my own mother that I feel a sense of responsibility to make known the service provisions of programs such as NFCSP to informal caregivers, particularly those residing in rural or low-income areas. Unlike many family caregivers, my mother was fortunate enough to be able

to resign from her position as office manager to become a full-time caregiver to my grandmother. Nevertheless, I have a strong sense of urgency to support the restructuring of FMLA policies to better support the needs of employed family caregivers who are not fortunate enough to give up their full-time careers to pursue caregiving to an old adult relative.

Chapter II

Review of the Literature

Variations in the estimated prevalence of informal caregiving in the U.S. are closely related to the definition of caregiving itself. The most common definition of informal caregiving in the gerontological literature includes the criteria of one who is aged 18 or older providing unpaid care or assistance to a relative aged 50 or older living in the community, with or without dementia, and with at least one personal care need (Alexih et al., 2001; Health & Human Services, 1998; NAFC/AARP, 1997; Spector et al., 2000). Caregiving duties may include help with activities of daily living (ADLs) (i.e., bathing, dressing, walking, toileting, and feeding), as well as with instrumental activities of daily living (IADLs) (i.e., everyday cognitive tasks, including household chores, meal preparation, medication use, food or clothes shopping, balancing a checkbook, and using a telephone and phone book). Caregivers, either living with or away from the care recipient, may also arrange for outside services, such as a visiting nurse, or visit regularly to check on the individual, though these activities are viewed as constituting the actual caregiving relationship less often than those associated with ADL and IADL assistance (Health & Human Services, 1998; NAFC/AARP, 1997).

The full range of family caregivers' needs is not always given sufficient attention by gerontological professionals and policymakers. Caregivers of old adults with or without dementia or related cognitive impairments may require a range of services and need additional support to cope with the old adult's increasing needs. These caregiver needs can range from financial assistance, emotional and social support, and physical assistance (e.g., in-home nursing care). While there are a variety of services available to caregivers in many states (e.g., in-home respite, housekeeping), many caregivers are unaware of the existence of such services, or do not

have the means to access these services on their own without the help of a social worker or other professional (Parish, Pomeranz-Essley, & Braddock, 2003; Philp et al., 1995; Worcester & Hedrick, 1997). It is also important to consider the characteristics of both the care recipient (e.g., age, number of household members, quantity of informal care, ADL limitations), and the caregiver (e.g., rearrangement of work hours, level of care performed) when examining caregivers' unmet needs and use of formal services and resources (Houde, 1998). Given the lack of a universal standard in service provision, it is important to consider the locale of the caregiver, which will determine the level of caregiving-related assistance one receives, in that available resources and supportive services vary across states and among counties (Kelly & Williams, 2005; Leith, 2005).

Theoretical Approaches to Family Elder Caregiving

The rational policy model, the foundation of the current theoretical framework, is based on a comprehensive assessment of all relevant alternatives to reveal the one option that will attain the desired goals and outcomes, meet articulated or anticipated needs, and is most efficient in implementation, as compared to other policy model alternatives. Moreover, rational policy is appropriate for policy analysis within a capitalistic society where businesses have a high level of power in the economy, in that economic theories serve as the underpinning to the rational model (Dunn, 2004; Haas & Springer, 1998; Koff & Park, 1993; Munger, 2000). According to the rational policy model, governments should aim to choose policies that offer a maximum gain to society that clearly exceeds costs, and likewise should avoid policies that are not exceeded by gains. In addition to avoiding policies that have costs not exceeding the benefits, decision makers should choose the policy with the greatest benefit over cost among the policy alternatives.

Moreover, a policy is rational when its social, economic, and political values are positive and greater than those of its alternatives (Dye, 2005).

The rational model was chosen over other models because its components make it a useful and appropriate tool for studying family elder caregiving as an entity that has a reciprocal influence on public policy. More specifically, family elder caregiving both influences public policy, and is influenced by policies and programs designed to meet the needs of informal caregivers. For instance, the needs of employed family caregivers directly influence the extent and provision of workplace policies, such as unpaid 12-week leave, allowing caregivers to remain productive in the workforce. The needs of informal caregivers in the home setting also influence the type and extent of services provided through NFCSP, such as long- and short-term respite, counseling, and in-home care services, which have a reciprocal effect on the quality of care provided by the caregiver. Additionally, the rational model is often primarily used as a tool to reveal the barriers to rational planning and problem solving within the existing policy process, which is helpful in determining specifically how to restructure the policy in question (Koff & Park, 1993). A primary example of this is the application of the rational model to social welfare policy. Programs such as Social Security Insurance (SSI), federal food stamps, and Medicaid, for example, have been initially implemented to support a rational approach to social welfare policy, with the benefits outweighing the costs – albeit minimally – in many cases (Dye, 2005; Murray, 1984).

The rational model attempts to explain the need for a clear definition of objectives, development of alternative strategies for achieving them, and a careful comparison and weighing of the costs and benefits of each objective. For a completely rational policy to be developed concerning social welfare, a universal definition of poverty is warranted, as opposed to the

generally stated government definition of poverty being based on minimum dollar amounts required for subsistence. A universal definition of poverty might include a variety of circumstances associated with need, hardship, and lack of resources. Poverty may be described in subjective and comparative terms, viewed as moral and evaluative in nature, or may be scientifically established. Poverty also may include descriptions of material need, including a lack of necessary goods and services and patterns of deprivation over time; economic circumstances, such as a lack of capital, money, material goods, or resources; and, social relationships, including social exclusion (e.g., segregation based on income level), dependency (e.g., welfare recipients), and the ability to live a life that is defined by society as *normal* (Wikipedia, 2005). Furthermore, the lack of knowledge, skills, training, recession and unemployment, the culture of poverty, and dissolving marital relationships are important factors to consider in the development of a rational policy regarding social welfare beyond the poverty level.

Another area in which the rational model has been implemented is crime and punishment. Crime is a central problem to society, and there is a conflict between a desire to retain individual freedoms and a desire to ensure the safety of all people. The goal of deterrence, the rational strategy of crime fighting efforts, is to make the costs of committing crimes far outweigh any potential benefits that criminals may derive from their acts (e.g., high amount of media attention). From a policy perspective, the intention is that a realization of these costs will deter individuals from committing crimes. Specifically, crime rates have been falling since 1993, with law enforcement officials attributing this decline to the adoption of public policies designed to deter crime and incapacitate criminals, such as extended imprisonment, community policing, gun laws, and the prohibition of drugs and alcohol (U. S. Bureau of Census, 2004). Furthermore, a

rational policy toward crime would make its costs (e.g., stricter and immediate punishment) greater than the benefits, further deterring criminals (Dye, 2005).

Rational policy can be applied to the topic of informal caregiving provided to an old adult family member, a widely researched area in the field of gerontology (Brooks, McCubbin, Thompson, Thompson, & Fromer, 1998; Brown & Stetz, 1999; Finley, 1989; Keith, 1995; Krause & Haverkamp, 1996; Mui, 1992; Parrott & Bengtson, 1999; Peterson, 2002; Piercy, 1998; Pillemer, Sutor, & Wethington, 2003; Rosswurm, Larrabee, & Jianlian, 2002). Family caregiving is also a prominent topic in the gerontological nursing literature (Cloyes, 2002; Coeling, Biordi, & Theis, 2003; Jeon, 2004; Yamashita, 1997), including the issues of stress and burden often experienced by many family caregivers (Aldous, 1999; Cloyes, 2002; Dow & McDonald, 2003; Dautzenberg et al., 2000), both of which play a direct role in workplace leave policies and stress-management training under FMLA.

Many issues shown to be relevant to caregiving policies, however, are not directly revealed by the use of rational policy theory alone. For instance, there are often a number of costs and benefits to role strain, role assignment, and stress among individuals involved in unpaid, informal caregiving. Role strain may cause an employed caregiver to be less productive in the workplace and need time off to focus on his or her caregiving duties at home, costing the employer both time and money (Burns, 2000; Lawrence, Tennstedt, & Assmann, 1998; Murphy, Schofield, Nankervis, Bloch, Herrman, & Singh, 1997; O'Rourke & Tuokko, 2000; Rapp & Chao, 2000). Role assignment may carry significant costs to an employed mother of a young child, who now must balance caregiving between child and aging parent; however, the benefit of this dual-assigned role may be seen in enhanced well-being (Elliot, 2003), and in increased role satisfaction and a reduction in feelings of guilt (Hammer & Neal, 2001; Murphy et al., 1997).

Finally, stress also may cost the informal caregiver in terms of his or her physical and mental health, particularly if he or she lacks the necessary supportive community services (Fast, Williamson, & Keating, 1999; Sayles-Cross & DeLorme, 1995). Therefore, rational policy theory applied to informal caregiving is most valuable in implementing new caregiving policies and analyzing the effectiveness of existing policies. To further strengthen the current analysis, the conceptual framework is supplemented with major gerontological theories.

Interdisciplinary Theories of Family Caregiving

The following subsections focus on the most prominent gerontology and psychology theories relevant to family caregiving and policy: social ecological perspective on caregiving, role theory, and life course approach to caregiving. The social ecological perspective on caregiving, for example, examines caregiving as occurring in a complex social ecology, as opposed to focusing on the dyad of caregiver-care recipient alone. It is equally as important to consider, however, the entire family system and its role in the informal caregiving process (Marks & Lambert, 1997).

Role theory clearly explains how the role of caregiver can produce strain on one's social relationships with the care recipient and others. This is particularly evident when faced with competing familial roles such as that of parent to young children, and how one balances the demands from the caregiving role. Thus, the multiple demands within the caregiving role are an important issue for caregivers (Conway-Turner & Karasik, 1987; Mui & Morrow-Howell, 1993; Murphy et al., 1997; Yates, Tennstedt, & Chang, 1999).

Similar to the social ecological perspective, the life course approach to caregiving considers the developmental timing of transitions of the caregiver role, the intersection of other roles (e.g., parent) in relation to the caregiving role, the changing historical context for enactment

of the caregiving role (e.g., retirement), and the patterns of caregiving across the life courses of varying birth cohorts (Coontz, 2000; Moen, Robison, & Fields, 1994). The timing of one's transition to the caregiving role, his or her competing roles in the context of the family, and the timing of life events such as retirement are important issues to consider. The wide variation in caregiving families is also an important factor to consider in designing and implementing policies and programs.

Social ecological perspective on caregiving. Social context is important in defining *change over time*, based on the social structure and social creation of the term, *change* (Bengtson & Allen, 1993). There are four distinct ways in which social context is important in analyzing families and family members' behavioral changes over time. First, the location of families in the social structure influences the events that they experience, such as a loss of income due to unemployment or a failing economy. Sociocultural variables, the second factor, define kinship and role expectations, such as the more kinship-oriented caregiving relationships in African American families as compared to their White counterparts. Third, the timing and sequence of family events vary according to a family's social class, such as the first marriage or birth of a child. Finally, family development and change should be examined at both the macro (e.g., aging of the population) and micro (e.g., aging process within the family context) levels, as well as the interactions of these two independent levels in influencing life span, generational, and historical events (Estes, 2001; Bengtson & Allen, 1993).

Continuing from a macro and micro perspective, it is clear that caregiving families are unable to effect change in policy through their own efforts. Government plays a vital role in caregiving policy development, deciding for or against certain policies and taking action to implement policies and programs in support of caregiving families. Implementing policies such

as the Family and Medical Leave Act (FMLA) and the National Family Caregiver Support Program (NFCSP) is similar to reducing state expenditures through the privatization of Social Security and Medicare. The government has three major functions with respect to family caregiving:

1. To ensure that the current conditions are favorable to economic growth and private profit, allowing for an accumulation of wealth;
2. To ensure the operation of social order by alleviating negative economic conditions from the free enterprise system (e.g., job termination due to family caregiving responsibilities), which is accomplished via publicly funded benefits (e.g., FMLA coverage);
3. To protect the democratic process, allowing the opinions and experience of informal family caregivers to shape policy (Estes, 2001).

According to Estes (2001), the first two functions require the expenditure of public resources. Government expenditures meet the needs of business and industry through favorable tax treatment and subsidies, such as the provision of vouchers for caregiving services under FMLA for employees to remain in the workforce, which lower overall costs to the business (e.g., hiring and training of new employees). National expenditures for social welfare programs such as FMLA and NFCSP reflect displacement costs, such as ageism (e.g., employers not allowing leave for the care of an aging relative), of the operation of the economic system. Furthermore, without such policies as FMLA and NFCSP, the responsibility would shift from the government to the individual. This shift would result in reduced corporate contributions from government expenditures for the policies and supportive programs, further leading to increased business expenditures to support caregiving employees in the absence of state funding, as well as a

diminished productive workforce. The above three functions of the state warrant future research to determine how to best support caregiving employees under FMLA and to utilize state grants to provide sufficient community support services to caregiving families (e.g., NFCSP). Moreover, research on the needs of caregiving families is crucial in the provisions of particular policies associated with workplace needs and contextual needs of the family such as respite care.

Based on a micro-level perspective, focusing on the caregiver, the majority of caregiving research thus far has concentrated on the factors used in predicting the provision of care and the consequences of caregiving. Houde (1998) examined predictive factors for formal service use by caregivers in the home setting, including the care recipient's gender, age, household structure, ADL/IADL limitations, as well as the caregiver's difficulty in getting around outside the home, the restructuring of work hours and extent of care provided by the caregiver, and found that utilization of formal services was less frequent as the hours of informal care increased (see also Davey & Patsios, 1999). Penning (2002), however, reported that an increase in the use of formal in-home services typically lessen levels of informal or self-care. The quality of the marital relationship among caregivers also plays an important role in predicting the provision of informal care within families (Pecchioni, 2001). Individual-level consequences of informal family caregiving such as increased depression, decreased life satisfaction and well-being, decreased physical health status, decreased social activities and social support, and increased burden, have also been examined (Baldwin et al., 1989; Grunfeld et al., 1997; Haley et al., 1995). The design of supportive workplace policies and community programs for caregivers aims to meet the range of caregivers' needs at the family and individual levels.

Besides focusing on the individual caregiver, however, the social ecological perspective on caregiving suggests that it is equally important to consider the family as a whole when

examining elder caregiving and public policy (Marks & Lambert, 1997). Continuing from a micro-level viewpoint, the social ecological perspective on caregiving involves personal informal caregiving, such as assistance with ADLs (i.e., bathing, dressing, feeding) and/or instrumental activities of daily living (IADLs) (i.e., paying bills, carrying groceries), and social caregiving (i.e., emotional support) by the nuclear and extended family. The informal dimension involves both primary (e.g., spouse) and secondary (e.g., niece, nephew) caregivers, non-family caregivers, the care receiver, and the caregiver-care receiver dyad (Arno et al., 1999).

Although an increasing amount of attention has been given to other family members, most research has focused largely on the primary caregiver. Thus, the implication of the use and effectiveness of multiple types of caregivers – particularly when the sole caregiver is unable to continue with his or her caregiving duties – such as spouses, extended familial caregivers (e.g., kin, friends, neighbors), and non-family caregivers (e.g., community church members, clergy), and their relationship with the care recipient, are important to consider. These efforts will expand upon previous perspectives, promote the value of multiple caregivers in dividing or taking over caregiving duties among family and non-family members, and advance the importance of a strong relationship and positive rapport between the caregiver and care recipient, regardless of relational tie. Taken together, these efforts will help to maintain a positive caregiving experience and successful outcomes for the caregiver, care recipient, and family members.

Turning the discussion to a macro-level analysis, informal family caregivers also rely on the more formal, professional provision of assistance, particularly when the care recipient requires hands-on medical interventions and mental and physical health-related services. The formal dimension of caregiving includes paraprofessionals (i.e., paid helpers and agency workers) and professional caregivers, such as physicians, nurses, and social workers. Service

workers, moreover, such as providers of medical and social services, largely influence the course of family caregiving, as well as the policies and services of local, state, and national governments (Kane & Penrod, 1995; Marks & Lambert, 1997). There is an interplay between informal and formal caregiving, with both lending support to one another while meeting the range of caregiver needs, as specified by the social ecological perspective on caregiving.

Role theory. Reuben Hill (1912-1985), a role theorist, based the tenets of the developmentally structured role-based theory on the conflict- and process-oriented perspectives of the symbolic interactionist approach. Hill originally applied role theory to the analysis of family crisis, claiming that it is not the crisis event itself that makes meaning for the family but, rather, the family's subjective definition of the crisis (LaRossa & Reitzes, 1993). According to Hill, family roles are constructed by the expectations that other family members have to perform a particular role. Family crises are stressful, Hill purports, because they modify role expectations and, in turn, require behavioral change. Thus, the success of a family lies in the sufficient performance of family roles (Hill, 1986; LaRossa & Reitzes, 1993). The discussion will now turn to role theory as it relates to the role of caregiver.

Fifty-nine percent to 75% of informal caregivers are women, and 44% of Americans between the ages of 45 and 55 have aging parents or in-laws as well as children under 21 years of age (Family Caregivers Online, 2005). Furthermore, approximately 25%-40% of women provide care to both their children and an aging relative, with half of these *sandwich generation* women working outside of the home (National Center for Health Statistics, 2001). The duality between roles can lead to crisis, which could occur when attempting to balance multiple roles, such as parenting a young child and simultaneously providing care to both an aging parent and other ailing relative, or not being allowed the necessary time off from work in order to bring the

care recipient to a doctor's appointment or engage in the necessary caregiving tasks. With the increase in participation in the professional labor force by women, it is not surprising that role strain, burden, and conflict is currently a widely researched phenomenon in the caregiving literature (Chumbler, Grimm, Cody, & Beck, 2003; Evandrou, Glaser, & Henz, 2002; Starrels, Ingersoll-Dayton, Dowler, & Neal, 1997).

According to the scarcity hypothesis of role theory, individuals lack the appropriate resources to adequately fulfill their multiple role obligations. Therefore, multiple role commitments produce role strain as a consequence of role overload and role conflict. Role strain is defined as the felt difficulty in the fulfillment of multiple role obligations (Mui & Morrow-Howell, 1993). Role overload occurs when one has too much to do in a given amount of time. This form of strain occurs when the total demands on time and energy associated with the prescribed activities of multiple roles are too great to perform the roles adequately (Conway-Turner & Karasik, 1997; Yates, Tennstedt, & Chang, 1999). Similarly, role conflict occurs when an individual has multiple roles with conflicting expectations (Murphy et al., 1997).

Dautzenberg et al. (2000) examined the scarcity hypothesis, and found that women's participation in the workforce reduced the likelihood of women becoming a caregiver to an aging parent, with their preference being for the career role. This phenomenon occurs regardless of a full- or part-time work schedule. Proximity to a parent was also an important factor in assuming the physical or more hands-on caregiving role, as well as never being married and having few or no siblings. Moreover, role strain was found to be more affected by personal characteristics of the caregiver such as having poor health, job satisfaction, and workplace demands (Dautzenberg Diederiks, Philipsen, Stevens, Tan, & Vernooij-Dassen, 2000; Edwards Zarit, Stephens, & Townsend, 2002); by parent characteristics such as deteriorating health; by relational

characteristics such as having a strained relationship with the parent (Dautzenberg et al., 2000; Mui & Morrow-Howell, 1993), and by the resources available to the caregiver (Mui & Morrow-Howell, 1993). Once women have accepted the caregiver role, they nevertheless seem to provide care based on the parent's needs and regardless of work and other family responsibilities (Dautzenberg et al., 2000).

In a study of caregiver strain among black and white caregiving daughters using four predictor variables – role demand overload, role conflict, resources, and parent impairment or caregiver sociodemographics – Mui (1992) found that black daughters reported less role strain than their white counterparts. Conflict between caregiving duties and the caregivers' personal and social life, however, was a predictor for both racial groups in that personal interests and social opportunities are often forfeited to perform caregiving duties, regardless of ethnic identity. Interestingly, other predictors included poor perceived health, unavailability of respite support, and lower caregiving role demand for black women, and poor quality of parent-daughter relationship and work conflict for white women (Mui, 1992). A strong sense of filial obligation has been reported to neither encourage caregivers to become a caregiver nor reduce role strain but rather, encourages daughters to provide a greater level and more hours of care than sons (Dautzenberg et al., 2000). This sense of filial responsibility, however, varies across ethnic groups, and is typically more pronounced in African American families than in White American families, although role strain is still an issue (Foley, Tung, & Mutran, 2002; Laditka & Laditka, 2001; National Academy on an Aging Society, 2000; Stommel, Given, & Given, 1998; Williams & Dilworth-Anderson, 2002).

Dyadic identity development, a component of role theory, proposes that a mutually agreed-upon care identity is developed when both the caregiver and care recipient negotiate a set

of rules and boundaries as part of their particular caregiving dyad. Failure to accept these rules by one or both dyad members, with the exception to factors external to the actual help (e.g., balancing work and family) results in role strain and conflict. Negotiation, consequently, is imperative in each of these dyadic care relationships (Coeling et al., 2003).

Life course approach to caregiving. The tenets of the life course perspective originated from Rowntree's (1901) life cycle of poverty, which purported that families in early childhood, the childbearing years, and old age most significantly experienced the effects of poverty, with one spouse's income insufficient to provide for the entire family, and a decrease of income from employment in old age (Bengston & Allen, 1993). Based on Rowntree's theory, there are three important factors that should be considered when analyzing families:

1. Ontogeny, or individual development, has important linkages to family outcomes, such as in the case of the life stage of the individual wage earner and the poverty status of the family;
2. The pattern of linkages occur over historical time and across generations; and
3. The social, political, and economic contexts underlie important variations in those linkages, such as an old adult's change in income affects the link of individual income level to family poverty.

Thus, families should be analyzed according to the linkages among individual development (age), generational development (life cycle), and socioeconomic behaviors (timing of retirement) (Bengston & Allen, 1993). The life course approach is based on five distinct principles: (a) development and aging are lifelong processes, (b) individuals act with choices that construct their lives, (c) the timing of early and late events and roles affects their impact, (d) lives are embedded in relationships with other people and are influenced by them, and (e) changing

historical times and places profoundly influence people's experiences, such as the adjustment of children of the Great Depression in adulthood. Thus, a life course perspective links lives to institutional and historical change, and for assessing the personal impact of social trajectories in life (Elder, 1974, 1999). The life course perspective is applied to the role of caregiver within the family context below.

The life course approach views caregiving as a life course role that one is likely to enter and exit several times during adulthood (Campbell, Abolafia, & Maddox, 1985; Dentinger & Clarkberg, 2000; Marks & Lambert, 1997), which is an important factor to consider in meeting caregivers' varying needs for finances, education, access, and social support at any given time. Likewise, it is important to consider the developmental timing of transitions to and from the role of caregiver (e.g., employee versus retiree), the interrelation of other roles with the caregiving role (e.g., social support), and the collective patterns of caregiving across the life course and among the various cohorts (Dentinger & Clarkberg, 2000; Marks & Lambert, 1997), which may influence the types of supportive services and programs that are offered to caregivers based on their evolving needs. It is important to note that not all caregiving roles follow the same pattern, causing variability in caregivers' individual needs. For example, some caregiving roles are short-term, while others are more long-term in nature. An exemplary career of caregiving, as posited by Marks and Lambert (1997), follows the stages of role acquisition or the transition to the caregiving role, role enactment, which includes both in-home and the possibility of long-term care, and role disengagement or the ending of caregiving, bereavement, and social readjustment after the death of the care recipient. Thus, by giving more attention to the informal caregiving network, and including a sequential facet in examining the caregiving career, researchers and

practitioners can more successfully identify the needs and outcomes of caregivers during the various caregiving stages.

Smith, Folan, and Haaland (2002) identify four distinct stages of caregiving: early, moderate, late and bereavement. Caregivers in the early stages tend to view their caregiving experience more positively than those who are in the later phase of their caregiving trajectory. Those who care for someone in the middle stage often describe the difficulty of caring for a family member and the overwhelming nature of the experience. The late stage of caregiving involves the most emotional, physical, and financial output by the caregiver, and caregivers in the bereavement stage often describe feeling a sense of relief mixed with feelings of chronic grief (Smith et al., 2002).

The trajectory of caregiving differs among caregivers, and is a role that one may enter and exit multiple times as an adult. The timing of the caregiving transition, competing roles, historical context of the caregiving role, and the patterns of caregiving across the life course are important factors in examining the diverse role of family caregiver. Moreover, the caregiving experience varies by individual and by caregiving stage.

Characteristics of Informal Family Caregivers

A clear understanding of theory is important in examining the process of family caregiving. Likewise, an understanding of the characteristics of those providing care is equally important in considering family caregivers' needs, which vary by gender and ethnicity. In addition to the caregiver characteristics identified by the previous theoretical constructs, two important caregiver characteristics that should be examined concurrently are gender and ethnicity, as both factors affect one's approach to the caregiving role.

Caregiving is not confined to one gender over the other, as both males and females participate in caregiving to old adult relatives at least once during their lifetimes. As history reveals, however, women have performed the majority of both household and caregiving tasks (Abel, 2000; Newbern, 1994; Robison, Moen, & Dempster-McClain, 1995). Therefore, it is no surprise that women continue to maintain the role of primary family caregiver, although males assume the caregiving role to a different degree, both in prevalence and in the type of tasks performed (e.g., keeping track of finances as opposed to hands-on care) (Campbell & Martin-Matthews, 2003; Crawford, Bond, & Balshaw, 1994; Houde, 2001; Laditka & Laditka, 2001; Lauderdale & Gallagher-Thompson, 2002; Mathew, Mattocks, & Slatt, 1990; Navai-Waliser, Spriggs, & Feldman, 2002; Thompson, Tudiver, & Manson, 2000). The extent of care also varies among ethnic groups, such as African Americans, Asian Americans, and Latinos, in regard to family members' sense of duty or obligation to care for an aging parent (e.g., Franks, Pierce, & Dwyer, 2003; Groger & Mayberry, 2001; Killian & Ganong, 2002; Kolb, 2000; Lee & Sung, 1997; Zhan & Montgomery, 2003). Differences in family caregiving by gender and ethnicity will be examined below.

Gender. Approximately 59% to 75% of caregivers to old adults are women, with the average age of women caregivers ranging between 46 and 60 years (Arno et al., 1999; Health & Human Services, 1998; NAFC/AARP, 1997). These caregivers are most often married and, depending upon the level (e.g., ADL assistance versus medical assistance) and degree (e.g., short-term versus long-term) of care provided, work outside the home earning an average annual income of \$35,000 (NAFC/AARP, 1997). Navaie-Waliser and colleagues (2002a) report that women's work as family caregivers may be directed to a spouse, child, aging parent or other relative, as well as to members of the extended family (i.e., aunts, uncles, in-laws, grandparents),

and may include tasks ranging from hands-on provider (e.g., ADL and IADL assistance), care manager, companion, healthcare proxy, and advocate.

Increasingly, women are deciding to delay childbearing until their later 30s or 40s. Twenty-two percent of women aged 30-34, and 17% aged 40-44 have at least one child in the household (U. S. Census Bureau, 2003). Furthermore, as more women enter or return to the paid workforce, female employees are facing dual responsibility for dependent children and for their aging parents, in addition to balancing a professional career (Rosenthal, Martin-Matthews, & Matthews, 1996). Women whose traditional caregiving roles have become divided between young children and an aging parent are known as the *sandwich generation*, in that they are “sandwiched” between their dependent children, ailing parent, and their jobs (Ingersoll-Dayton, Neal, & Hammer, 2001; Schlesinger & Raphael, 1993; Nichols & Junk, 1997; Rosenthal et al., 1996). The NAFC and AARP (1997) report that 41% of caregivers of adults aged 50 and older also have children under the age of 18 present in the home. Although low-income and minority women have always worked outside the home, the existence of this segment of the caregiving population, however, is a phenomenon that has recently begun to receive increasing attention (Dautzenberg, Diederiks, Philipsen, & Stevens, 1998; Ingersoll-Dayton, Neal, & Hammer, 2001; Stephens & Townsend, 1997; Stephens, Townsend, Martire, & Druley, 2001).

Several studies incorporating feminist grounded theory have reported on the prevalence and workplace needs of caregiving women. For instance, Wuest (2000) reported that women use a process of repatterning, that is, reorganizing caring activities in order to enhance the gains (e.g., less of a sense of guilt) and limit the losses (e.g., role strain) of caring demands. Repatterning may be in the form of juggling time, setting ground rules, anticipating needs, and relinquish or replenishing personal resources through professional in-home care services, for example. Wexler

(1997) provided Congressional testimony regarding FMLA as an example of how federal policies—and the debates which fashion such policies—maintain and promote a system of policy stratification based on gender, race, class and marital and occupational status. Typically, White, married women with higher education levels are more aware of and more likely to utilize the provisions of FMLA than are their male or minority coworkers. Additionally, women more often serve as primary family caregivers than their male counterparts. Women also are more aware than men of their FMLA rights and thus more likely than men to utilize them. Consequently, the gender divide is prevalent in the role of family caregiver and in caregiving policy.

Males also provide assistance to aging relatives, although male caregivers tend to provide more assistance with IADLs than with ADLs or direct care (Houde, 2001; Laditka & Laditka, 2001; Lauderdale & Gallagher-Thompson, 2002; Navaie-Waliser, Spriggs, & Feldman, 2002). Women caregivers, moreover, may spend approximately 50% more time providing care than male caregivers overall (Family Caregiver Alliance, 2001). The ratio of female to male caregivers ranges from 63.1% to 35.1%, respectively (Spector et al., 2000) to 75% to 25%, respectively (Health & Human Services, 1998).

Ethnicity. The sense of duty of informal family caregivers not only varies across age, gender, and within individual family dyads and dynamics, but also among various ethnic groups (Dilworth-Anderson, Williams, & Gibson, 2002; Laditka & Laditka, 2001; Tennstedt, Chang, & Delgado, 1998). A study of American baby boomers revealed that a much higher percentage of Asian Americans (42%) provide informal care for older relatives than do white, non-Hispanic Americans (19%) (AARP, 2001). Similarly, the NAFC and AARP (1997) reported a higher prevalence of African American informal caregivers to adults aged 50 and older (29%), compared to 27% of Hispanic American caregivers. Likewise, approximately 43% of baby

boomers born outside of the U.S., compared to 20% of native boomers, provide care for aging relatives (AARP, 2001). Feelings of familial responsibility, or the obligation of an adult child to assume parent care and to meet the needs of his or her aged parent, emphasizes duty and is usually connected with protection, care, or financial support. African Americans typically express a stronger sense of responsibility within their family systems and tend to share more of a sense of kinship with both kin and nonkin compared to Whites. Given their strong familial-like ties to nonkin, African Americans are also more likely to receive informal caregiving and assistance from a nonfamily member (e.g., friend, neighbor) than are their White counterparts (Foley, Tung, & Mutran, 2002; Laditka & Laditka, 2001; National Academy on an Aging Society, 2000; Stommel, Given, & Given, 1998; Williams & Dilworth-Anderson, 2002).

Meeting Caregivers' Needs

It is important to explore caregivers' needs in that policies and programs can be designed and implemented to effectively meet these needs, which, in turn, allows caregivers to provide better quality of care to old adults. Caregivers have a variety of needs, including financial, educational, social, and structural. Each of these needs is further explained below.

Financial. Williams and colleagues (2003) reported that low-income caregivers have increased needs for support and education compared to caregivers who can afford to pay for their support services. Low-income caregivers also experience significantly greater caregiver distress than do caregivers who are not low income (Williams et al., 2003). It is important for the unique needs of lower-income caregivers to be considered in the formation of eldercare policy, particularly workplace policies such as FMLA. Education is also a common need among informal family caregivers, particularly in the area of ADL and IADL assistance (Diwan, Shugarman, & Fries, 2004; Houts, Nezu, Nezu, & Bucher, 1996). A more comprehensive,

family-friendly policy reform with local and national government involvement would provide financially disadvantaged informal family caregivers with necessary services (e.g., training, respite), paid and unpaid leave from the workplace, and financial assistance (e.g., vouchers) (Brubaker & Brubaker, 1995; Family Caregiver Alliance/National Center on Caregiving, 2002; Knickman & Snell, 2002; Laditka & Laditka, 2001; Marks & Lambert, 1997; Wisensale, 2003).

Education. In order to provide the best quality of care possible, it is important for informal caregivers to be educated on the full range of services that are provided in the community and the process for accessing these services, particularly in lower-income areas. Through increased education and training, caregivers are able to become better consumers of support services, as well as decipher and advocate for areas that need improving within the program to better meet their individual needs (Leith, 2005; Simon-Rusinowitz et al., 2002; Wilner, 2000). Various education and training models have been established to help educate informal caregivers, such as community workshops and forums; lectures followed by discussions; psycho-educational, skills building, and support groups; individual counseling and training; family counseling; problem-solving training; care coordination and management; and technology-based interventions (Chambers, Connor, McGonigle, & Diver, 2003; Houts, Nezu, Nezu, & Bucher, 1996; Toseland & Smith, 2001). Family caregiver education and skills training have also been reported to enhance caregivers' self-efficacy and promote positive views of caregiving, further producing more positive family caregiving outcomes (Hepburn, Tornatore, Center, & Ostwald, 2001; Huang, Shyu, Chen, Chen, & Lin, 2003; Schmall, 1995).

Accessibility. Caregivers' accessibility to services through a particular program, service accessibility, and the development of those services based on increasing or more specific caregiver needs (Houde, 1998; Kelly & Williams, 2005; Leith, 2005). A number of factors act as

barriers to caregiving services, such as low population density, low financial and community resources, lack of transportation, and poor communication between service providers and caregivers. Consideration of demographic, geographic, economic, and socio-cultural factors can assist case managers to better meet the needs of their rural-based, lower-income clients (Bushy, 2003). Increased accessibility to needed services, therefore, will assist caregivers in providing enhanced quality of care to old adults, particularly when caregivers' needs are fully met through access to various community services, such as long-term respite and individual counseling.

Concerning the role of ethnicity in serving as a barrier to accessing services, Li (2004) reported that approximately half of Asian American caregivers experience service barriers, such as those related to personal issues that caregivers often felt too proud to accept it, did not welcome outsiders in their caregiving role, unavailable services, bureaucracy too complex, or lack of qualified providers. With respect to unmet service needs, such as adult day care, meal services, and personal care, more than one half of caregivers reported that those services that were provided did not meet care receivers' needs. Additionally, the old adult's chronic conditions, caregivers' educational attainment, and levels of informal assistance were significantly related to unmet service needs (Li, 2004). Instances when one's ethnicity and residence determines access to caregiver services is also evident, such as in Korea where parental care is the norm and, consequently, formal elder caregiving services are limited (Chee & Levkoff, 2001), or ethnic disparities in accessing services (Crist, 2002; Hinton, 2002). Gender also plays a role in accessibility to community services, with women being more knowledgeable of available services, such as day centers, day hospitals, and formal respite services (Strain & Blandford, 2002), as well as greater awareness of FMLA policies in the workplace (Baird & Reynolds, 2004; Secret, 2000).

Technological advances also affect family elder caregivers' awareness of available services, particularly those residing in rural and lower-income areas. One recent solution to the issue of service accessibility for informal caregivers – regardless of gender or ethnic background – is technology-based delivery methods, such as videophone skill training, and one- and two-way interactive computer networks. Such technological advances may improve rural elder residents' and their family's access to services and information, individualize rural health and general care, increase rural health practitioners' continuing education opportunities, and improve quality and cost-efficiency of care (Buckwalter, Davis, Wakefield, Kienzle, & Murray, 2002; Czaja, & Rubert, 2002).

Social Support. Caregivers also have a variety of social support needs, including emotional (Chambers, Ryan, & Connor, 2001; Langford, Bowsher, Maloney, & Lillis, 1997), instrumental (e.g., respite, assistance with physical care, financial compensation) (Langford et al., 1997; Ploeg, Biehler, Willison, Hutchison, & Blythe, 2001), informational (Langford et al., 1997; Wackerbarth & Johnson, 2002), appraisal or evaluating the significance of one's caregiving role by self and other family members (Langford et al., 1997), and availability and sustainability of support groups (Langford et al., 1997; Monahan, Greene, & Coleman, 1992; White & Dorman, 2001). Increased social support allows caregivers to provide improved quality of care, particularly when there is equal distribution of caregiving tasks among family members and kin (e.g., friends, neighbors). Social support in the community is also beneficial when caregivers experiencing similar circumstances are able to come together to discuss their experiences among one another, provide feedback or advice, or to give helpful information on available services in the community.

Social support to family caregivers is provided in a variety of ways, such as community support groups (in-person or on-line formats) and peer discussion meetings as a forum to share experience among caregivers of all age ranges, employment status, and those providing various types of care (Leith, 2005). The structure of the service delivery system (Litwin & Lightman, 1996), family and household structure (Burton, Kasper, Shore, Cagney, LaVeist, Cubbin, & German, 1995; Peek, Coward, & Peek, 2000), and caregiving structure (e.g., only one caregiver versus more than one caregiver) (Dilworth-Anderson, Williams, & Cooper, 1999; Himes & Reidy, 2000; Neuharth & Stern, 2000) are also important factors in family caregiving. For example, Litwin and Lightman (1996) reported that needs-driven versus service-driven social care provisions, accessibility concerns and the aspiration for one-stop entry to the delivery system, and the growing involvement of the private sector in the delivery of domiciliary-based personal care services were all relevant issues for informal family caregivers. Hence, by considering the unique family, household, and caregiving structures, the various issues related to informal family caregiving will be most successfully understood and managed through the implementation of efficiently structured and comprehensive support services and programs.

Current Family Caregiving Policy

Previous caregiving policy analyses in gerontology have focused on the economic needs of caregivers (Williams, Forbes, Mitchell, Essar, & Corbett, 2003), the cost of informal caregiving (Fast & Frederick, 1999), and attitudes toward government policies that assist family caregivers (Miller & Mukherjee, 1999; Silverstein & Parrott, 2001). Much of the research on workplace policy and family caregiving has focused on the effects of family structure on the balance of work and family, and the need for employers and workplace environments to become more amenable to caregiving families (e.g., Bogenschneider, 2000; Gerstel & McGonagle, 1999;

Glass & Estes, 1997). Employed and unemployed caregivers alike often need similar types of assistance in performing their role as caregiver, such as in-home care, education on caregiving-related topics (e.g., how to perform ADLs more efficiently), and social and emotional support (e.g., having someone with whom to share caregiving experiences). As a result, two federally funded programs have been established with the intent to provide employed and unemployed informal family caregivers with the above services.

P.L. 103-3: Family and Medical Leave Act

As the Baby Boomers age and live longer through advanced medical technologies, the demand for family care will likely increase, and vouchers to receive in-home care services and telecommuting options for employees who are family caregivers to one or more old adults may be warranted (Brubaker & Brubaker, 1995; Knickman & Snell, 2002; Laditka & Laditka, 2001; Marks & Lambert, 1997; Wisensale, 2003). Given the various needs of families and the unresponsiveness of employers, there is an increased need for policies designed to support the employed family caregiver. Currently, the Family and Medical Leave Act (FMLA) (5 CFR 630.1201), implemented under the Clinton Administration in 1993, allows employees to take up to 12 weeks of unpaid leave in any 12-month period for the birth or adoption of a child, to care for a sick child, spouse, or parent with a serious health condition, or for the worker's own health condition. Additionally, employees are allowed to schedule a total of 24 hours of unpaid leave during any 12-month work period for school and early childhood educational activities, routine family medical purposes, and elderly relatives' health or general care needs. The policy also guarantees workers their job at the end of the leave, and requires the employer to maintain the same health benefits. Additionally, employees are required to notify their employers prior to

taking leave, and the employer may request medical documentation to justify the employee's absence (Wisensale, 2003; P.L. 103-3).

The FMLA applies only to companies with 50 or more employees (approximately 6% of U.S. corporations) and to those who have been employed for at least one year or 1,250 hours (60% of the U.S. labor force) (P. L. 103-3). Additionally, if employees decide not to return to work after they take a leave, the employer may require them to repay all health care premiums paid during the employees' absence. The policy allows a company to deny leave to a salaried employee who is in the highest 10% of the company's payroll, if the employee's leaving would put the business at financial risk (Wisensale, 2003). Between 1993 and 1995, nearly 15 million people used the FMLA for either personal reasons or to care for a family member. It was reported, however, that 3.4% of employees who needed leave refused it, and of those, about 66% reported that they did not use the FMLA because they could not afford it (Wisensale, 2003).

Amendments to the FMLA proposed by President Clinton to improve the policy's accessibility and affordability include employees taking up to 24 hours of unpaid leave per year to attend parent-teacher conferences or take a child to dental or medical appointments, and for the policy to cover more workers. Consequently, House Representative William Clay (Democrat, Missouri), who sponsored the original leave bill, introduced H.R. 91, the Family and Medical Leave Improvement Act. Under this bill, the employee cutoff requirement of 50 workers was changed to 25, and included elder care in the additional 24-hour provision proposed by Clinton. Likewise, in his commencement address at Grambling State University on May 23, 1999, Clinton proposed two new initiatives for the FMLA:

1. The Department of Labor was to explore ways in which states may use surplus unemployment insurance (UI) funds to subsidize parents who use the

FMLA to care for a newborn or newly adopted child, as well as to caregivers of old adults;

2. Federal employees should be permitted to use up to 12 weeks of accrued sick leave to care for a seriously ill child, parent, or spouse, as opposed to the original 13 days of sick leave per year (Wisensale, 2003).

Between May 23, 1999 and July 2000, 13 states introduced legislation that included a provision for paid family leave, including California, Connecticut, Georgia, Illinois, Indiana, Maine, Massachusetts, Maryland, Minnesota, New Hampshire, New Jersey, Vermont, and Washington. Although no state was successful in passing paid leave legislation, three states – Connecticut, Massachusetts, and New Jersey – proposed care that included coverage for elder care (Wisensale, 2003). For example, Connecticut's proposal was designed to use only UI funds to cover the birth or adoption of a child, whereas other leaves, such as time off for elder care, would be covered under a new Medical Leave Insurance Fund. Similarly, Massachusetts and New Jersey both proposed for UI to cover childbirth and adoption, but care of other family members would be funded through the Family Employment Trust Fund and Family Temporary Disability (FTD), respectively. In 2001, the number of states proposing paid leave doubled from thirteen to twenty-six. However, Hawaii, Indiana, Massachusetts, New Hampshire, and New Jersey were the only states to include coverage of elder care in their initiatives. Unfortunately, few states agree to provide support to caregivers of old adults, despite the growing elderly population and an increase in dual-earner couples (Wisensale, 2003).

Increasingly, caregivers are finding it economically necessary to remain in or enter the workforce at some point during their caregiving trajectory. A total of 25% of all employees provide care to an elder individual over the age of 65 (Bond, Galinsky, & Swanberg, 1998), with

58.1% of all caregivers for persons aged 50 and older employed full-time and approximately two-thirds employed either full- or part-time (NAFC/AARP, 1997). Among employed caregivers over the age of 65, two-thirds report having to rearrange their work schedule, decrease their hours, or take an unpaid leave in order to meet their caregiving responsibilities (Health & Human Services, 1998). Many family caregivers facing the dual role of employee and caregiver are turning to the Family and Medical Leave Act of 1993 for assistance to meet the demands of their simultaneous roles (Department of Labor, 2004). The purpose of FMLA is to accommodate the interests of employers, while also balancing the demands of the workplace with the individual needs of families, by providing employees the opportunity to take temporary 12-week leave for medical reasons, the birth or adoption of a child, and/or for the care of a child, spouse, or parent who has a serious health condition. It is also the goal of FMLA to uphold the Equal Protection Clause of the Fourteenth Amendment to minimize discrimination on the basis of gender for employees requesting leave, which is particularly salient for women who fulfill the majority of caregiving responsibilities in society (Arno, Levine, & Memmott, 1999; Health & Human Services, 1998; NAFC/AARP, 1997; Navaie-Waliser et al., 2002; U.S. Department of Labor, 2004).

Title III-E and Title VI-C: The Older Americans Act/National Family Caregiver Support Program

The National Family Caregiver Support Program (NFCSP), a federal law enacted under the Older Americans Act Amendments of 2000, supports family and other informal caregivers of old adults. The passage of the NFCSP was the first federal legislation to recognize the needs of family caregivers of old adults, and to provide services to support family and friends in their oft long-term caregiving role (Family Caregiver Alliance/National Center on Caregiving, 2002). The

NFCSP is authorized under the Older Americans Act and is administered by the Administration on Aging (AoA). The AoA provides state units on aging (SUAs) Title III-E formula grants to work in partnership with local area agencies on aging (AAAs) and faith-based services and community-service providers. These grants provide direct support services to meet the full range of caregiver needs, which could include information, assistance, individual counseling, support groups and training, respite care, and supplemental services to family caregivers of persons aged 60 and older, as well as to caregiving and custodial grandparents and other relatives of children under the age of eighteen.

Each SUA and AAA is given discretion in the use of these formula grants to provide the services needed by their local clients. Thus, AAAs within each state and across different states often offer different services. For example, in 2002, formula grants were made available to all U.S. states to run programs that provide critical support, including home and community-based services, to help families successfully maintain their caregiving roles. Additionally, caregiver program demonstration grants were awarded to 39 organizations, agencies, research institutions, and faith-based organizations to focus on systems development, service components, linkages to special populations to focus on systems development, service components, linkages to special populations and communities, field-initiated demonstrations to develop and test new approaches to support caregivers, and national projects that enhance the development of caregiver programs. Title III-E requirements, however, stipulate that it is optional for a state to provide families with additional assistance in allocating services and supports (AoA Executive Summary, 2003).

Caregivers' characteristics, such as ethnicity and gender, play a role in the type of services that are accessed by the individual, with men caregivers needing more IADL-related services, for example (Houde, 2001; Laditka & Laditka, 2001; Lauderdale & Gallagher-

Thompson, 2002; Navaie-Waliser, Spriggs, & Feldman, 200). One's ethnicity and gender often negatively affects his or her access to and knowledge of caregiving services, respectively. One's personal characteristics may, in turn, negatively impact the caregiving situation if the necessary services are not located to meet the specific needs of the care recipient. It is, therefore, important for service providers and caregiver support agencies to consider how ethnicity and gender can act as barriers to services and to work to reduce such barriers.

Since the enactment of the NFCSP in November of 2000, the AoA and the *Aging Network* have provided information to families to assist them in their caregiving roles, educated the public on the importance of supporting family caregivers, improved access to services, provided outreach to special populations and caregivers who may not have access to services, and permitted employees to continue participation in the workforce. In addition, the AoA is building new partnerships among informal caregivers, business and industry, and the government to promote family caregiver support systems (AoA Executive Summary, 2003). Such a collaborative approach will be most effective in supporting family caregivers of older adults (Bull & McShane, 2002; Chernesky & Gutheil, 2002).

Many services have been made available to informal family caregivers in several states under the NFCSP since its enactment in 2000. For example, occasional respite from caregiving has been found to be one of the most desired services by grandparent caregivers. To date, however, relatively few programs exist that offer short- or long-term respite services to family caregivers. One such program, the Oklahoma Respite Resource Network (ORRN), was created in conjunction with the Aging Services Division of Oklahoma's Department of Human Services. For the past 10 years, the ORRN has provided respite to low-income grandparents and other family caregivers. More specifically, caregivers have a wide array of choices of respite care

providers, with the only criteria being that they are 18 years of age or older and not household members, and a respite guide for families and providers is available. Department of Human Services payments are made directly to the respite care provider, and the State's eleven AAAs are funding partners, whose accounts are charged if an eligible grandparent caregiver in their service area participates in the voucher program. Currently, Oklahoma's NFCSP funds are being used to expand this program to reach more relative caregivers aged 60 and over, while other state funds are allotted to assist younger caregivers in need of this service (Beltran, 2001; Minkler, 2001).

As a result of the National Family Caregiver Support Program (NFCSP) initiative, a number of programs targeting both middle-aged rural caregivers in the workforce, as well as older employed and retired rural caregiving spouses are currently in the design phase (AoA Executive Summary, 2003; Buckwalter & Davis, 2001). The following are two examples of such programs in Iowa. Under the leadership of the Iowa Association of Area Agencies on Aging (with Betty Grandquist, Coordinator), a collaborative project is underway to assist caregivers in rural settings, involving the Iowa Association of AAAs, the State Unit on Aging, and the AAAs. The project combines case management with physical and mental health screening and referral to the nearest AAA where a family caregiver expert is introduced who has a background in human services and aging issues, and is knowledgeable about available community resources. A software program (ESP) developed by the Atlanta Regional Commission has been purchased which will provide a standard information and assistance network, a directory of resources, and match caregivers' needs to available services. Data will be collected statewide at the Association office, although each AAA will develop support services responsive to the needs of caregivers in their area. In addition, a toll-free number has been established in the movement toward a single

point of entry for services. An Iowa Family Caregiver Project Web page has also been developed, and a marketing and education plan is being established to provide consistency across the network (Buckwalter & Davis, 2001).

Another service currently underway as part of the National Family Caregiver Support Program, is funded by the Heritage Area Agency and operated by Elder Services Incorporated, Iowa City, Iowa. The program serves family caregivers in a seven county region and is comprised of two primary components: Information and Assistance (I & A), and Family Caregiver Counseling. The I & A Specialist receives inquiries from a nationwide toll-free telephone number and provides callers with information about appropriate state or local caregiver resources. A family caregiver counseling specialist works one-on-one with family caregivers in their home to assess their needs, develop a plan to address problems, and enable caregivers to successfully maintain their role in providing the best quality of care possible (Buckwalter & Davis, 2001).

Typically, a short-term counseling model consisting of one to six meetings supports caregivers during times of transition and assists them in making important decisions, and crisis intervention services are available. The counseling specialist may provide assistance in the form of I & A, skill building (e.g., caregiving skills training), short-term counseling, family mediation, and arrangement of appropriate community services and resources. Information is targeted to each caregiver's unique needs, which helps to alleviate their sense of isolation and to feel supported in their role. Family Caregiver Support services are funded by the NFCSP and are provided free of charge. The majority of referrals come from case managers who oversee services to care recipients involved in the Case Management Program for the Frail Elderly, a specialized program that offers a counseling specialist to address the caregiver's needs of frail

elders with unique requirements (e.g., assistive devices, nutrition needs), which may go unnoticed in the traditional case management program. Other referral sources include health care centers, aging service providers, and members of the local community (Buckwalter & Davis, 2001).

Most states have implemented a caregiver initiative, such as a respite care program or entitlement, or information and referral for caregivers (Neal & Wagner, 2001; Wagner, Hunt, & Greene, 2000). Although few states have developed programs to address the needs of working caregivers, New Jersey is one state that is in the planning stage of a systematic effort on behalf of these caregivers. The state commissioned a study and planning process, funded by the Grotta Foundation, and found that ongoing and collaborative outreach to the business community, employed caregivers, and the aging network strengthens the support available through partnerships, thus making known and supporting the heterogeneous needs of caregivers in the workplace (Neal & Wagner, 2001; Wagner, Hunt, & Greene, 2000). The State of Delaware has also recognized the importance of work-family issues to economic development efforts and has a link to information and resources on its Economic Development Office web page for Delaware businesses. The State of Oregon launched the Oregon Business and Aging Coalition, with a focus on educating businesses to understand the needs of their employees with elder care responsibilities and how they could best support these employees. Although funding for state staffing is no longer available, the Coalition continues to meet and pursue its goals as an interest group of the Oregon Gerontological Association (Neal & Wagner, 2001).

In 2001, a new demonstration project for working caregivers in St. Louis, Missouri, was funded by the Administration on Aging. The project, St. Andrew's Resources for Seniors, was funded to create a comprehensive model for cost-effective elder care management services.

Project objectives included identifying employers' awareness of the issues and barriers to their participation; quantifying costs of employee caregiving; collaborating with organizations to design cost-effective elder care management approaches; improving access to services and support; and educating employers on the issues and their impact. The goal of project staff is to develop a business advisory council, conduct a pilot project with 10 employers to evaluate alternative elder care approaches and provide assessments and services to approximately 1,000 caregivers, and conduct a general business education campaign (Neal & Wagner, 2001).

One final example of the provision of effective services to informal family caregivers is in fiscal year 2001, funds were provided to 56 states and area agencies on aging to provide multifaceted systems of support services for family caregivers. Project Grants (Title III-E) Funds are provided to public agencies and organizations such as state and local governments, private, public and nonprofit organizations, institutions and federally recognized Indian Tribal Organizations or Native American Organizations. The purpose of the funds is to promote quality and continuous improvement in the support provided to informal family caregivers through program evaluation, training, technical assistance, and research. Additional Project Grants (Title VI-C) Funds are provided to Indian Tribal Organizations and Native Hawaiian organizations to provide multifaceted systems or support services for informal family caregivers of old adults (P. L. 106-501).

Summary

There is no universal definition of informal family caregiving of old adults. The most common definition of informal caregiving describes one who is aged 18 or older providing unpaid assistance to a relative aged 50 or older living in the community, with or without dementia, and with at least one ADL and one IADL need (Alecxi et al., 2001; Health & Human

Services, 1998; NAFC/AARP, 1997; Spector et al., 2000). However, for the purposes of the current analysis, the definition of informal caregiving includes the in-home assistance provided by a family member to a non-demented old adult aged 65 and older with at least one ADL limitation (e.g., difficulty bathing, dressing, toileting).

The characteristics of informal caregivers, particularly gender and ethnicity, vary greatly from caregiver to caregiver, and these two primary characteristics play a significant role in caregivers' access to and knowledge of community services. Women typically provide care to an aging relative more often than do their male counterparts, and are often employed during their caregiving tenures, as well as caring for their young children (Rosenthal, Martin-Matthews, & Matthews, 1996) as part of the sandwich generation (Ingersoll-Dayton, Neal & Hammer, 2001; Schlesinger & Raphael, 1993; Nichols & Junk, 1997; Rosenthal et al., 1996). Men who do serve as family caregivers typically provide the more IADL-related assistance (e.g., managing finances), while women provide the hands-on ADL care (Houde, 2001; Laditka & Laditka, 2001; Lauderdale & Gallagher-Thompson, 2002; Navaie-Waliser, Spriggs, & Feldman, 2002).

Ethnicity, the second caregiver characteristic presented in the current analysis, also varies among caregivers and their sense of duty to the family (Dilworth-Anderson, Williams, & Gibson, 2002; Laditka & Laditka, 2001; Tennstedt, Chang, & Delgado 1998). Asian Americans and Hispanic Americans provide informal care to older relatives more often than their white, non-Hispanic American counterparts (AARP, 2001), although African Americans provide a greater amount of informal care to adults aged 50 and older than Hispanic American caregivers (NAFC & AARP, 1997). Furthermore, African Americans, with their strong sense of kinship ties, are more likely to both provide and receive informal caregiving from nonfamily members than are White Americans (Foley, Tung, & Mutran; 2002; Laditka & Laditka, 2001; National Academy

on an Aging Society, 2000; Stommel, Given, & Given, 1998; Williams & Dilworth-Anderson, 2002).

Americans are finding it economically necessary to participate in the workforce, which often simultaneously occurs at some point during their caregiving trajectory. Employed and unemployed caregivers need similar levels of assistance, such as in-home care, education and training, and social and emotional support, which further speaks to the importance of policies such as FMLA and NFCSP. The shrinking size of modern families, increased employment of women, increased longevity of Baby Boomers, and the increasing demand for informal family care and paid/unpaid leave under FMLA and related workplace policies are factors to be considered in implementing policies and developing programs for informal caregivers. The costs and benefits of informal caregiving to employers, communities, and to overall society are also important to consider in policy and program development. There are multiple financial costs to society in providing financial assistance to family caregivers, and these costs must be outweighed by the benefits of policy and program implementation (e.g., extended leave from work to allow for better quality of care to old adults and more productive caregiving employees). Moreover, caregivers deciding to care for an ailing aging relative in the home setting, as opposed to a long-term care setting, has saved society approximately \$196 billion in financial output (Arno, Levine, & Memmott, 1999). The primary focus of the current analysis is the investigation of the congruency between the needs of these caregivers and current policies, as well as the costs and benefits of the policies.

The link between theory and policy formulation and implementation in an attempt to develop a more comprehensive approach to understanding the role of family caregivers within the family system has become a salient research area. The effectiveness of FMLA and NFCSP in

meeting the four main needs of caregivers outlined in Chapter 2 – finances, education, access, and social support – will be included in the current analysis, based on the tenets of the current conceptual framework rooted in rational policy theory, social ecological perspective, role theory, and life course theory. The current policy analysis employs a framework that suggests the importance of the following concepts related to informal family caregiving: (a) multiple roles/role conflict, (b) family social location, (c) role expectations, (d) family development and change at various levels, (e) sociocultural and sociopolitical context, and (f) timing/role transition.

Competing familial roles and how one balances the demands of the caregiving role causes strain on one's social relationships with the care recipient and others. Therefore, these multiple demands within the caregiving role indicate specific needs within the workplace. The developmental timing of transitions to the caregiver role, competing roles in the family context, and the timing of life events such as retirement play an important role in shaping caregivers' needs. Additionally, social context, such as the location of families in the social structure (e.g., nuclear family structure, cultural context), sociocultural (e.g., kinship care) and sociopolitical (e.g., societal influences, economy), timing and sequence of family events, and family development and change should be considered at the macro and micro levels. It is equally important, moreover, to consider the entire family unit, as opposed to the caregiver-care recipient dyad alone, when examining family caregiving policy.

Chapter III

Materials and Methods

Theory and Policy Selection Criteria

The rational policy model served as the foundation for the theoretical framework. In the area of policy studies, numerous models have been developed to aid in understanding the various components associated with social policy. The rational model, for example, is based on a comprehensive assessment of all relevant alternatives to reveal the one option that will attain the desired goals and outcomes, meet articulated or anticipated needs, and is most efficient in implementation, as compared to other policy model alternatives (Dunn, 2004; Haas & Springer, 1998; Koff & Park, 1993; Munger, 2000). In that many policy researchers tend to view the rational model as the best available approach (Haas & Springer, 1998), the rational model was chosen over other models because its components make it a useful and appropriate tool for studying family elder caregiving as an entity that is reciprocally influenced by public policy (e.g., option for time off under FMLA for employed caregivers), and that can advocate for caregivers' needs (Koff & Park, 1993). For instance, community advocates on behalf of informal caregivers are an effective strategy for making the diverse needs of family caregivers known to policymakers. Informal caregivers themselves also can act as advocates to express their individual needs for policies and community services (e.g., long-term respite) and effect change in current government policies (Leith, 2005). Additionally, the rational model is often primarily used as a tool to reveal the barriers to rational planning and problem solving within the existing policy process, which is helpful in determining how to specifically restructure the policy in question (Koff & Park, 1993).

In order to determine the alternative that will best meet the intended goals and outcomes of a particular policy, application of the rational model to family caregiving requires the identification of relevant theories to support the chosen option. The selection criteria that were used to choose the theories for analyzing policies related to caregiving were that the theories are prevalent in the family gerontology literature and provide a solid foundation for examining the specific and varying needs of informal family caregivers to old adults. The theories that meet these criteria are social ecological perspective, role theory, and life course approach to caregiving. The social ecological perspective on caregiving, for example, examines caregiving as occurring in a complex social ecology, as opposed to focusing on the dyad of caregiver-care recipient alone. Alternatively, role theory clearly explains how the role of caregiver can produce strain on one's social relationships. This is particularly evident when faced with competing familial roles such as that of parent, and how one balances the demands of the multifaceted caregiving role. Similar to the social ecological perspective, the life course approach to caregiving considers the developmental timing of transitions of the caregiver role, the intersection of other roles (e.g., parent or employee) in relation to the caregiving role, and the patterns of caregiving across the life course (Moen, Robison, & Fields, 1994). Hence, the above theories provide a comprehensive view of the complex nature of family caregiving.

The FMLA and NFCSP were the focus of this analysis because of the prevalence of both programs in the caregiving policy literature and their direct financial, social, and structural effects on family caregivers and society. FMLA and NFCSP policies will be analyzed based on the rational model supplemented with social ecological, role, and life course theories. Based on this model, the FMLA and NFCSP were examined according to what each program offers, and suggestions provided to expand services that are warranted for informal caregivers in the future.

Design and Procedure: Analysis Framework

Based on the current theoretical perspective of family elder caregiving, and the costs and benefits to society of the current implementation of FMLA and NFCSP, the policy analysis research questions are:

- (1) What is the effectiveness of FMLA in supporting the following caregivers' needs?
 - a. Finances
 - b. Education
 - c. Access
 - d. Social support
- (2) What is the effectiveness of the NFCSP in supporting the following caregivers' needs?
 - a. Finances
 - b. Education
 - c. Access
 - d. Social support

A theoretical framework based on the rational policy model and supplemented with social ecological perspective, role theory, and life course approach to caregiving guides the analysis of the costs and benefits of current family caregiving policies and programs through the provision of a comprehensive understanding of the caregiver role, and determine policy effectiveness in meeting the various needs of informal caregivers. Taken together, these theories provide a comprehensive description of the multiple factors that are significant in the caregiver role. For instance, it is important to consider the entire family system in examining the caregiver-care recipient dyad and individual caregiving situations, including the timing of transitions to the caregiver role, balancing multiple caregiving roles, historical context of the family system and

caregiver role, type and level of care provided, and patterns of caregiving across the life course and throughout the caregiving trajectory.

Chapter IV

Results and Discussion

In the current normative policy analysis, the costs and benefits of FMLA and NFCSP will be examined from the caregiver's perspective, based on social ecological, role, and life course theories. Additionally, the effectiveness and limitations of each program will be critiqued based on the proposed framework of four primary needs of caregivers – financial, educational, social, and structure. Rather than describe the policy process, the current analysis will result in specific recommendations for reform in existing policies.

Theoretical Framework

According to rational policy theory, there are a number of costs and benefits to implementing the current FMLA and NFCSP policies, and these costs and benefits vary according to the perspective that is used. The following sections will address the major costs and benefits of FMLA and NFCSP for individual caregivers, based on each of the three theoretical components of the current conceptual framework (see Appendix A). First, important theoretical concepts are discussed as they relate to caregivers' needs. Second, FMLA and NFCSP are evaluated separately as to the degree of support offered to caregivers. Third, recommendations for future policy revisions are offered.

Social ecological perspective. Based on the tenets of the social ecological perspective, caregiving is examined beyond the caregiver-care recipient dyad and within the context of the entire family system (Moen, Robison, & Fields, 1994). As such, the benefits of the current FMLA policies include the consideration of the needs of the entire family, as opposed to the caregiver's needs alone, allowing leave for caregivers of both young children and aging parents. In terms of costs of informal caregiving, it is important for NFCSP's services to consider the

needs of the entire family (e.g., respite during weeks of family vacation), as opposed to the caregiver's needs alone. Additionally, both policies in question should consider as costs of informal caregiving the variances in individual caregiving situations, including the timing of transitions to the caregiver role, which is typically during crisis situations (e.g., after a divorce), the balancing act of multiple roles faced by caregivers (e.g., parenting young children simultaneously), and the patterns of caregiving across the life course (e.g., earlier caregiving career for adult child of older parents).

Role theory. With the increase in employment outside of the home, women are facing the challenge of balancing dual caregiving roles among school-aged children and an aging parent. This balancing act often produces stress and strain on female caregivers, serving as a major cost of informal caregiving (Chumblor, Grimm, Cody, & Beck, 2003; Evandrou, Glaser, & Henz, 2002; Starrels, Ingersoll-Dayton, Dowler, & Neal, 1997), and workplace policies such as those provided under FMLA should take into account the strain among family caregivers with multiple daily roles. For example, the provision of unpaid leave to care for an ill child *or* ailing parent needs to be more sensitive to the fact that today's caregivers are often faced by both types of care situations simultaneously, and should, therefore, be allowed either paid or unpaid leave to provide the necessary care to both parties. This allowance for leave from the workplace will, in turn, foster a more productive workforce, a major benefit for employers of implementing FMLA.

Life course approach to caregiving. In designing and implementing policies in support of informal family caregivers, such as FMLA and NFCSP, it is important to consider the costs of informal caregiving, such as the timing of one's transition to the role of caregiver, and the variances in caregiving situations (e.g., short-term versus long-term care arrangements). Furthermore, one's overall caregiving career may vary by the type of care (e.g., in-home versus

institutional care) required, effects of bereavement, and the social readjustment after the death of a care recipient. Thus, a great deal of consideration should be given to the costs of informal caregiving, such as the timing, length, and type of one's caregiving trajectory, which vary by individual caregivers (Dentinger & Clarkberg, 2000; Marks & Lambert, 1997), when implementing caregiving policies in the workplace and providing support services in the community.

Evaluation of FMLA and NFCSP

A theory-based analysis of the effectiveness of FMLA and NFCSP in supporting the various needs (e.g., educational, financial, social) of informal caregivers of old adults can be an effective approach to informing change. Applying a theoretical framework to the analysis of caregiving policies provides a better understanding of the caregiving role in the context of the caregiver-care recipient dyad, and services and programs currently available can be modified to more effectively meet caregivers' multiple needs. Policies designed to support both working and unemployed informal family caregivers are important in that they provide the foundation for program development and service implementation, as evidenced by FMLA and NFCSP. Without such policies, caregivers would lack the necessary supportive services, such as in-home care options, education and training, and paid leave, which would further increase individual stress levels and negatively affect the quality of care provided. The implementation of supportive policies for informal family caregivers, therefore, will positively impact the overall well-being of caregivers and care recipients alike.

Effectiveness of FMLA in Meeting Caregivers' Needs

Evaluation of overall costs and benefits. Rational choice theory postulates that company policy makers adopt leave policies in order to maximize profits by supporting employees to be

more productive while they are in the workforce, and to remain competitive with their corporate counterparts (Dye, 2005). According to the rational model, therefore, the benefits of FMLA would outweigh the costs in that employees needing – and being granted – leave would ultimately be more productive while in the labor force. It is estimated that the cost of informal caregiving in terms of lost productivity to U.S. businesses is \$11.4 billion annually (Metlife Mature Market Group, 1997). Therefore, a major benefit of FMLA support to informal caregivers is temporary leave and having the opportunity to devote their undivided attention to their caregiving responsibilities. Employed caregivers also have the ability to resume their career responsibilities following the end of their leave period, further supporting the promotion of a productive workforce, a significant benefit to the U.S. business industry. Such a policy, however, does not apply to all caregiving employees and, as a result, other policies are necessary in order to allow informal family caregivers to simultaneously balance work and caregiving responsibilities, without risking the company's profits and production.

Based on the tenets of the rational model, it is the goal that FMLA would only be implemented in the workplace if the overall costs to society were outweighed by the benefits of the policy. There are, indeed, literal financial costs to society in providing financial assistance to family caregivers, and these costs would have to be deemed as being outweighed by the benefits (e.g., better quality of care to old adults, financial savings in other areas). Costs related specifically to FMLA include increased financial pressure on employers to provide paid leave, and an implementation of telecommuting options, which can be expensive in terms of equipment and time, and may negatively influence the company's communication among on-site employees. Additional FMLA-related costs involve the provision of vouchers for in-home care,

further increasing the financial strain on employers, and the restrictions on FMLA to serve only larger companies.

Despite its numerous personal costs to caregivers, the monetary value of informal caregiving exceeds expenses for nursing home care and paid home services combined by \$81 billion, a major financial benefit to the larger society (Arno, Levine, & Memmott, 1999). A major benefit to society of informal caregiving is the decision to care for an ailing aging relative in the home setting, as opposed to placing them in long-term care, saving society significantly in financial output. Arno, Levine, and Memmott (1999) report that if the services provided by informal caregivers had to be replaced with paid services, it would cost an estimated \$196 billion. Moreover, in 1997, a total of \$83 billion was spent on nursing home care compared to \$32 billion for home care. Additional benefits of FMLA include the flexibility of 12 weeks of leave for employees, and the consistency of FMLA with the needs in the caregiving trajectory.

Finances. The 12 weeks of leave under FMLA are unpaid leave, which adds stress to the employee who experiences a great deal of conflict between maintaining economic stability and his or her role as family caregiver. If an employer does provide paid leave for less than 12 weeks, any additional weeks of leave necessary to achieve the 12 weeks of leave provided under FMLA may be taken without compensation, which again speaks to the stress faced by many caregivers striving to maintain financial security through their jobs. Furthermore, an employee may elect, or an employer may require the employee, to substitute any of the accrued paid vacation leave, personal leave, or family leave for any of the 12-week leave period, with a 30-day notice prior to the requested leave under FMLA, which may not be feasible for caregivers of old adults with chronic or acute illness. Employers may also request a medical note supporting the employee's need for leave, and may request up to three such medical notices prior to deciding to grant leave

(U.S. Department of Labor, 2004). Despite the provision of benefit packages, albeit minimal, to employees under FMLA, informal caregivers are estimated to lose an average of \$25,494 in Social Security benefits, an average of \$67,202 in pension benefits, and an average of \$566,433 in pre-retirement wage earnings per caregiver. These estimates combined, the result is a loss of \$659,139 over the course of the caregivers' lifetime (Metlife Mature Market Institute, 1999). Moreover, even if FMLA is supported by employers, workers are still at risk of losing certain benefits (e.g., return to same position, pension earnings) due to their caregiving responsibilities.

Education. Caregiver education is not the focus or the goal of FMLA. However, it is important for employers to consider the need for caregiver education for employees, and to implement education programs in the workplace or allow for leave for employed caregivers to attend training sessions during work hours. Training sessions may include topics pertaining to ADL and IADL assistance, challenges of disabilities and chronic conditions, cross-training of employees to compensate for absences, balancing work and family effectively, negotiating conflict, and stress management. Caregiver education will allow for a more productive staff by educating caregivers on topics that will prevent or delay problematic or crisis caregiving situations, further minimizing extended absence from work.

Social Support. While social support is not a major focus of FMLA, social awareness of FMLA and its provisions is a primary concern, as many caregivers are unaware of their entitlements under the Act and, consequently, do not take advantage of the title's provisions (Pyle & Pelletier, 2003; U.S. Department of Labor, 2004). An important element of FMLA is establishment and employee knowledge about the Act. FMLA requires that covered employers provide employees with notification of their rights (e.g., posting Act provisions in the workplace, listing provisions in employee handbooks). In order for FMLA to be successfully implemented,

both employers and employees must be aware of its provisions (U.S. Department of Labor, 2004). Among employees of both covered and non-covered establishments, approximately half reported they do not know if the Act applies to them (49.0% in covered establishments; 51.2% in non-covered ones). For employees in covered establishments, 37.9 percent reported that FMLA applies to them, compared to 22.4% of their non-covered corporate counterparts. Similarly, a significantly smaller percentage of employees in FMLA workplaces reported the Act does not apply to them, compared to employees in non-FMLA workplaces (U.S. Department of Labor, 2004). Baird and Reynolds (2004) report that few women and even fewer men are aware of their rights under FMLA. Researchers also have found that work situations more than family situations affect knowledge of family leave benefits, and that gender shapes the impact of some work and family factors on awareness, with women being made more aware of their FMLA rights than their male coworkers (Baird & Reynolds, 2004; Secret, 2000). Therefore, in order to increase employees' awareness of their entitlements under FMLA, workshops, discussion groups, or information sessions on the workplace premises, either during or following employees' work hours, would prove effective. Such efforts would promote employees' awareness of FMLA provisions, as well as provide an opportunity for employed caregivers to congregate and discuss pertinent work- and caregiving-related issues with their coworkers.

Access. FMLA allows employees to take up to 12 weeks of unpaid leave in any 12-month period for the birth or adoption of a child, to care for a sick child, spouse, or parent with a serious health condition, or for the worker's own health condition. Additionally, employees are allowed to schedule a total of 24 hours of unpaid leave during any 12-month work period for school and early childhood educational activities, routine family medical purposes, and elderly relatives' health or general care needs. The policy also guarantees the workers their job or an equivalent

position at the end of the leave, and requires the employer to maintain the same health insurance benefits. Additionally, employees are required to notify their employers prior to taking leave, and the employer may request medical documentation to justify the employee's absence (Wisensale, 2003; P.L. 103-3).

Effectiveness of NFCSP in Meeting Caregivers' Needs

Evaluation of overall costs and benefits. Examining NFCSP from the rational model perspective, the benefits of the program must outweigh the costs, which is evidenced by the fact that through the provision of various support services for informal family caregivers, old adults are able to continue to be cared for in the home, saving taxpayers billions of dollars per year (Arno, Levine, & Memmott, 1999). In fiscal year 2002, for example, Title III-E funding for the NFCSP was \$141.5 million. Formula grants were made available to all U.S. states to run programs that provide critical support, including home- and community-based services, to help families successfully maintain their caregiving roles in the home setting (Family Caregiver Alliance/National Center on Caregiving, 2002). NFCSP's provision of Title III-E formula grants through the AoA are currently optional per state. These grants would only be agreed upon if the monies were evidenced to benefit informal family caregivers through the provision of information, assistance, individual counseling, respite care, and the like (Family Caregiver Alliance/National Center on Caregiving, 2002). However, without a guarantee that the formula grants are benefiting informal family caregivers at some level, additional state funding is highly unlikely in the future.

Perceived benefits of NFCSP include the provision of comprehensive and flexible service options, increasing education and respite to promote more effective caregivers, assisting caregivers in becoming more discriminate consumers of available services, and the possible

delay of institutionalization of the care recipient. Benefits in the form of direct payments to caregivers are offered in some regions, and flexibility in the use of funds to meet the needs of regional residents is evident. Likewise, support of demonstration projects to explore creative and effective ways of meeting caregivers' and care recipients' needs, and an opportunity for interagency collaboration to more efficiently meet caregivers' and care recipients' needs are also perceived benefits.

Costs of NFCSP include the increased need for funding through grants to maintain the provision of caregiver support services, and to implement a universal standard across states and counties for the provision of comprehensive education and services without charge to family caregivers of old adults (Leith, 2005). Additional costs of NFCSP include a limited number of short-term or long-term respite programs to relieve role strain, and inconsistent program offerings across regions that may be based on what AAAs can provide instead of caregivers' needs. A lack of demonstration projects in other areas, warranting further attention to the sustainability of such programs, has also been perceived as a major cost of NFCSP.

In general, family caregiver support programs have been developed specifically to respond to the unique state infrastructures currently in place. The specific needs of caregivers identified by both formal (e.g., quantitative studies to test hypotheses) and informal (e.g., field notes of community service staff interacting with family members) data collection are also considered in the implementation of caregiver support programs. The distinct programs that have emerged demonstrate the commitment of the aging network to support caregivers in ways that respond to their various situations and needs (Administration on Aging [AoA], 1997).

Finances. NFCSP was not initially implemented to provide financial assistance to caregivers in that the program itself is primarily funded through grants to states. These grants

provide direct support services to meet the range of caregivers' needs, including information, assistance, counseling, support groups and training, respite care, and supplemental services (e.g., transportation, home-delivered meals). However, financial assistance continues to be a real need of many caregivers, and future efforts aim to increase funding to distribute substantial stipends to individual caregivers for supportive community- and home-based services. Additionally, NFCSP aims to include more caregivers as eligible recipients of these stipends (AoA Executive Summary, 2003; Leith, 2005).

Education. A primary goal of NFCSP is to educate caregivers on available services in order to become better consumers and more satisfied with services. The NFCSP provides to caregivers information on and referral to available service options in the community, assistance in gaining access to available services, individual counseling, and education (e.g., ADL/IADL needs), including web-based education options (AoA Executive Summary, 2003; Leith, 2005). Such training and education options would assist family caregivers in providing more effective care by allowing them to discriminately seek out services that best meet their full range of needs. However, grant money would be necessary to fund the provision of comprehensive caregiver support services, particularly in states and counties consisting largely of low-income residents who are unable to afford or access support services on their own.

Social Support. For social support of caregivers, NFCSP seeks to organize support groups across states and throughout communities where caregivers can congregate and discuss issues and challenges they are currently facing with their care recipient. Peer support networking and support among caregivers is a key component to NFCSP (Kelly & Williams, 2005; Leith, 2005). Peer support is vital for family caregivers in fulfilling their role with a sense that they are not alone, and gleaning insight from peers concerning care-related challenges and issues in order for

caregivers to become more effective problem solvers and, thus, better providers of care to their loved ones.

Access. Since its enactment, NFCSP has provided information to families to assist them in their caregiving roles, educated the public on the importance of supporting family caregivers, improved access to services, provided outreach to special populations and caregivers who may not have access to services, and permitted employees to continue participation in the workforce through FMLA policies. In addition, building partnerships and expanding outreach among informal caregivers, businesses, faith- and community-based organizations, rural health systems, national aging organizations, universities, and the government are important structural components of NFCSP to promote and expand family caregiver support systems (AoA Executive Summary, 2003). A collaborative approach to providing comprehensive caregiver support services under NFCSP would produce a high level of benefit to caregivers, as well as spread the potential costs of support services throughout several entities rather than holding the state or county solely responsible.

Combined, FMLA and NFCSP are effective in meeting the wide range of informal caregivers' needs. The workplace-related policies of FMLA speak more to the financial assistance – albeit minimal – and work environment-structural components of caregiver support, while NFCSP pertains more to the education and supportive aspects of family caregiving support. Therefore, implementing one policy or program over the other is not a practical solution to sufficiently meet the various levels of need of family caregivers. A feasible solution would be to make improvements to each policy and implement FMLA and NFCSP as a joint policy.

Policy Limitations

Each program, with its individual strengths, also has points of weakness. For example, FMLA needs restructuring to provide support for companies consisting of less than 50 employees, as well as more flexibility to address the heterogeneity of employed caregivers. Employers need to be more cognizant of individual differences in family caregiving situations and realize that not all caregivers have the same needs. A thorough understanding of these individual differences will allow for a more acquiescent and collaborative relationship between employer, caregiving employee, and fellow coworkers, further increasing work morale. The U.S. Department of Labor (2004) reports that employees are also unable to take leave on an intermittent or reduced leave schedule, unless the employee and the employer have a predetermined alternative agreement, with a maximum of 12 weeks still applicable in such circumstances. Moreover, an extended period of paid or unpaid leave beyond the original 12 weeks under FMLA is necessary for caregivers whose caregiving situations span 10 or more years. Under the current FMLA provisions, those caregivers in multiple roles (e.g., employee, parent, elder caregiver) are penalized, because their leave is spread across many needs. Flexible workplace policies would be a logical approach to supporting individual caregivers in the workplace.

Likewise, NFCSP is not without its demerits. In 2003, 86% of states reported a need for additional caregiver support, with the greatest need for additional respite and supplemental service support. Moreover, there is currently no system in place to support long-distance family caregivers of old adults. Most State Units on Aging (SUAs) and Area Agencies on Aging (AAA) expect the need for caregiver services and supports to increase, with these needs being met to a greater degree by NFCSP in the future through programmatic changes and additional funding

requests (AoA, 2003). SUAs have identified several challenges in implementing NFCSP, such as unawareness and inaccessibility of services by caregivers; developing comprehensive programs with limited budgets; reaching employed caregivers and employers of working caregivers; balancing flexibility with the need for structure in the design of NFCSP; meeting the match requirements associated with NFCSP despite severe state budget cuts; differences in AAAs' program resources and the impact on NFCSP program implementation; defining each of the services offered in NFCSP and ensuring that each service is provided; and coordinating state programs with the new NFCSP while avoiding duplication of services and conflicts in program administration. Many states have purported similar challenges, but state-specific differences in the way the challenges are addressed and whether the challenges are statewide or applicable only to some regions of the state are ongoing issues (AoA, 2003; Kelly & Williams, 2005; Leith, 2005).

Recommendations

FMLA

In general, there is a need for workplace policies to be expanded to smaller companies (e.g., less than 50 employees), and for the creation and provision of governmental subsidies for small businesses to enable small companies to continue to function. Workplace policies should also support family caregivers to become more individualized. More specifically, the multiple demands within the caregiving role should be considered in designing supportive services and workplace policies for caregivers. The timing of one's transition to the caregiving role, his or her competing roles in the context of the family, the timing of life events such as retirement, and the relationship of the individual to the care recipient (e.g., spouse, kin, neighbor, friend) should also

be considered in the reform of current policies, and in implementing more comprehensive and effective services and programs for caregivers whose individual situations widely vary.

Specific recommendations for improving current FMLA policies include, creating a mechanism for employee-employer communication, such as weekly or monthly forums or individual meetings where each party is able to make their needs known to the other, and allowing employees to file worker complaints when their needs as caregivers are not being fully met, or when they feel that they have been discriminated against due to their role as caregiver. Additionally, training human resource personnel and employees in educating caregivers, managers, and administrators on the needs of employed family caregivers, and providing employee education on caregiving issues, such as stress-management and resolving family conflict, each on the workplace premises, are also feasible recommendations. Employee education will also provide an opportunity for caregivers to discuss current issues they are facing as employed caregivers with their coworkers, which speaks indirectly to caregivers' social needs.

NFCSP

As is true of other human service programs, the program itself is only as strong as its components, and the professionals overseeing the program are the crux of the program's effectiveness. An initial step for NFCSP to become more effective relates to the negotiation between formal and informal caregivers and human service professionals that is imperative in understanding these unique and dyadic care relationships, and should be a goal of healthcare and social service employees in fostering and facilitating a positive relationship between the informal caregiver and care recipient (Coeling et al., 2003). Kelly and Williams (2005) and Leith (2005) reported several logical recommendations for programmatic restructuring of NFCSP and related community-based programs. First, there is a need for more formal, in-depth advocate training.

Professional expertise on behalf of family caregiver advocates will lead to active caregiver support and more effective program delivery. Advocate training should focus on networking, developing caregiver education components, and establishing community-based support groups. Furthermore, in-depth training should also make computerized entry of NFCSP data elements consistent across counties and states.

Secondly, augmentation of advocate training with web-based technology will also prove useful in today's technologically focused world. Web-based discussion boards, for example, may be a good way for both advocates and caregivers to post information and feedback, ask questions, and to discuss complex advocate cases and caregiver issues. A third recommendation tied to NFCSP is the close monitoring and sharing of results of standard data entry in order to provide consistent data entry methods across states and counties and within programs. Training in this area should include education on service definitions, standard data element definitions, and computer support (Glueckauf et al., 2004). State agencies should be able to easily access data pertaining to NFCSP services according to county or state at any given time. The hiring of effective caregiver advocates to increase awareness of NFCSP services among caregivers deserves further consideration. A consensus approach to the final hiring decision should be implemented. Such an approach would hold as top priority one's educational background, personal predilections, the ability to exercise autonomy within a flexible program, and to adhere to input from technical support staff, AAA directors, and experienced advocates to help launch the NFCSP forward in the future.

In terms of NFCSP itself, there is a need for a more uniform, statewide approach to program implementation and increased public awareness and recognition of the program. Advocates and AAA directors are in a prime position to provide feedback on service definitions

to increase their universality across states and counties. There also is a need for restructuring the delivery of the five program services, including respite and supplemental services, referral, education and training, and less of a sole focus on grant funding, which has the potential of hampering successful program outcomes for the caregivers and their families, who need tangible services and support programs as opposed to money alone to support their caregiving efforts. Additionally, a systems-level outcome analysis should be incorporated into future evaluation, with objective, measurable outcome indicators that can be feasibly assessed over time to establish trends in service use. Through such an analysis, program evaluators and stakeholders are able to determine if the program has been successful in reducing caregiver stress and decreasing institutionalization of care recipients. Furthermore, a top-down organizational analysis – such as a thorough assessment of organizational structures involved in the implementation of NFCSP – will be most effective in determining the proper allocation of funds, guidelines, and administrative decisions based on the current political climate of the state or region. Equally as important as a structured analysis, albeit challenging, is determining the interconnections between state, regional, and local aging services agencies in order to provide a better understanding of future program evolution and restructuring efforts (Kelly & Williams, 2005; Leith, 2005).

Based on the tenets of social ecological, role, and life course theories, the trajectory of caregiving differs among caregivers of old adults, and is a role that one may enter and exit multiple times throughout the life course. The timing of the caregiving transition (e.g., middle versus late adulthood), competing roles (e.g., work versus family), historical context of the caregiving role (e.g., retirement), and the patterns of caregiving across the life course are important factors in examining the diverse role of family caregiver. Moreover, the caregiving

experience varies by individual and by caregiving stage. The above factors are imperative for employers and policymakers to consider when implementing workplace policies and community programs in support of family caregivers of old adults. A collaborative approach involving family caregivers, employers, policymakers, and other stakeholders will allow for more effective and comprehensive provision of caregiver support.

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Appendix A

Rational Model Theory – Caregiving

Needs	Social Ecological Perspective		Role Theory		Life Course Perspective	
	Costs	Benefits	Costs	Benefits	Costs	Benefits
Finances	\$81B total in c/ging per year (Arno, Levine, & Memmott, 1999)	Save family finances by c/ging at home, as opposed to long-term care	C/ging role may influence financial obligations in other roles (e.g., child care, retirement)	Many women balancing elder and child care continue to work and earn income	>1 year c/ging = high costs	Save money on c/ging over the long-term than on nursing home expenses, depending on life stage of wage earner (e.g., employee vs. retiree)
Education	Need for training to encompass all c/ger needs (AoA Executive Summary, 2003; Leith, 2005)	Comprehensive training programs/options available to some (AoA Executive Summary, 2003; Leith, 2005)	Lack of information on variety of services; lack of knowledge of how to administer appropriate care	Enable c/ger to more effectively meet their multiple role demands	Changing needs of c/rer = need for ↑ edu for c/ger (Dentinger & Clarkberg, 2000; Marks & Lambert, 1997)	Improve adjustments to transitions related to the c/ging trajectory
Social Support	No universal standard across states and counties for familial, friend, or community-based (e.g., AAA, church) support in c/ging role	Family and fictive kin (e.g., friends, neighbors) support in c/ging role for all family members (e.g., c/ger, spouse, children)	Lack of family and community (e.g., church) support and involvement (i.e., support and prayer groups) when balancing multiple roles	Community support from church and support groups for parenting and c/ging roles	Lack of family and community support throughout c/ging tenure	Support from family, friends, and community throughout the c/ging trajectory
Access	C/gers' interpretation of service use as losing independence, not contributing to society	Formal and informal c/gers collaborate to meet c/rers' needs	Guilt; preferring to provide care on one's own (Hammer & Neal, 2001; Murphy et al., 1997; Wuest, 2000)	Services may help alleviate role strain and burden	Changing c/ging tenure = changing needs (Marks & Lambert, 1997) Timing – during crisis situations (e.g., illness) (Chumbler, Grimm, Cody, & Beck, 2003; Evandrou, Glaser, & Henz, 2002; LaRossa & Reitzes, 1993; Moen, Robison, & Fields, 1994)	Service availability may improve adjustment to c/ging trajectory

Rational Model Theory – NFCSP (Title III-E & Title VI-C)

Needs	Social Ecological Perspective		Role Theory		Life Course Perspective	
	Costs	Benefits	Costs	Benefits	Costs	Benefits
Finances (Kelly & Williams, 2005; Leith, 2005)	Need for stipends for low-income families/c/gers	Funded through state grants, as opposed to out of c/gers' pockets Old adults able to receive care at home, saving cost of institutionalization	Need for financial support in multiple roles simultaneously	Reduction of multiple financial demands (e.g., childcare, eldercare, retirement savings)	Financial obligations may change over time; potential to be compounded in old age Funding through state grants may run out over time	Funded through state grants, as opposed to out of c/gers' pockets
Education (Kelly & Williams, 2005; Leith, 2005)	Lack of education for low-income families = low quality of care	Education/training on c/ging topics (e.g., ADL assistance, stress management) to improve quality of care and lower stress and burden on family members	Lack of education/training for c/gers in multiple roles = increased stress, role strain, and role conflict.	Comprehensive training on range of c/gers' needs in conjunction with multiple roles (e.g., elder c/ger, parent)	Lack of training on c/ging issues pertaining to life stage of both = increased pressure and stress on c/ger	Training on topics (e.g., ADL assistance) to improve quality of care
Social Support	Lack of family and community support leads to increased pressure on c/ger	Increased support from family and kin = increased quality of care via multiple c/gers' assistance	Lack of family and community support = increased role strain and burden	Support groups with other c/gers who are also parenting children to develop effective coping strategies and time management	Lack of family and community support over life course = increased pressure to continue role as c/ger	Support from family and community over life course in c/ging role
Access (Kelly & Williams, 2005; Leith, 2005)	Need for more collaborative approach to outreach and community partnerships/integration of services among entire c/ging family	Increased access leads to more services to meet entire range of c/gers' needs (e.g., respite, counseling, info assistance/referral)	Multiple roles = multiple service needs to meet entire range of c/ger needs	Increased access to cover range of c/ger needs based on familial, ethnic, and gender roles (e.g., respite, counseling, info assistance/referral)	Lack of access to community-based c/ging services over life course and during c/ging tenure = poor quality of care over time	Access to range of services based on c/ging role in life course (e.g., employed vs. retired)

Rational Model Theory – FMLA (P.L. 103-3)

Needs	Social Ecological Perspective		Role Theory		Life Course Perspective	
	Costs	Benefits	Costs	Benefits	Costs	Benefits
Finances	Loss of paid work due to c/ging role = loss of family income	Clinton Adm.: \$ for child <i>and</i> elder care (Wisensale, 2003)	Need for ↑ \$ for multiple care recipients	FMLA under Clinton = services for c/gers of children <i>and</i> old adults	Longer than 12-week c/ging tenure; \$659,139 (loss in SS benefits, pensions, pre-retirement savings) (Metlife Mature Market Institute, 1999)	C/ger keeps job with same benefits after leave ends
Education	Lack of inclusion of entire family in c/ger training/education programs to enhance care provided and care experience	Flexibility based on family situation	Changing c/ger role = ↑ edu (on-going) – cuts into work hrs.	Family conflict resolution	Changing educational needs over c/ging tenure; if educational program is static, it will prove ineffective	Emerging education and training for c/gers to meet changing needs throughout life stages & c/ging tenure
Social Support	Unaware of c/gers' own needs and provisions under policy to help c/rer (Baird and Reynolds (2004; Pyle & Pelletier, 2003; U.S. Dept of Labor, 2004; Secret, 2000)	Family and employed c/ger support groups on-site during or following work hours	Having to balance multiple doctor's appointments between children and old adults	24 hours of 12-week- unpaid leave to tend to childcare and elder care needs (e.g., health, child education, general care)	Retired employees' benefit packages not including company's continual efforts to inform c/gers of provision of ongoing c/ger training/education at former worksite	Workshops, discussion groups, info sessions during or after work hours throughout employment and c/ging tenure
Access	Only available to companies with 50+ employees; does not consider family needs and how they relate to c/ging role	↑ social awareness of benefits on behalf of c/ger; focuses on c/ger – c/rer dyad for provisions (Baird and Reynolds (2004; Pyle & Pelletier, 2003; Secret, 2000)	Caring for child and older adult – “sandwich generation” (Ingersoll-Dayton, Neal, & Hammer, 2001; Schlesinger & Raphael, 1993; Nichols & Junk, 1997; Rosenthal et al., 1996)	Increased access = meet multiple roles effectively (e.g., parent, elder c/ger)	Need for policy to meet changing c/ging roles over c/ging tenure (Marks & Lambert, 1997)	Availability to support c/gers over time

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- Utilizing SPSS statistical programs extensively
- Survey, interview, and program and policy evaluation research techniques
- Conducting extensive literature searches, formulating hypotheses, developing data sets and data entry on SPSS, developing surveys and questionnaires
- Preparing and submitting research proposals and experimental reports to the Institutional Review Board (IRB)/Human Subjects Review Board (HSRB).

COMPUTER SKILLS:

- Extensive knowledge of SPSS; software used to analyze data for all major research projects
- Extensive experience working with EndNotes reference program

- Working knowledge of SAS, ATLAS Ti, and NUD*IST data programs
- Other familiar software programs include: WordPerfect, Microsoft (MS) Access, MS Excel, MS Outlook, MS Powerpoint, MS Publisher, Adobe Acrobat, QuickBooks, and GroupWise.
- 65 wpm

LANGUAGES:

- Working knowledge of verbal and written French and Spanish

CERTIFICATIONS:

- CPR, Virginia Tech, 2003-present
- Institutional Review Board (IRB), Virginia Tech, 2003

PROFESSIONAL EXPERIENCE:

Summer Conference Desk Manager, May 2005 –

Joey Wilkerson, MS, Summer Conference Coordinator
 Summer Conferences, Virginia Tech, Blacksburg, VA

Hiring and training 15-person desk attendant staff to operate cash register and handle money, checks, and credit card transactions; managing and balancing daily till monies and deposits; attending weekly staff meetings and providing input on the operation of the Summer Conference activities; interacting and communicating constantly with other staff, such as administrators, housekeeping/maintenance, as well as Conference guests and staff persons.

Graduate Research Assistant, August 2003 – May 2005

Drs. Alison Galway and Shannon Jarrott
 Adult Day Services, Virginia Tech, Blacksburg, VA

Assisting with activities for older adult participants; administrative duties; facilitating the biweekly Alzheimer's caregiver support group; facilitating weekly intergenerational activities with ADS participants and students in the Child Development Lab School; training new undergraduate and work study students on collecting data, using SPSS, and data management; assisting with various research tasks pertaining to current ADS research projects under the supervision of Dr. Shannon Jarrott.

Historian: Responsible for organizing all electronic photos for publication purposes.
Editor, quarterly ADS newsletter.

Graduate Teaching Assistant, January – May, 2005

Drs. Rosemary Blieszner and Michelle Stevenson
 HD 3004 – Undergraduate Human Development II course
 Virginia Tech, Blacksburg, VA

Maintaining a password protected Excel spreadsheet for students' personal information and grades; grading papers and quizzes/exams; formulating quiz/exam questions;

proctoring exams; photocopying; Blackboard administration; guest lecturing; holding office hours for students.

Graduate Research Assistant, May – December, 2004

Dr. Michelle L. Stevenson

Virginia Tech, Blacksburg, VA

ASPIRES Research Grant, Health Disparities Project

Assisting with survey development; conducting interviews; contacting local agencies and senior centers for potential participants; developing data sets; entering and analyzing data in SPSS.

Graduate Research Assistant, May – July, 2004

Dr. Tammy Henderson

Virginia Tech, Blacksburg, VA

Grandparents Raising Grandchildren Project

Literature searches; assisting with development of community services evaluation surveys; assisting with grant searches; contacting community agencies; coding qualitative data using ATLAS Ti.

Desk Attendant, May – August, 2004

Summer Conference Desk Staff

Virginia Tech, Blacksburg, VA

Operating cash register and handling money, checks, and credit card transactions; answering multi-line telephone and directing calls to appropriate individuals; recording and responding to voicemail and e-mail messages; photocopying and collating documents and handouts for conference staff and guests; word processing and data entry.

Graduate Research Assistant, August 2003 – May 2004

Dr. Karen Roberto

Center for Gerontology, Virginia Tech, Blacksburg, VA

Assisting with current research projects conducted by Dr. Roberto, such as literature searches, analyzing statistics, and administrative tasks.

Assistant Editor, Center for Gerontology quarterly newsletter.

Research Assistant, June 2002 – August 2003

Dr. Lisa Krissoff Boehm

Urban Studies Department, Worcester State College, Worcester, MA

Contacting potential sources (i.e., patrons of local senior centers) for the provision of oral histories for Dr. Lisa Krissoff Boehm's forthcoming book, *Attempting Double Victory: African-American Domestic Workers in the Industrial North*. Other duties include collecting and transcribing oral histories, organizing research data, and researching oral histories in the archives of the Schlesinger Library at Harvard University. All transcribed oral histories will be submitted to the archives at the University of Chicago Library.

Assistant Office Manager/Secretary, May 1998 – August 2003

Everlift Industrial Truck Service, Rochdale, MA

Answering multi-line telephone and directing calls to appropriate individuals;

recording and responding to voicemail and e-mail messages; photocopying and filing important documents; accounts receivable/payable; word processing and data entry.

Research Assistant, January – August 2002

Dr. Maureen E. Power

Urban Studies Department, Worcester State College, Worcester, MA

Conducting extensive literature searches; formulating survey questionnaires for participants and staff members of an intergenerational reading tutor program and contacting related agencies and program directors for program information; formulating registration forms for Elder Registration, fall 2002 at WSC; tutoring Urban Studies faculty on the use of various computer programs (i.e., MS Word, e-mail and Internet functions).

Writing Tutor, Spring semester, 2002

Writing Center, Worcester State College, Worcester, MA

Reviewing and editing traditional and ESL students' writing assignments, both in paper form and on-line, for correct use of grammar, punctuation, conciseness, and clarity.

Peer Advisor for the Dean of Academic Services and Freshman Studies, 2000-2002

Worcester State College, Worcester, MA

Answering students' questions pertaining to course schedules, academic calendar deadlines (i.e., last day to change major/minor); providing directions to specific academic and faculty offices on campus; answering multi-line telephone; developing, photocopying, and collating computer-generated publications for mailing to new undergraduate students and student employees; mentoring new student employees.

Dietary Aide, 1995-1998

The Meadows of Leicester Skilled Nursing and Rehabilitation Center, Rochdale, MA

Training newly hired employees; washing and putting away dishware and utensils; preparing meals for meal trucks according to residents' dietary specifications; serving meals to dining room residents and room-bound residents; sanitizing workstations; dating and organizing food/supply orders.

INTERNSHIP EXPERIENCE:

Social Worker Assistant, May – August 2001

Christopher Heights of Webster, MA, Assisted Living Residence

Becoming familiar with the rehabilitation staff and team approach; participating in the inquiry and pre-admission screening processes; compiling social histories, individualized care plans, and discharge plans; participating in interdisciplinary care planning conferences and social service therapeutic groups; becoming familiar with referral sources, community agencies, and other specialists in geriatric and rehabilitative services; and assisting the Activities Director with designing and implementing activities for residents of varying cognitive abilities, including Alzheimer's disease, on a weekly basis.

PUBLICATIONS:

Kemp, A. J. (2002). Worcester State Hospital: An urban asylum - The genesis and reformation of an urban asylum (1833-Present). *New England Urban Review*, 1(1), 9-21. Department of Urban Studies, Worcester State College.

Kemp, A. J. (2002, 1 October). Grade inflation nationwide problem: Professors agree WSC hit by trend. *The Student Voice*, 35(11), Worcester State College.

PAPERS SUBMITTED FOR PUBLICATION:

Kemp, A. J. & Mosher-Ashley, P. M. (2005). The influence of spirituality on coping with life in long-term care. Paper submitted to the *Journal of Religious Gerontology* (under review).

Kemp, A. J. (2005). All of God's children deserve A's: Grade inflation and the age of entitlement. Paper submitted to the *Academic Exchange Extra* (under review).

Stevenson, M. L., & **Kemp, A. J.** (2005). Medical service use and cultural health beliefs of older rural adults. Manuscript prepared for submission to *Journal of Psychology and Health*.

PRESENTATIONS AT PROFESSIONAL MEETINGS:

Kemp, A. J., & Stevenson, M. L. (2005, April). *Family elder caregiving and FMLA: A theoretical approach to a policy analysis*. Abstract submitted for presentation at the 26th Annual Meeting of the Southern Gerontological Society, Orlando, FL.

Jarrott, S. E., **Kemp, A. J.**, & Husser, E. (2005, September). *Achieving intergenerational goals through a results management approach*. Abstract submitted for presentation as a workshop at the 13th Biennial Conference of Generations United, Washington, DC.

Stevenson, M. L., Hayhoe, C. R., & **Kemp, A. J.** (2004, April). *Unbroken support: Predicting intergenerational resource transfers to adult children*. Paper presented at the 25th Annual Meeting of the Southern Gerontological Society, Atlanta, GA.

Roberto, K., Gigliotti, C., Husser, E., & **Kemp, A. J.** (2004, November). *Women's experiences with chronic health problems: Daily challenges and care practices*. Poster presented at the 57th Annual Scientific Meeting of the Gerontological Society of America, Washington, DC.

Morris, M., Jarrott, S. E., **Kemp, A. J.**, & Stremmel, A. J. (2004, November). *Intergenerational cross-training partners: Collaboration at a shared-site community*. Paper presented at the 57th Annual Scientific Meeting of the Gerontological Society of America, Washington, DC.

Kemp, A. J. & Mosher-Ashley, P. M. (2002, March). *The influence of spirituality on coping with life in long-term care*. Poster presented at the 73rd Annual Meeting of the Eastern Psychological Association, Boston, MA;

Id. (2002, April). Poster presented at the Third Annual Student Symposium for the Consortium Gerontology Studies Program, Worcester State College, Worcester, MA.

Mosher-Ashley, P. M., & **Kemp, A. J.** (2002, April). *Facilitating an understanding of statistics at the undergraduate level through an advanced research course*. Poster presented at the 17th Annual Conference on Teaching and Learning of Psychology: Ideas and Innovations, Ellenville, NY.

Kemp, A. J. & Mosher-Ashley, P. M. (2002, November). *The influence of spirituality on coping with life in long-term care*. Poster presented at the 55th Annual Scientific Meeting of the Gerontological Society of America, Boston, MA.

INVITED LECTURES:

Leisure and aging (2005, April). Guest Lecture at the Virginia Polytechnic Institute and State University, Undergraduate Human Development course, Blacksburg, VA.

Family caregiving and diversity (2004, April). Guest Lecture at the Virginia Polytechnic Institute and State University, Undergraduate Human Development course, Blacksburg, VA.

Sexuality and aging (2004, June). Guest Lecture at the Virginia Polytechnic Institute and State University, Undergraduate Human Sexuality course, Blacksburg, VA.

Careers in Gerontology (2004, September). Guest presentation at Virginia Polytechnic Institute and State University, Undergraduate Community Programs in Family Life course, Blacksburg, VA.

Grandparents raising grandchildren (2004, October). Guest Lecture at the Virginia Polytechnic Institute and State University, Undergraduate Human Development II course, Blacksburg, VA.

SCHOLARLY ACTIVITIES:

- Editor, *APEX*, Graduate Student Assembly, Virginia Tech, 2005 -
- Editor-in-Training, *Journal of Family Relations*, Department of Human Development, Virginia Tech, 2005 -
- Assistant Editor, *Humanity & Society*, Department of Sociology, Worcester State College, 2002
- Associate Editor, *New England Urban Review*, Department of Urban Studies, Worcester State College, 2002
- Student Representative for the Consortium Gerontology Studies Program at Worcester State College, 2001-2002

PROFESSIONAL MEMBERSHIPS:

- Sigma Phi Omega, Graduate Student Honor Society in Gerontology, 2003-present
- Southern Gerontological Society of America, 2003-present
- Gerontological Society of America, 2003-present
- Psychologists for Social Responsibility, 2002-2003
- American Association of University Women, 2002-2003
- President of Psi Chi, The National Honor Society in Psychology, 2001-2002
- Treasurer of Psi Chi, 2000-2001
- Inducted as a Member to Psi Chi, Spring 2000

HONORS AND AWARDS:

- Accepted into and graduated from the Honors in Psychology Program at Worcester State College, 2002
- Awarded the *Julia Mack Award for Intergenerational Service*, Urban Studies Department, Worcester State College, 2002
- Awarded the *Who's Who in American Colleges and Universities Award*, 2001
- Nominated for the *New England Psychological Association (NEPA) Honorary Undergraduate Scholar Award*, 2002
- Nominated for the *Gerontological Society of America Social Research, Policy and Practice Section Student Research Award*, 2002

REFERENCES:

The following persons have agreed to provide recommendations on my behalf at your request:

Academic References:

Dr. Rosemary Blieszner
313 Wallace Hall
Department of Human Development (0416)
Virginia Polytechnic Institute and State University
540.231.5437
rmb@vt.edu

Dr. Tammy L. Henderson
401B Wallace Hall
Department of Human Development (0416)
Virginia Polytechnic Institute and State University
540.231.2701
thender@vt.edu

Dr. Michelle Stevenson
Department of Human Development (0416)
315 Wallace Hall
Virginia Polytechnic Institute and State University
540.231.3194
mstevens@vt.edu

Professional References:

Dr. Alison Galway
Director, Virginia Tech Adult Day Services
102 Wallace Hall (0416)
540.231.3160
agalway@vt.edu

Mr. Michael Gaudette
Director of Food Services
The Meadows of Leicester Nursing & Rehabilitation Center
Leicester, MA 01524
508.892.4858

Michael "Joey" Wilkerson, M.S.
Coordinator, Virginia Tech Summer Conferences
109 East Eggleston Hall (0428)
540.394.3211
mwilkers@vt.edu