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PERCEPTION OF RURAL CAREGIVING

A Thesis Presented

by

Megan L. O'Brien, BS, RNC

to

The Faculty of the Graduate College

of


The University of Vermont

In Partial Fulfillment of the Requirements
for the Degree of Master of Science
Specializing in Nursing

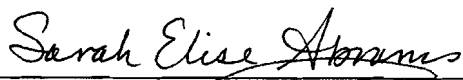
May, 2008

Accepted by the Faculty of the Graduate College, The University of Vermont, in partial fulfillment of the requirements for the degree of Master of Science specializing in Nursing.

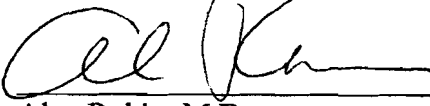
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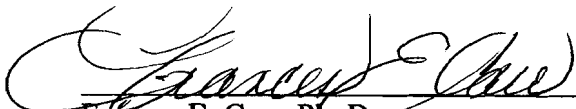
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ABSTRACT

Families providing informal care for loved ones face challenges with aging population expansion, shrinking families, and rising health care costs. Analysts predict a doubling of the aging population in the next half century, while concurrent decreasing birth rates propose a future mismatch of family caregiving resources. Similar trends are expected for the state of Vermont. With the majority of aging adults living in rural areas, an estimated 64,000 informal caregivers provide between 64 and 69 million hours of care annually, at an estimated market value of \$683 million dollars. Partnering with families to provide care within these constraints will necessitate understanding the impact of caregiving from the family perspective.

Role theory posits the experience of caregiving is influenced by personal and external resources. The purpose of this research was to investigate which variables produce strain or facilitate well-being within the rural informal caregiving role by investigating five identified domains: a) disrupted schedule, b) financial problems, c) lack of family support, d) health problems, and e) caregiver self-esteem. The previously validated *Caregiver Reaction Assessment* was distributed by six Vermont agencies serving rural elders to solicit subjective experiences to caregiving through a one-time survey.

When working with families, practitioners need to be sensitive to the dynamics of the caregiving relationship. The results of this study promote the understanding of variables influencing the caregiving role for rural Vermonters. Findings identified the domain of 'disrupted schedule' as the most impacted by assuming the caregiving role. The advance practice nurse can use these findings to advocate for families through barrier identification, education and resource allocation.

DEDICATION

This Thesis is dedicated to my Family
who provided me the inspiration for this
study, and the support to complete it

ACKNOWLEDGEMENTS

The challenging and rewarding process of completing this thesis would not have been possible without the help and support of many people to whom I will be forever grateful. My committee members Dr. Nancy Morris, Dr. Sarah Abrams, and Dr. Alan Rubin shared many hours from their busy schedule through e-mails, meetings, and the editing process to continually challenge and guide my efforts. I am thankful for my professors within the graduate Nursing program who fostered my professional development. I am particularly thankful for the warm patience and support from my advisor Carol Buck-Rolland, and the support from the Freeman Nurse Scholars program that made my education financially possible.

I was fortunate to meet several new individuals who made the implementation of this study a reality: Robin Way, director of Champlain Islanders Developing Essential Resources; Jeanne Kern, Central Vermont Council on Aging; Nancy Oakes, Northeast Vermont Agency on Aging; Laura Murphy, Champlain Valley Agency on Aging; Louise Rauh, Central Vermont Home Health and Hospice; Jeanne Hutchins, Megan Cross and Dr. William Pendlebury, the Memory Center at Fletcher Allen Health Care.

I am indebted to Alan and Pam Patunoff for sharing their expertise of survey design and statistical analysis with me. I'm appreciative of the support from my friend

Cassy Lamothe who was always willing listen to my frustrations, kept her fingers crossed, and knew never to ask “how’s the thesis going?”!

To my husband, Benjamin O’Brien, I owe more than I could write for the love and understanding he continued to provide while cheerleading me to the end; and our dogs Shannon, Fynn and Chase who quickly learned that my sitting at the computer was cue for them to go take a long nap. Also, I thank my loving family for their support and unfailing confidence that I would meet this goal.

Finally, I thank all the caregivers who participated in this study. Emotional handwritten sentiments that accompanied returned surveys gave me the strength to keep going with the hopes their sharing may help others in the future.

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CHAPTER I: THE PROBLEM

Introduction

The predicted doubling of the aging population (U.S. Department of Health and Human Services Agency on Aging [AoA], 2004) over the next half century presents a challenge for political, fiscal, and health resources. With one in four persons currently providing the primary source of assistance for both activities of daily living and instrumental activities of daily living for a loved one (AoA), the role of families as informal caregivers will be vital in serving the future needs of this expanding population

The degree of family involvement has remained constant for more than a decade despite trends in increasing geographic separation, greater numbers of women in the workplace, and change in the composition of traditional nuclear families (U.S. Department of Health and Human Services [HHS], 2003). This is despite efforts such as Vermont's Act 160 legislation of 1996 marking the State's efforts to transfer institutional care of elders to home and community (Vermont Agency of Human Services Department of Aging and Disabilities [VAHSDAD], 2007). The National Caregiver Health Promotion Survey (HHS, 2003) has identified primary caregivers to be spouses, adult children, friends or relatives. Approximately 38% of informal care is in the form of adult children caring for aging parents; the typical caregiver is female, 46 years of age, married, and employed outside the home (HHS, 2003).

When working with families to support caregiving, practitioners need understand the dynamics of the caregiving relationship. The purpose of this study is to advance

knowledge regarding the experience of caregiving, with particular focus on how rural individuals perceive burden and benefits from participating in this role.

Background

Aging of the generation identified as baby boomers (those born between 1946 and 1964), is predicted to double the population aged 65 years and older between the years 2011 and 2030 (AoA, 2004; U.S. Census Bureau [USCB], 2005). The cost of caring for this aging cohort will strain both funded and informal programs. In 2003 informal caregiving services were estimated to be valued near \$257 billion nationally (AoA). More recent estimates of informal caregiving services range between \$149 and \$483 billion dollars annually (Arno, 2006).

Vermont is projected to advance to 8th highest in the nation for population over 65 years old (USCB, 2007). The aging population combined with decreasing birthrates across the State will present a future mismatch for caregiving resources (VAHSDAD, 2007). An estimated 64,000 informal caregivers provide between 64 and 69 million hours of care in Vermont annually with an estimated market value of \$683 million dollars (National Family Caregivers Association & Family Caregiver Alliance, 2006). While other states are experiencing similar population trends, the Vermont aging population is distinctive with 81.8% residing in rural areas (USCB, 2007).

With the exception of parts of Chittenden County, all of Vermont is considered to meet the federal definition of rural (United States Department of Agriculture Economic Research Service [USDA ERS], 2007). The designation of rural is made by exclusion; it

is defined as a non-urban area with a population of less than 2,500 (United States General Accounting Office, 1993). Rural elders are more likely to live in poverty, be less educated, receive help predominantly from informal services, and have less access to services than their urban counterparts (Bedard, Koivuranta & Stucky, 2004; Tryssenaar & Tremblay, 2002; USDA ERS, 2007). It is unknown how Vermont families perceive caregiving of the aging population, or how their experience compares to other caregiving studies that historically investigated predominantly urban families.

Hypothesis and Aims

Informal family caregiving is a reality for many Vermonters. How individuals experience the caregiving role is subject to influence from both personal and external burdens and privileges. A role theory foundation (Goode, 1960) was used to determine which variables produce strain or facilitate well-being within the informal caregiving role. Five variables identified in a review of relevant literature tested how rural caregivers perceive selected dimensions of a) disrupted schedule, b) financial problems, c) lack of family support, d) health problems, and e) caregiver self-esteem in relationships caring for an older adult.

Conceptual Framework

Role theory was the supporting conceptual framework for this study examining perceptions of the caregiving role. Role theory posits that individuals possess the ability to partake in diverse roles and relationships, but each is comprised of unique sets of privileges and obligations. Well-being is the product of an individual's ability to retain

balance among varying life roles (Marks & MacDermid, 1996). Role theory has prominent opposing hypotheses regarding the impact of roles on an individual. Most commonly noted are the scarcity (Goode, 1960) and role accumulation (Sieber, 1974) hypotheses. A large extent of caregiver literature has focused on the scarcity hypotheses, with multiple roles thought to contribute to increasing stress (Goode). As a result of this assumption, many current burden evaluation tools seek to quantify burden objectively as a product of caregiving tasks. In contrast, the role enhancement hypothesis supports that multiple roles will create a positive experience by providing support, resources, social status, and self-esteem (Sieber).

Scarcity Hypothesis

The scarcity hypothesis, also known as role strain, includes role demand overload and role conflict. Goode's theory of role strain (1960) proposed an individual's unique role system will experience strain with conflicting role demands and obligations. The number of roles an individual could successfully manage is dictated by a finite amount of resources (such as time, energy, and finances), after which negative outcomes increase more rapidly than the number of role rewards (Goode). Role strain is not specific to one particular life role, but is a normative product of an individual's total life pattern of relationships, interactions and roles (Goode; Marks & MacDermid, 1996). Resource perception serves as a predicting variable for caregiver strain. In this study, key caregiving resources were defined by previous studies to include finances, personal health, time for self, and help from others.

While role demands are unique and individualistic, universal skills of role analysis and delegation can promote stability and well-being. During role analysis an individual evaluates their perceptions and actions about starting, maintaining, avoiding, or leaving a particular role (Goode, 1960). After introspective appraisal, strain can be reduced by choosing roles that are less demanding, are mutually supported by a social network, and present minimal inter-role conflicts (Goode).

The second method of mitigating role strain is the process of creating role structure through bargaining and delegation with self and others (Goode, 1960). Resources impacting the bargaining function relate to social position, transactional relationships, desire to perform the role, context of the role, and presence of situational urgency or crisis (Goode). Intimate family relationships serve key functions in both role allocation and support, with individuals living in urban society assuming more life roles (Goode). This study collected both subjective perceptions and demographic measures of intrinsic and extrinsic resources to better understand the rural experience of the caregiving role.

Role Accumulation

In the absence of evidence that role strain causes societal destruction or chaos, Sieber (1974) proposed an alternative theory of role accumulation. In contrast to Goode's theory of finite resources, Sieber postulated role demands and resources were dynamic and flexible over time. In the role accumulation framework, stressors from multiple roles are offset by the greater opportunity for benefits and gratification as a result of plural

roles. Sieber proposed four rewards of role accumulation: role privilege, security of social status, enhanced resources, and intrinsic enrichment and gratification.

Role privilege through expansion of multiple roles provides opportunities for personal motivation and self-esteem, while socially advancing authority and value within relationships (Goode, 1960; Sieber, 1974). Similarly, role expansion with increasing role quantity may work to dilute responsibilities and increase resources through networking (Goode). Caregiving privilege suggests increased availability of choice and benefits, but Sieber cautions that recipients' failure to endorse role rewards may lead to the caregiver renouncing their duties.

Roles & Caregiving

Individuals identify with multiple life roles and the growth of the aging population is likely to cause many families to experience duties of providing informal care. Role theory as a conceptual framework serves this research well as it facilitates unique perceptions to emerge as a result of varied resources and interpersonal relationships. Subjective burden captured in this study can be defined as the caregivers' perception, attitude and emotional reaction to caregiving experience (Montgomery, Gonyea & Hooyman, 1985).

With the divergent hypotheses of scarcity and accumulation both supported in caregiving literature, a previously validated tool known as the Caregiver Reaction Assessment (CRA) was selected for this study based on its unique ability to capture both positive and negative responses regarding this role (DeFrias, Tuokko & Rosenberg, 2005; Given, Given, Stommel, Collins, King & Franklin, 1992; Nijboer, Triemstra, Tempelaar,

Sanderman & van den Bos, 1999). This study examines how variables within the caregiving role influence the perceptions of burden or benefit when providing care to an older adult. Findings from this study will assist health care professionals to understand the dynamics of informal family caregiving.

Significance

When advocating for healthy families it is important health providers understand how the demands and responsibilities of caregiving are perceived. With a large portion of research examining the caregiver role from urban perspectives, this work investigates the less understood phenomenon of rural caregiving.

The North American Nursing Diagnosis Association (NANDA) acknowledges the pressures of caregiving through the nursing diagnosis of caregiver role strain (Gulanick, Myers, Klopp, Galanes, Gradishar & Puzas, 2007). The caregiving process requires the acquisition of skilled tasks, interpersonal communication, and resource management. With limited health care resources it is paramount to develop programs that maximize efficiency and create rewarding experiences for participants. Identifying caregiving as a concern of nursing fosters the development of systems for assessing, intervening, and monitoring outcomes necessary to sustain the individuals who will serve this role (Gulanick et al., 2007).

Implications for Advanced Nursing Practice

Guided by the National Organization of Nurse Practitioner Faculties (NONPF) domains of practice, the advanced practice nurse (APRN) demonstrates competence in

the professional role by promoting health and wellness through practice based on theory and research (2006). Results of this study provide insight regarding the perceptions and dynamics of family caregiving. This information can serve as guidance during interactions between the APRN and family by serving to anticipate their needs, and advocating on their behalf as appropriate.

In Chapter II a review of the literature is presented regarding the current state of science regarding caregiving perceptions. With caregiving undoubtedly a concern for the future, there continues to be a paucity of research examining a primary caregiving cohort, the rural caregiving daughter. Of additional concern is the propensity of caregiving research to seek validation of subjective caregiving perceptions through objective measurements of burden. These trends are presented in chapter II while suggesting the need for further research of rural caregivers.

CHAPTER II: LITERATURE REVIEW

Introduction

This chapter reviews research regarding the experience of providing care for an older adult. The systematic process of collection and analysis was driven by the theoretical framework: investigating the perceptions of burden within the caregiving role. Five variables contributing to perception of responsibility or privilege were explored: disrupted schedule, financial problems, lack of family support, health problems and self-esteem. Common themes and divergent findings are highlighted.

Search Strategy

Previous studies investigating the perceptions within the elder caregiving role were reviewed in 2005 and 2007 using electronic searches of: The Cochrane Library, CINAHL, HAPI, MEDLINE (including In-Process and other non-indexed citations), and PsychINFO databases. Key word searches of caring, caregivers, women, rural, parents, and daughter were unrestricted to publication date but restricted to primary research in the English language. Quantitative and qualitative studies were collected to provide different perspectives on the caregiving experience. Articles were scanned by title with those appearing to study the experience of caregivers further examined by electronic abstract.

Filtering and Analysis

Fifty-six articles were collected from bound and electronic journals for in-depth review. Studies were examined to identify the objective, population, duration, methods, underlying theory, limitations, and findings. Twenty-one papers were selected that met the focus of this review to present how individuals perceive variables impacting the caregiving role. Table 1 provides a summary of the key features of articles included in this review.

Findings

Disrupted Schedule

Individuals experience the sum of their relationship patterns. Incompatible pressures between the requirements and responsibilities within relationships represent the normative process of inter-role conflict (Goode, 1960). In the absence of an established routine, the beginning of the caregiving relationship is marked by a period of trial and error. Caregivers described this time period as being hectic, stressful, and full of uncertainty (Bull & Jervis, 1997). When care produced interference within personal and social lives caregivers experienced depression, negative self-concept, and poorer physical health (Cheung, Yui-huen Kwan & Hung Ng, 2006; Dautzenberg, Diedricks, Philipsen & Frans, 1999; Kim & Lee, 2003). Perception of disrupted schedule may be related to the number of additional roles a person assumes, or may be a result of cumulative role demands causing resource depletion.

The scarcity hypothesis posits that plural roles will result in strain when one or more demands is not addressed satisfactorily (Goode, 1960; Wuest, 2000). Quantity of role participation as a predictor of stress was supported by Dautzenberg et al. (1999), who identified lower levels of stress in the caregiving role when women participated in fewer life roles. Similarly, in 2004 Van Excel, Brouwer, Van den Berg, Koopmanschap and Van den Bos, found non-spousal caregivers experienced role strain when simultaneously maintaining a home, family, and career. It is possible that acting as a non-spousal caregiver is inherently stressful, but Dautzenberg and colleagues found no association between parent caregiving and increased strain when the confounders of multiple roles (mother, spouse, and employee) were controlled.

Goode's scarcity hypothesis proposes time as a limited resource that concurrent roles deplete and result in the perception of role strain (1960). Time commitment constraints were identified by caregivers as more stressful when providing more caring hours per week (Brouwer, van Exel, van de-Berg, Dinant, Koopmanschap & van den Bos, 2004; Jacobi, van den Berg, Boshuizen, Rupp, Dinant & van den Bos, 2003; Navaie-Waliser, Feldman, Gould, Levine, Kuerbis & Donelan, 2002). Strain regarding time was attached to responsibilities both directly and indirectly. Directly the time to complete tasks was found as burdensome. A regression analysis performed by Brouwer et al. (2004) found only time spent on housecleaning to significantly contribute to higher subjective burden. Indirectly, caregivers experienced inter-role conflict with leisure activity restriction. Rural caring was found to be protective as caregivers reported more leisure and physical activity than urban caregivers (Bedard, 2004; Parris-Stephens,

Townsend, Martire & Druley, 2001). Overall, findings exploring the burden of disrupted schedule suggest the need for balance between caregiving demands and other roles to facilitate well-being.

Goode's concept of role analysis is a process in which individuals reduce role strain through careful resource and role selection (1960). "Juggling time refers to purposeful efforts to order responses to caring demands for optimum harmony..."(Wuest, 2000, p.404). The decision to initiate the caregiving role occurs after a process of consciously deciding what will be sacrificed as a result of added demands. This assessment is mediated by internal perception of ideals, rewards, and availability of resources to provide a sense of control in the situation (Wuest). This would suggest that the ability to evaluate internal and external resources should promote role patterns within an individual's capacity for well-being.

The process of identifying resources starts with the caregiver seeking information through reading and questioning others for advice (Wuest, 2000). After a period of fact finding, the caregiver begins to piece information together about what works, what services are able to be utilized, and how this could be incorporated into the daily schedules and routines of the family (Bull & Jervis, 1997). This individual course of structuring will facilitate participation in concurrent roles. Reasons cited for hesitancy to accept help or utilize services were: lack of confidence, discomfort in asking for help, or unprepared for transition on the part of the caregiver (Wuest). Interventions found to overcome these barriers promoted development of interpersonal social skills which resulted in higher levels of role adaptation (Brackley, 1992). Successful transition to the

caregiving role encompasses learned skills such as organization and communication that must be internalized. Without understanding how caregivers perceive their capabilities, programs targeting caregiver strain by superficially listing available resources will fall short.

While the experience of disrupted schedule may be a product of the caregiving role, there are multiple contributing variables. If the scarcity hypothesis is supported, the quantity and tasks of plural roles are predictors for resource depletion and resulting role strain. Alternatively, role enhancement may result from multiple roles as increased connections and relationships afford new opportunities for resources (Goode, 1960; Seiber, 1974; Wuest, 2000).

Financial Problems

While not unique to the caregiving role, the perception of financial burden was identified in several studies. Monetary burden presented as direct concern over finances as well as indirect strain over quality of life and relationships. Wuest (2000) identified lower incomes correlated to fraying connections of caregiver relationships. Inter-personal conflict as a result of financial stressors may negatively impact the caregiver-care recipient relationship and promote resentment toward the care recipient. Similarly, it is possible that lower income is an independent risk factor for caregiver burden.

Employment was a theme commonly identified in caregiving studies reviewing financial strain. Variables investigated surrounding employment included quantity of hours worked, time conflict, and social isolation. For employed caregivers the number of worked hours correlated with negative quality of life indicators for patient and caregiver,

while leave of absence or resignation was conversely found to reduce caregiving burden (Brouwer et al., 2004). Unemployed caregivers perceived fewer resources were available and required more assistance with identifying community resources (Hawkins, 1996; Pohl, Given, Collins & Given, 1994). In contrast, Hawkins and Pohl et al. found employment to have a protective effect for caregiver well-being, thus supporting the role enhancement hypothesis.

While serving multiple roles simultaneously, van Excel et al. (2004) found that caregivers identified lack of time and resources as predictors for financial strain. Under the scarcity hypothesis, role elimination should promote a reduction in strain. This was supported by Brouwer's et al. 2004 finding that removing the responsibilities of the employment role reduced caregiving burden. Women who had quit their jobs to assume the caregiving role were older, more involved in providing care, had less income, education, and social support (Phol et al., 1994). Phol et al. identified higher levels of depression and decreased health among unemployed caregivers as they became more socially isolated and financially dependant.

Socioeconomic dependence was identified by several studies as a factor contributing to women accepting the caregiving role. Kramer (2005) inferred that family caregiving may be thought of as social labor, similar to household labor, which is unpaid and discounted in value. Through the current social structure which links capital directly to status and power, some women were obligated to provide care and would not have elected this role if they had been financially independent. Guberman, Maheu and Maille (1992) illustrated cases of female caregivers that did not have access to financial funds or

a home. Such cases were representative of women forced to provide care for a husband's parent when the husband was the wage earner, or care for a parent who had superior housing and financial status. Lower income and less control over finances were risk factors for vulnerability (Forssen, Carlstedt & Mortberg, 2005) and depression (Cheung et al., 2006) in women.

Of interest were conflicting trends illuminated by Phol et al. (1994) and Brouwer et al. (2004) who showed that as caregiver income increased, so did negative reactions and outcomes. The authors hypothesized that lower income caregivers had more resiliency due to lifestyles accustomed to adversity when compared to the protected life of the affluent. Another idea presented was the possibility of guilt resulting from the ability to provide resources financially in conflict with the expected societal norm to become the caregiver.

Lack of Family Support

Behavior that becomes habit grows to be unquestioned and representative of a societal standard (Kramer, 2005). Societal values of filial piety provide the moral foundation for family caregiving (Kim & Lee, 2003). Conflict within the caregiver role was experienced when caregivers reported feeling unsupported by other family members (Kim & Lee). Diminishing negative experiences of caregivers will require a vigorous re-evaluation of societal practices that see family caregiving as the expected and devalued work of women (Kramer).

Caregivers who reported burden due to a lack of family support also identified financial concerns, decreased physical strength, and lower self-esteem (Brouwer et al.,

2004; Jacobi et al., 2003). The same factors, when studied by De Frias et al. (2005) and Pohl et al. (1994) were mitigated by the presence of social and family support. The need for additional support increased as parents required more care with highest burden scores found where the care recipient was on a waiting list for professional services (Brouwer et al.; Cheung et al., 2006; Cicirelli, 2003). Sharing the demands of caregiving with outsiders led to increased stress in the caregiving relationship due to resource scarcity, having unfamiliar persons involved in care, and variations in cultural background (Bull & Jervis, 1997).

Family caregiving is viewed as both a social relation and a social act, duties women are expected to fulfill (Guberman et al., 1992; Kramer, 2005; Pohl et al., 1994). Women described social pressure to take on caring work originating from childhood (Forssen et al., 2005), and are considered to be socially vulnerable with expectations to assume care in a society that undervalues caring (Pohl et al.). Parris-Stephens et al. (2001) investigated conflict between simultaneous roles of female caregivers: daughter, wife, mother and employee. While 96% of the women experienced conflict, the majority reported the most conflict to be associated with the parent care role. This was also supported by Dautzenberg et al. (1999) and Hawkins (1996) who found caregiving daughters to have higher stress scores than women not providing care. Rural caregivers are also more likely to have non-spousal relationships (Bedard et al., 2004). In general, women experiencing parent care conflict tended to have parents who were more impaired while they, as caregivers, were less educated, had lower incomes, and were employed in lower status occupations.

Effective family caregiving was a product of organization and communication skills. The ability to create routines and define expectations served to facilitate common understandings while limiting conflicts and disagreements (Wuest, 2000). Decision making by daughters in the caregiving role was found by Cicirelli (2003) to be the additive effect of both the caregiving daughters and care-recipient mothers' beliefs about paternalism. Caregiver beliefs about paternalism influenced the degree of conflict experienced when making decisions for a parent, but were not found to affect the satisfaction caregivers perceived over decision making responsibilities (Cicirelli, 2003). Cicirelli posits a cultural theory regarding how families transition through role changes, and proposes that older mothers believe adult daughters should assume the role of caregiver and decision maker. Care-recipient mothers perceived that daughters were acting from a position of genuine best interest. They accepted the transfer of autonomy and trust, and were open to the opportunity to reconnect with their family (Cicirelli, 2003). Not all transitions were received seamlessly. Caregiving daughters reported interference when the care-recipient parent dictated the selection and distribution of the caregiving role (Cicirelli, 2003). Higher levels of guilt in the caregiving role were experienced when the decision to provide care was made by someone other than the caregiver (Guberman et al., 1992).

Married female caregivers use both physical and emotional resources to attend additional roles of homemaker, mother, and spouse; illustrating that perception of responsibilities and task distribution affect role performance (Forssen et al., 2005). How caregivers perceive relationships will impact their experience as demands and resources

overlap among roles. Women who felt they prioritized their roles as mother and spouse reported a higher degree of content with caregiving, while marital disagreement was found to correlate with poorer mental health and increased depressive symptoms (Center for Demography and Ecology [CDE], n.d.; Forssen et al.).

Among multiple roles, the quality of spousal relationship was specifically found to influence women's satisfaction and well-being when providing care for a spouse or biological parent (CDE, n.d.; Forssen et al., 2005). When women experienced equal caregiving demands, their subjective experience and feelings differed depending on how they perceived personal priorities and support from their husbands (Forssen et al.). Caregiving daughters who felt the distribution of work was unequal, or that caregiving spouses and family increased dependency, reported higher levels of burden and inter-role conflict (Forssen et al.).

Health Problems

Family caregiving can be stressful and negatively impact caregiver health despite cultural values to care (Kim & Lee, 2003). Experience of the caregiving role was impacted by the health of both the care provider and care recipient. Several studies evaluated participation in the caregiving role as a predictor for quality of health, while others explored how the health of the care recipient acted as a variable for caregiver well-being.

Navaie-Waliser et al. (2002) found that physical health of caregivers suffered due to the demands of providing care. This concerning finding suggests that providing care is associated with increased individual health risk. With rising costs of health care and

predicted growth of the aging population requiring caregiver support, promoting health of caregivers is crucial. Contrasting studies support the role enhancement hypothesis with multiple roles contributing to improved physical and mental health when compared to women functioning in fewer roles (Dautzenberg et al., 1999; Kim & Lee, 2003).

Caregivers have also reported more positive experiences with caregiving when the care recipient was healthier (De Frias et al., 2005). Another study identified discrepancy between how the definition of health was interpreted by both the caregiver and recipient. Adult child caregivers reported parent health to be significantly poorer than the parent reported themselves to be with regard to incidence and persistence of symptoms, and severity of chronic conditions (Cicirelli, 2000).

Caregiver Self-Esteem

Several studies examined how the relationship between the caregiving role and another identified role impacted self-esteem. This variable was often evaluated from a role enhancement hypothesis which allowed the totality of an individual's roles to provide multiple outlets for success and mastery. The accumulation of roles was shown by Christensen, Paris Stephens and Townsend (1998) to promote significant life satisfaction, further suggesting the need for successful role performance outside of caregiving.

Mastery of family roles such as spouse and mother were found to be related to psychological well being according to the caregiving model they were raised with (Christensen et al., 1998; Guberman et al., 1992). Intimate relationships of providing care for partners were found by Jacobi et al. (2003) to increase self-esteem as a result of

giving care. It is possible this was similar to Guberman et al. who found caregivers felt a profound need to help others, and the act of caregiving gave meaning to their lives. Alternatively, wives serving as caregivers may experience further conflict with the perception of having compromised their performance in the spouse role (CDE, n.d.).

Mastery of the employee role was specifically found to result in both psychological and physical well-being (Christensen et al., 1998). Christensen et al. found positive associations between the employee role and perceived control of daily structure and expectations. While employee training was also found to minimize inter-role conflict, in general higher educated caregivers reported more role strain (Christensen et al.; Dautzenberg et al., 1999).

The caregiving role was found to positively impact the caregiver when the relationship had reciprocity (Guberman et al., 1992). Reciprocity was defined as ability of the parent to provide assistance to the caregiver, such as providing aid with childcare or financial support. Perception of burden may vary with residence location and configuration of relationships. Positive caregiving relationships were more prevalent in caregivers who did not live with the elder parent (Guberman et al.).

Women in the caregiving role reported lower self-esteem than male counterparts (De Frias et al., 2005). Forssen et al. (2005) coined the term “compulsive sensitivity” from their qualitative study which illuminated caregiving women’s propensity to place others needs and responsibility ahead of their own, and resulted in stress when women felt they were being exploited. Women regarded this behavior as a personal trait and held

themselves responsible for their shortcomings and negative outcomes related to caregiving.

Kramer (2005) found female caregivers to characterize self as *duty bound*, which was defined as being obligated to care out of a general sense of duty or repayment. A combination of guilt, duty, resignation, and pity mixed with love, shared with a sense of responsibility for family were found by Guberman et al. (1992) to be factors which motivated some women to assume care.

Discussion

This review of relevant literature surrounding caregiving explored five themes with considerable overlap and inter-role influence, with the collection of studies supporting both the scarcity and accumulation hypotheses of role theory.

The variable of disrupted schedule proved to be related to the quantity of additional roles and accumulating demands resulting in activity disruption. It is unknown if there is a set quantity of roles which results in the perception of burden. It seems unlikely that a specific number would be applicable as individuals have unique relationship patterns which dictate customized demands and resources. Further investigation regarding the mechanism of increased education leading to higher levels of burden is needed. It is possible that higher education correlates to involvement in more life roles with resulting burden primarily in the disrupted schedule domain.

In a pervasively rural state such as Vermont, could distance from services or lack of resources increase schedule conflict; or might community networks provide additional

respite? Rural caregivers reported less activity disruption with increased leisure and physical activity. It is curious if rural individuals place more value in these self-preserving activities, or it is the consequence of other activities being unavailable.

The domain of financial problems elicited concern regarding finances and how money impacted relationship quality. With the rising costs of living and healthcare, financial strains are likely to be experienced within the caregiving role. Future studies evaluating the experience of caregiving may consider investigating decisions people make when stretching limited monies.

Family support was identified as an important resource for caregivers. Within family relationships the dynamics of spouses, siblings, partners, and children are variables that may enhance or impede the experience of providing care. Overall found to be protective to caregiver well-being, quality of spousal relationship was specifically found to impact satisfaction within the care role. Lack of family support may also contribute to other resource burdens as assuming care may strain finances, health, and availability of time to complete other role demands.

Health problems of both the care provider and care recipient impact the caregiving role. It is plausible that healthier care recipients require fewer caregiving tasks representing less impact on resources such as time and finances. Further studies are indicated to research how health relates to living arrangements that may be a product of care need. Forced co-habitation may alter the quality of the relationship with either resentment or reciprocity.

Self-esteem was frequently viewed from a role accumulation framework with multiple roles providing life satisfaction and contributing to caregiver well-being. Feelings of guilt and indebtedness were often reinforced by the attitude of the care-recipient.

Further research is indicated to enhance power and generalizability since many studies were limited by small sample size and grounded theory design which is context specific. While providing beneficial information about the experience of caregiving, more detail would need to be examined to explore if this data would be appropriate for other populations. The cross sectional design of many of the studies limited causation of temporal relationships, while selection bias was a potential confounder as many participants were recruited from previously established caregiver support resources.

Caution should be taken with inherent assumptions providers may have about the caregiver relationship and experience. Vermont's continued rural majority, limited public transportation, and sparse resource infrastructure may reduce the ability to generalize concepts of rural caregivers from other areas. Common "myths" of caregiving, such as it being a pervasively negative experience, may prove to be a fallacy in the rural caregiver. The myths of rural stoicism and self reliance may also prove false, or highlight a barrier to seeking support. Exploring issues and barriers can identify vulnerable populations and examine programs and policies to maximize support for these caregivers.

Implications

A rapidly aging population has the potential to strain political, fiscal and health resources. The role of families as informal caregivers will be more vital than ever before in collaborating to serve the needs of this expanding population. The process of caregiving must be understood as a dynamic endeavor that requires the development of skill and conscious effort by the caregiver. The ability to evaluate internal and external resources should promote role patterns within an individual's capacity for well-being.

A holistic approach to care will respect caregivers' unique needs for knowledge and interventions. Providers will best serve their clients in assisting to identify barriers, provide education, and support resource allocation (Gulanick et al., 2007). The care relationship additionally warrants evaluation of communication, willingness to become care provider, and the potential neglect or abuse.

In the following Chapter III, a manuscript for publication presenting the perceived experience of caregiving is presented. This research examines the variables: disrupted schedule, financial problems, lack of family support, health problems and self-esteem, as experienced by Vermonters providing care to aging elders. This scholarly paper includes an abstract, introduction, abbreviated review of the literature, description of the study design, sample selection, instrumentation, and data analysis, while presenting study conclusions and possible future implications.

Table 1: SUMMARY OF ARTICLES

Author Name	Study Objective	Population/ Duration	Study Method/ Theory	Findings	Limitations	Conclusions
Bedard et al.(2004)	Examine the differences of rural and urban caregivers' health that provide care for cognitively impaired elders.	20 rural and 17 urban caregivers; majority were daughters; in Northern Ontario/ One time survey	Quantitative	More rural caregivers are non-spousal and employed. Most rural caregivers received help from informal services. Rural caregivers were less likely to seek a second opinion.	Cross-sectional convenience sample.	The experience of caregiving varies between rural and urban settings.
Brackley (1992)	Study the impact of nursing educational intervention to support positive role transition as caregiver.	30 women from a large health science center in the southwest / Four weeks	Quantitative/ Meleis, Fawcett	Educational support group did not have a decrease in role insufficiency, but did have an increase in role adaptation.	Small sample size from an above average educated population. The health science center possibly resulted in increased awareness of available resources.	Addressing the goals of finding: help, new ways of relating to loved ones, and new ways of coping through communication and problem solving was found to be an effective means of increasing the daughters adaptation to the caregiver role.
Brouwer et al. (2004)	To improve understanding regarding the burden of informal care.	153 caregivers of rheumatoid arthritis (RA) patients from the Netherlands. Caregivers were mostly male and partners to the patient/ One time postal survey	Quantitative	Employed caregivers: amount of worked hours correlated with negative quality of life indicators for patient and caregiver;, and reduced income correlated with lower subjective burden scores.	Small sample with potential selection bias as selected from larger study sample. Caregivers had been in this role for limited amount of time.	While not statistically significant, data suggested informal caregivers experienced more personal health loss and higher subjective burden of care.

Author Name	Study Objective	Population/ Duration	Study Method/ Theory	Findings	Limitations	Conclusions
Bull & Jervis (1997)	To learn how older women and their caregiving daughters managed care.	33 mother-daughter pairs/ 2 semi-structured interviews: one at two weeks after discharge, one at two months.	Qualitative/ Role Theory and coping	Transition to caring required recognition of a problem, belief that something could be done to fix it, and time to seek necessary information and access resources.	Context specific nature of grounded theory	Gaps in communication between health care professionals, mothers, and their caregiving daughters contributed to difficulties managing care following hospitalization.
Cheung et al. (2006)	Examine the impact of filial piety on desire and preference for kin/friend and government support for care.	Random sample of 963 Hong Kong Chinese/ One time telephone survey	Quantitative/ Compensatory & Complementary theories of individual preference	People with higher filial piety have more preference for intimate caregiving sources. Parent care need did not negatively impact filial piety practice.	Random sample with telephone bias included non-caregivers. Average age 33.6 years. Cultural influence of filial piety.	Promoting filial piety is an effective intervention to enhance familial caregiver support and reduce reliance of governmental programs.
Christensen et al. (1998)	Examine the experiences of women who simultaneously occupied the parent care, mother, wife, and employee roles.	296 adult daughter caregivers/ Ninety minute interview	Quantitative/ Role Theory	Higher levels of mastery yielded well-being. The highest level of mastery was found in the employee role.	Cross sectional design limits interpretation about causal links between mastery and well-being. Self selection (volunteer) of sample could limit generalization.	Mastery in the three family roles was related to psychological well-being, whereas mastery in the employee role was related to both psychological and physical well-being. The more roles in which women experienced higher levels of mastery, the greater their satisfaction in life.

Author Name	Study Objective	Population/ Duration	Study Method/ Theory	Findings	Limitations	Conclusions
Cicirelli (2000)	Delineate stages in filial role development.	53 adult child-elderly parent dyads / one interview and survey of caregiver and care recipient.	Quantitative/ Normative Family Stress	Child concern was unrelated to parent health, urging by child was moderately related. Child's help was found to improve parent's functional ability.	Cross-sectional random block sampling from predominately Caucasian middle-upper class Indiana.	Most frequent behavior of caregivers was concern. Observable limits of parent functioning prompts adult children into care action. Adult children reported parents' health status as poorer than parent did.
Cicirelli (2003)	How mothers' and daughters' paternalism beliefs influenced decision making.	50 urban midwest mother/daughter dyads/ one time interview and survey of caregiver and care recipient.	Quantitative	Decision making was the result of beliefs about paternalism and level of dependency. Daughters perceived conflict with perceived differences.	Small, nonrandom, paired sample of white/Northern European ancestry. Caregiver inclusion was self-report from the daughter.	Beliefs surrounding caregiving and paternalism correlated with decision tasks and conflicts, but did not affect satisfaction over decisions.
Dautzenberg et al. (1999)	Does the caregiver role negatively affect women's well-being? Do caregivers with multiple roles feel more distressed and have the higher burden of care?	934 responses in 1994, 743 in 1996/ Two waves of telephone interviews in the southern part of the Netherlands.	Quantitative/ Role Theory: strain, accumulation, expansion	Caregivers felt strain with larger amounts of need, when their own health deteriorated, or when the elder had bad health. Higher educated caregivers reported more role strain, whereas a good relationship with the elder reduced strain.	Generalizeability between different styles of health care systems, cultural differences.	The caregiver role may add a sense of meaning and belonging to the life of women who perform very few other roles, but increases the pressure on women when their life is already filled with multiple responsibilities.

Author Name	Study Objective	Population/ Duration	Study Method/ Theory	Findings	Limitations	Conclusions
De Frias et al. (2005)	Explore reported negative and positive effects of providing care to older adults with cognitive or physical impairments.	135 referred family members from a variety of geriatric services, most caregivers were spouses/ One time survey	Quantitative	Older caregivers reported higher self-esteem; less family support, finances and more impact on personal health. Caregivers reported more positive experience with caregiving when the care recipient was healthier.	Cross-sectional with self report	Older caregivers experienced worse health and more difficulties with the caregiving role. Caregivers in poorer health are at higher risk for stress and personal health decline from caregiving
Forssen et al. (2005)	To increase understanding of the phenomena "compulsive sensitivity" which denotes the compulsion respond to other people's needs regardless of one's own situation.	Unstructured interviews of 20 women lasting 1.5-3hours with 2-4 contacts. Purposeful sampling was used to identify a variety of demographics.	Qualitative Feminist Theory	Quality of spousal relationship was found to largely impact women's satisfaction and well-being. While caregiving was found to bring strength and meaning to some women's lives, others reported suffering as a result of being overextended. The same time women began to assume more caring responsibility their spouses and other relatives increased their dependency on the women.	Small sample size, participants chose not to check their transcripts of the interviews.	Financial security and marital quality influence how women relate to the caregiving role.

Author Name	Study Objective	Population/ Duration	Study Method/ Theory	Findings	Limitations	Conclusions
Guberman et al. (1992)	To examine the process and elements in the decision to become a caregiver.	40 caregivers of nonspousal kin, Francophone Quebecois family caregivers/ 1 interview	Qualitative	14 distinct factors identified that play a role in the decision to assume the role of caregiver.	Study was done in Quebec, comparable to findings mirrored in American studies.	There is more than one reason to explain women's decisions to assume caregiving for a dependant adult relative. Psychological, political, social factors come into play.
Hawkins (1996)	To identify the stressors experienced by caregiving daughters of frail, elderly parents.	21 caregiving daughters/ 2 questionnaires	Quantitative	Caregiving daughters had significant higher stress scores "Wondering about the future" was the area of most caregiving concern.	Small sample size, potential bias of sample drawn from a group with prior use of community resources.	Due to frequent maladaptive coping mechanisms, anticipatory guidance and positive methods of coping are crucial for educational interventions or group programs.
Jacobi et al. (2003)	Assess subjective caregiver burden and partner/patient variables of related objective burden in caregivers of partners with rheumatoid arthritis (RA).	134 partner/patient dyads identified on the third follow-up of a longitudinal study among RA patients in Amsterdam/ One postal survey to both caregiver and care recipient.	Quantitative	Self-esteem was negatively correlated to lack of family support or loss of physical strength. Lack of family support was positively correlated with financial problems and loss of physical strength.	Mostly male caregivers	Caregiving partners derived high levels of self-esteem from providing care. Caregiver burden was more related to disrupted schedule compared to lack of family support, financial problems or loss of physical strength. Higher levels of caregiver burden were noted with mobility, pain and self-care deficits.

Author Name	Study Objective	Population/ Duration	Study Method/ Theory	Findings	Limitations	Conclusions
Kim & Lee (2003)	Investigate cultural vs. non-cultural factors in predicting depression and physical health for daughters providing care to impaired elderly.	120 daughter and daughter-in-law caregivers who lived with care recipient in Korea/ 1 hour face-face interview.	Quantitative/ Riegel & Lerner's Human Development Theories	Non-cultural factors had more impact on caregiver mental and physical health than cultural factors. Korean caregiving daughters reported higher levels of depression and poorer health than western counterparts.	Cross-sectional. Several instruments newly translated into Korean language/cultural sensitivity.	Family caregiving is stressful and negatively impacts caregiver health despite cultural values to care.
Kramer (2005)	Examine relationship between informal female caregivers describing self, and literature derived stereotypical female gender identity traits.	36 women/ One time interview.	Qualitative/ Gender Identity, Critical feminism, Post-structuralism.	Characterizations of self as "duty bound" reflected the gender identity traits of playing by the rules, obedient, and focusing on others rather than oneself.	Sample study was derived from a population that already had some resources known to them. Religious factors could have altered responses.	Supporting caregiving women to use different language of self-identity, and think of themselves differently.
Navaie-Waliser et al. (2002)	Examine the characteristics, activities, and challenges of high-risk informal caregivers.	Telephone interviews of 1002 informal caregivers given in English or Spanish from a Random digit dialing sample.	Quantitative	36% of caregivers were vulnerable and more likely to have difficulty providing care.	Sampling error of landline telephone, coverage bias, item response bias.	Safe caregiver/care recipient environments require an assessment of ability to provide informal care.

Author Name	Study Objective	Population/ Duration	Study Method/ Theory	Findings	Limitations	Conclusions
Parris-Stephens et al. (2001)	Investigate conflict between caregiving to parent and other roles.	278 women (Christensen article) Ohio and Pennsylvania. / One 90 minute interview	Quantitative/ Role theory	Overall when parent care conflicted with family roles (mother and wife) there was a trend of being married for fewer years.	Cross sectional study, temporal direction of influence is ambiguous.	Women who experience parent care conflict tend to have parents more impaired, have less education, lower incomes, and employed in lower status occupations.
Pohl et al. (1994)	How social vulnerability of caregivers in general, and women in particular, might exacerbate reactions to caregiving.	159 daughters and daughter-in-laws/ 2 existing data sets in the Midwest	Quantitative/ Social vulnerability	Negative reactions to caregiving a. When social support increased, negative reactions decreased b. Caregiver health declined, negative reactions increased c. Income increased, negative reactions increased.	Quality of data set being re-examined not addressed.	Caregivers may become increasingly socially isolated as the result of the caregiving experience They perceived their health as worsening. Social support was a major predictor of caregiver reactions.
van Excel et al. (2004)	Assess which dimensions informal caregivers perceive as being important to their overall burden from care giving.	Caregivers for stroke survivors (n = 196), and rheumatoid arthritis patients (n=131) in Denmark. Questionnaire for caregiver and care recipient.	Quantitative	Stroke and RA patients scored similar in both objective burden and subjective burden. 'lack of family support' did not influence the overall burden in either group.	Cross-sectional nature limits causation. Varied caregiver relationships. Stroke sample caregivers were more often non-spousal females.	Not all dimensions of burden are equally important to informal caregivers.

Author Name	Study Objective	Population/ Duration	Study Method/ Theory	Findings	Limitations	Conclusions
Wuest (2000)	Explain the complex process of family caregiving by women within the current context of health and social reform	21 women/ repeat interviews.	Qualitative/ Leininger	Principle strategies for repatterning: 1) Anticipating 2) Making Ground Rules 3) Juggling Time	Grounded theory is context specific	The process of caring must be understood as a whole and cannot be explained in terms of individual perspectives. The rewards of caring are intervening conditions that may offset the development of fraying conditions by replenishing women's energies.

CHAPTER III: MANUSCRIPT

Abstract

Providers working with families will need to understand the perceptions associated with informal caregiving as families face challenges of aging population expansion, rising costs of health care, and shrinking families. The purpose of this research was to investigate which variables are most impacted by the informal caregiving role: a) disrupted schedule, b) financial problems, c) lack of family support, d) health problems, or e) caregiver self-esteem. Using a Role Theory framework, subjective experiences were investigated during a one-time survey using the *Caregiver Reaction Assessment*. Previous studies have identified positive impacts on 'self esteem' as the dominating perception, while findings from this study suggest rural informal caregivers are most impacted by variables of 'disrupted schedule' with 'self esteem' ranking lowest of the five domains. The advanced practice nurse can use these findings to advocate for families and support the informal caregiving role.

Key Words: Caregiving, Caregiver Reaction Assessment, Rural

Perception of Rural Caregiving

Introduction

The degree of informal family caregiving has remained constant over the past decade despite increasing geographic separation, greater numbers of women in the workplace, and change in the composition of traditional nuclear families (U.S. Department of Health and Human Services [HHS], 2003). One in four persons provides the primary source of assistance for a loved one, with 38% of informal care delivered by adult children for an aging parent (HHS, 2003; U.S. Department of Health and Human Services Agency on Aging [AoA], 2004). The un-captured value of informal caregiving services is estimated by Arno (2006) to range between \$149 and \$483 billion dollars annually. Growth of the aging population will present a challenge for political, fiscal, and health resources, while continuing to depend on intimate family support. With the population aged 65 and older predicted to double by the year 2030 (AoA, 2004; U.S. Census Bureau [USCB], 2005), many families will experience the duties of providing informal care.

Background and Framework

Individuals experience the sum of their relationship patterns and achieve well-being through the ability to balance varying life roles (Marks & MacDermid, 1996). Through the opposing scarcity (Goode, 1960) and role accumulation (Sieber, 1974) hypotheses, role theory posits that diverse roles and relationships are comprised of unique privileges and obligations. The scarcity hypothesis proposes role strain results from

cumulative life roles depleting an individual's resources (Goode). In contrast to Goode's theory of finite resources, Sieber postulated role demands and resources were dynamic and flexible over time. In the role accumulation framework, stressors from plural roles are offset by the greater opportunity for support and resources (Sieber).

While caregiving research and assessment tools predominantly examine the burdensome impact of this role, a smaller portion has investigated the possibility of positive responses and allowed for both the scarcity and accumulation hypotheses to be supported in caregiving literature. Quantitative and qualitative studies using key word searches of caring, caregivers, women, rural, parents, and daughter were collected to examine different perspectives on the caregiving experience.

Disrupted Schedule

Perception of disrupted schedule was related to the quantity of additional roles a person assumes, and the result of cumulative role demands causing resource depletion (Dautzenberg, Diedricks, Philipsen & Frans, (1999); van Excel, Brouwer, van den Berg, Koopmanschap & van den Bos, 2004). Caregivers experienced depression, negative self-concept, and poorer physical health when care demands and time constraints interfered with personal and social lives (Brouwer, van Exel, van de-Berg, Dinant, Koopmanschap & van den Bos, 2004; Cheung, Yui-huen Kwan & Hung Ng, 2006; Dautzenberg et al., 1999; Jacobi, van den Berg, Boshuizen, Rupp, Dinant & van den Bos, 2003; Kim & Lee, 2003; Navaie-Waliser, Feldman, Gould, Levine, Kuerbis & Donelan, 2002).

Financial Problems

Monetary burden presented as concern over financial strain (van Exel et al., 2004), or decreased quality of life amid fraying relationships (Wuest, 2000). Lower income and socioeconomic dependence were risk factors for vulnerability (Forssen, Carlstedt & Mortberg, 2005) and depression (Cheung et al., 2006) in women.

Additional employment roles were found to correlate with both negative (Brouwer et al., 2004) and protective (Hawkins, 1996; Pohl, Given, Collins & Given, 1994) outcomes. Removal of the employee role was found to reduce caregiving burden by Brouwer et al. On the contrary, Hawkins and Pohl et al. found increased levels of depression and poorer health outcomes among unemployed caregivers related to increasing social isolation, less perceived resource availability, and financial dependence.

Lack of Family Support

Societal values provide the moral foundation for family caregiving (Kim & Lee, 2003). Perceptions of relationships impact caregiver experience as demands and resources overlap among roles. Caregivers who reported burden due to lack of family support identified inter-role conflict with financial concerns, decreased physical strength, and lower self-esteem (Brouwer et al., 2004; DeFrias, Tuokko & Rosenberg, 2005; Jacobi et al., 2003; Kim & Lee; Phol et al., 1994). Supportive intimate relationships were found to enhance satisfaction and well-being within the caregiving role (Center for Demography and Ecology [CDE], n.d.; Forssen et al., 2005).

Health Problems

Experience of the caregiving role was impacted by the health of both the care provider and care recipient. Navaie-Waliser et al. (2002) found the physical health of caregivers suffered due to the demands of providing care. Conversely, role quantity was a

predictor of health as multiple roles contributed to improved physical and mental health when compared to women functioning in fewer roles (Dautzenberg et al., 1999; Kim & Lee, 2003).

Caregiver Self-Esteem

The accumulation of roles was shown by Christensen, Paris-Stephens, and Townsend (1998) to promote significant life satisfaction. Benefits of self esteem related to caregiving was found with perceived mastery of the employee or family roles, the experience of proving care for partners, or when the relationship had reciprocity (Christensen et al., 1998; Guberman, Maheu & Maille, 1992; Jacobi et al., 2003).

Alternatively, women in caregiving roles reported lower self-esteem than male counterparts (CDE, n.d.; De Frias et al., 2005). Kramer (2005) found female caregivers to characterize self as *duty bound*, which was defined as being obligated to care out of a general sense of duty or repayment. A combination of guilt, duty, resignation, and pity mixed with love, shared with a sense of responsibility for family were found by Guberman et al. (1992) to be factors which motivated some women to assume care.

While the body of literature surrounding caregiving is extensive, less is known about how rural families perceive this role. Rural culture values independence, stoicism, and privacy while often experiencing poverty, limited diversity, and isolation (Slama, 2004). Rural individuals differ both cognitively and behaviorally from their urban counterparts (Slama) which may alter their perceptions of the caregiving role. The purpose of this study was to explore how rural caregivers perceive burdens and benefits from participating in this role; specifically the rural caregiver perceptions of: a) disrupted

schedule, b) financial problems, c) lack of family support, d) health problems, and e) caregiver self-esteem when providing care for an older adult. Practitioners can use the results from this research to gain insight regarding the dynamics of the rural caregiving relationship, and as a foundation for enhanced future development of family caregiving support systems.

Method

Design

A descriptive study design was used to examine variables influencing perceptions of burden or wellbeing within the caregiving role. Data regarding objective care measures or tasks were not elicited with the rationale that perception and experience have inherent legitimate value. This study met criteria for exempt protocol review from the University of Vermont Committees on Human Research to ensure ethical treatment of subjects participating in research.

Sample

In conjunction with six agencies serving elders and caregivers in the state of Vermont, purposeful sampling was utilized to identify 284 caregivers meeting the criteria of: self-identified primary caregiver, over 18 years of age, with the ability to read and write English. These agencies provided care across ten rural counties with a combined estimated population of 1980 persons over the age of 65 requiring assistance with 2 or more activities of daily living (Wasserman, 2007). Between November 26, 2007 and January 4, 2008, participants received a prepared mailing that included an introductory letter, survey, and return envelope. A total of 98 surveys were returned for a response rate

of approximately 35%. After removing 6 incomplete surveys with missing responses exceeding 50%, a final cohort of 92 surveys was used for statistical analysis.

Instruments

To gather positive and negative perceptions of providing care for a family member, the Caregiver Reaction Assessment (CRA) was selected for this study. The caregiving experience has been investigated among varied caregiver-care recipient relationships using the CRA tool. (DeFrias et al., 2005; Given, Given, Stommel, Collins, King & Franklin, 1992; Nijboer, Triemstra, Tempelaar, Sanderman & van den Bos, 1999). Using a five-point Likert scale, 24 questions are grouped into five subscales measuring the impact of caregiving on: disrupted schedule, financial problems, lack of family support, health problems and self-esteem. Subscales are evaluated as an average of the related questions with a score possibility ranging from 1 (strongly disagree) to 5 (strongly agree), with ten questions reverse scored to avoid response set bias. A higher score in the four negative domains represents stronger burden impact from caregiving, while a higher value for self-esteem denotes positive impact of caregiving. An effort to reduce social acceptance bias was facilitated through participant recruitment and return of materials that allowed for anonymous responses.

For this study minor alterations were made to the CRA instrument. The neutral Likert column was re-named from 'neither agree nor disagree' to 'not sure' for ease of interpretation. During survey construction three questions across three subgroups were inadvertently omitted. Despite this error in survey design, internal consistency among the subscales was supported (Table 2) with Cronbach's alpha varying from 0.75-0.88 and

consistent with instrument reliability of 0.62-0.90 in other studies (DeFrias et al., 2005; Nijboer et al., 1999).

Table 2
Comparative Cronbach's Alpha

CRA Dimension	Cronbach's Alpha		
	O'Brien, 2008	Nijboer et al., 1999	DeFrias et al., 2005
Disrupted Schedule*	0.815	0.81	0.82
Financial Problems*	0.765	0.83	0.67
Family Support	0.871	0.62	0.70
Health Problems	0.750	0.68	0.79
Self-Esteem*	0.880	0.73	0.86

* denotes dimensions with missing question in current study

Data Analysis

Data entry was transcribed by the investigator and reviewed for accuracy by an independent party. Statistical analysis of data was performed in collaboration with a statistician using SPSS software version 15. Comments participants wrote on returned surveys were included in the discussion to provide rich personalization to the quantitative data.

Results

Descriptive demographic data (Table 3) were collected simultaneously with the survey. Primary caregiver relationships in this study were caregivers caring for mother 41.3% (n= 38) and spouse 34.8% (n= 32). Caregivers were predominately female 78.9% (n= 71), Caucasian 92.2% (n= 83) and married 71.1% (n= 64). The caregiver age ranged from 23-89 with average age 59.4 years old. Years of care provided was divided with 52.8% (n= 47) providing less than three years, and 47.2% (n= 42) providing care for over 3 years.

During data entry discrepancies were identified among two demographic questions: “I have another job other than this caregiving job”; and “I work for pay less than half time or more than half time.” These questions were a linked pair to identify the additional career demands as a variable impacting the caregiving relationship. Survey responses illustrated discrepancy when 41.1% (n=37) of caregivers noted ‘no other employment’, yet 32% (n=12) reported working for pay on the second question. Participants selected from several of the participating agencies were receiving minimal stipends for providing care, often as a result of not qualifying for other funding sources in conjunction with financial need.

Statistical analysis of CRA responses allowed for intra and inter-dimension trends to be discovered. Specific question impact and response rates were able to be identified within each dimension. Study results supported the negative dimensions of caregiving burden as having the most impact on rural caregivers (Table 4).

Table 4
Dimension Scores

CRA Dimension	Number of Questions	Mean	Standard Deviation
Disrupted Schedule	4	3.76	0.97
Financial Problems	3	2.98	0.99
Family Support	4	2.50	1.05
Health Problems	4	2.74	0.87
Self-Esteem	6	2.35	0.88

Disrupted schedule was the predominating domain with an average subscale score of 3.76 (SD 0.97). Other burden domain averages were financial strain 2.98 (SD 0.99), lack of family support 2.50 (SD 1.05), and poor health 2.74 (SD 0.87). Benefits of

caregiving impacting self esteem was the lowest dimension with an average subscale score of 2.35 (SD 0.88).

Consistency of responses varied across dimensions with ‘health problems’ completely answered for each survey and ‘family support’ the most inconsistently completed domain with a total of 20 missing responses across four questions. The question “my family left me alone to care” had the most missing responses (n=9); 5 participants reported they were an only child or there was no other available family.

After ‘family support’, ‘self-esteem’ followed with a total of 15 unanswered questions. The question “I will never be able to do enough caregiving to repay” led this domain with an average of 3.29 (SD 1.15) despite 5 unanswered responses. The survey question with least impact on caregiving experience was “caring is important to me” with a mean of 1.74 (SD 0.85).

Discussion

Disrupted Schedule

Of the presented variables, participants identified schedule disruption to be the most burdensome outcome of the caregiving role (3.76). While other studies have supported ‘disrupted schedule’ as the leading burden domain, the dimension of ‘self-esteem’ was identified as the leading dimension in other studies (Brouwer et. al, 2004; Grant, Bartolucci, Elliot & Giger, 2000; Grov, Fossa, Tonnessen & Dahl, 2006; Jacobi et al., 2003; Nijboer et al., 1999; Phol et al., 1994). Among these studies care relationships were predominately intimate partners (Brouwer et. al; Grov et al.; Jacobi et al.; Nijboer et al.), but Phol et al. and Grant et al. included large samples of caregiving daughters.

Causation regarding burden of disrupted schedule cannot be made from the design of this study but review of the data proposed several possible relationships for future study.

Four questions investigated the perception of centering daily activity and demands around caregiving at the expense of other personal life roles. The question “my activities are centered around care” scored highest for burden (4.02; SD 1.02) across the entire study and was supported by remarks participants offered:

My activities are centered totally around caregiving 24/7. I have given up my profession in order to be home with them [parents].

I left my friends and job...(also sold my house) to come here and care for my parents. While I don't enjoy the tasks involved I am glad to be doing this for them. Still, it's been hard giving everything up to do this.

Information regarding distance from services was collected during this survey as a potential factor impacting rural care. Other studies examining caregiving using the CRA were performed in metropolitan areas of the United States and Europe and did not include similar data. While the distance to the closest hospital averaged 11.41 miles (SD 1.02), the average round trip travel to health appointments averaged 45.46 miles (SD 6.90). It is reasonable to consider that lack of locally available services could result in extended travel time and impact ability to complete other tasks. Distances from services such as respite providers or first response teams may also predict perception of isolation as found in one written comment: “I am just as homebound as they [parents] are.”

Alternatively, disrupted schedule may be a product of proximity, as 84.6% of caregivers were within ten miles of the care-recipient and 67% shared the same residence. Circumstances surrounding care were not elicited and may provide direction for future study. When caring involves co-habitation, increased disruptions to other life roles may seem more intrusive. It is probable the need for proximity is influenced by poorer health of the care-recipient, or reflects lack of other services available to rural communities. Co-habitation in other studies were higher 89.9% (Brouwer et al., 2004) and 85% (Grosv et al., 2006), but represented predominantly partner/spouse care relationships. It is possible that intimate partner caregiving relationships allow for more reciprocity and positive feedback allowing for higher levels of 'self-esteem'.

Experience of disrupted schedule may also be a product of education. Compared to other studies (Brouwer et al., 2004; Grant et al., 2000; Grosv et al., 2006; van Exel et al., 2004), participants had more education with 41.2% (n=34) having completed a college or advanced degree. The advanced educational level of this cohort was also reflected by 4.4% reporting less than a high school education compared to 2000 US Census data of 13.6% Vermonters and 19.6% nationwide respectively (U.S. Department of Agriculture Economic Research Service, 2008). Education may have facilitated greater involvement with care resources, thus higher educated caregivers under more strain may have inadvertently been targeted as a product of working with service agencies. Bias from education contributing to increased response rates from this demographic may have resulted from academic backgrounds that valued the research process. Another possibility is the potential for higher levels of education to correlate with burden as a result of

increasing role conflicts. Women maintaining multiple professional roles were found to experience guilt (CDE, n.d.; De Frias et al., 2005; Guberman et al., 1992; Kramer, 2005) similar to the experience of caregivers with higher incomes (Brouwer et al.; Phol et al., 1994) who relied on other resources for caregiving.

Further investigation is warranted to explore the significance of this finding and validate the possibility that rural families differ in their experience of burden when providing care. A Wuest (2000) grounded theory study of female caregivers identified the theme of repatterning as necessary skill development to organize care demands. This is similar to Goode's concept of role analysis to promote resource evaluation as the mechanism to reduce role strain and enhance well-being within roles (Goode, 1960). If replicated in other caregiving studies, disrupted schedule suggests the need for balance between caregiving and other roles.

Financial Strain

Financial strain was the second highest dimension for perceived burden 2.98 (SD 0.99). Impact of financial strain was ranked higher among the 5 dimensions in this study despite consistent or superior reported household incomes when compared to other caregiving studies by Grov et al. (2005) and Teel, Duncan & Lai (2001). Household income was reported as less than \$40,000 for 54.5% of the population, with 30.7% earning over \$40,000 annually, and the remainder declining to answer.

The assumption of lower socioeconomic status as a predictor of caregiving strain was questioned in studies by Phol et al. (1994) and Brouwer et al. (2004) who identified higher incomes correlated with negative reactions to providing care. The authors

hypothesized increased resiliency among lower income caregivers due to lifestyles accustomed to adversity; or the possibility of guilt resulting from the ability to provide resources financially being in conflict with the expected societal norm to become the caregiver (Brouwer et al.; Phol et al.).

The question ‘my financial services are adequate to pay for things that are required for caregiving’ had the most missing responses (n=5), but represented leading impact within the dimension (2.99; SD 1.17) with 42.5% of responses in disagreement. Many surveys alluded to the fragility of the caregiving relationship and uncertainty for the future through a variety of handwritten commentary such as: “for now”, “its always a burden money wise”, and “living expense is more of a concern. I wish I could get more help.” Future studies investigating the financial burden experienced with caregiving might seek to determine specific aspects of monetary strain related with this role.

Lack of Family Support

Of the negative burden domains, ‘family support’ had the lowest mean score 2.50 (SD 1.05). This dimension accounted for the most missing responses, possibly related to lack of other family members, a trend similarly noted in a study by van Excel (2004). The almost 10% of surveys (n= 9) that did not respond to the question ‘my family left me alone to care’ may have caused this domain to be underestimated. The question representing the most impact was ‘my family works together to care’ (2.78; SD1.31), with 55.7% of responses either ‘disagree’ or ‘strongly disagree’. This was contradicted by results of other questions within the domain which demonstrated caregivers perceived they had not been abandoned in the caregiver role. One participant commented:

“My family hasn’t abandoned me, I feel abandoned in the role.”

This sentiment may be representative of the conflict caregivers felt regarding the questions in this domain as they considered the impact of support from both personal and caregiver aspects. Leading additional sources of support identified were children (38%), spouses (31.5%), sisters (25%) and “other” (23.9%). Hand entries for ‘other’ frequently noted a private care service.

Pohl et al. found that as social support increased, negative reactions to caregiving decreased. This was supported by Jacobi (2003) who found lack of family support to decrease self-esteem of caregivers while increasing concerns regarding finances. Conversely, Wuest (2000) found that the addition of substitute care could be problematic for caregivers due to uncertainty of involving strangers in intimate family relationships, problematic management, or marked a transition the caregiver was not ready for. Further studies may consider comparing the experience and satisfaction of caregiving when supplemented by family support vs. formal care services. Such studies may provide valuable information for the future of our long-term care systems.

Health

The average score for the health dimension was 2.74 (SD 0.86). Interestingly ‘health problems’ was the only dimension with a 100% response rate over 4 questions. This may be reflected by the general positive outlook participants had regarding their health with 78.9% reporting personal health of “good or better.”

The health dimension question with the most impact on care was ‘since caring it seems like I’m tired of all the time’ (3.38; SD 1.28). Comments offered by participants

provided rich insight to the perception of health. These quotes suggest that average dimension scores of the CRA are useful for descriptively ranking importance of variables to prioritize caregiving support, but serve as a reminder that even lower average dimensions have clinical significance.

I often have to put my own health needs behind my parents.

I manage with strength but wonder if I will collapse before Dad dies.

The only reason I can manage is by giving everything else in my life up.

The psychological pressures of caregiving far outweigh the physical demands.

And they run the whole range of human emotions.

Brouwer et al. (2004) suggested health losses may be incurred as a result of the caregiving role. The nature of this one-time survey may underestimate the impact of caregiving on health over time. Additional longitudinal studies monitoring the impact of caregiving on health are warranted.

Self Esteem

Self-esteem had the lowest average score, representing the domain perceived as having been impacted the least by the caregiving role (2.35; SD 0.88). Six questions investigated concepts of importance, privilege, and resentment surrounding the caregiving role. Esteem was one of the three dimensions missing a question in this study. Comparing Cronbach's Alpha (0.88) to other published studies using the original seven

questions showed consistency within the esteem dimension was maintained. Overall this dimension was second highest for missing responses (n=15), led by 5 missing responses to the question 'I will never be able to do enough caregiving to repay.' Several surveys supplied written remarks near this question such as: "there's no way to measure unconditional love." Another offered perspective was: "caring doesn't make me feel good, but I'm glad to be doing it."

The ranking of the esteem domain in this study was in stark contrast to other studies which found it to be the leading domain and most impacted by caregiving (Brouwer et al., 2004; Grant et al., 2000; Grov et al., 2006; Jacobi et al., 2003; Nijboer et al., 1999; Phol et al., 1994). While several possibilities are reviewed regarding 'disrupted schedule' as a leading domain, it is unknown why there was such a dramatic difference in this study. One hypothesis for the difference in the self-esteem variable was the possibility that completely anonymous survey design may have reduced social response bias. Previous studies done with face to face interviews may have over-estimated the positive effects of caregiving due discomfort with speaking negatively about caring for a loved one. While this may have been a contributor in this study, studies with both interview (Brouwer et al.; Nijboer et al.) and mailed questionnaire (Grov et al.; Jacobi et al.; Teel et al., 2001; van Exel et al., 2004) methods found consistently more impact in the self esteem dimension. Further investigation regarding this finding is warranted to determine the possibility of study error opposed to potentially accurate, but previously unidentified findings.

Limitations

Several limitations to this study are acknowledged. Generalization and the ability to infer temporal cause and effect are limited by small sample size and cross-sectional study design. The lack of diversity within the sample population raises concern of interpreting these findings with other racial or ethnic groups.

While a heterogeneous sample of caregivers was targeted in effort to produce a broad understanding of the rural caregiving experience, indiscriminate selection of caregiver/care-recipient relationships may have affected results. Differing care-recipient diagnoses may impact perceived strain within a relationship. For example, a terminal or unanticipated condition may create different burdens than chronic or perceived routine care of aging. Participants were also established with a caregiving support resource which may have impacted results.

The amount of care was not quantified by hours per day or type of care tasks which may have led to over or underestimating burden depending on the extent of care provided. Timing of study took place around major cultural holidays which may have impacted the sense of schedule disruption.

Summary

Results provide insight regarding the perceptions and dynamics of family care, and demonstrate that the impact of caregiving is not uniform. The alternative findings in this study identified 'disrupted schedule' as the domain most negatively impacted by the caregiving role, and the domain of 'esteem' least impacted.

This study suggests the experience of rural families providing care may differ from metropolitan populations and warrants further investigation. Previous studies have found rural elders to be more likely to live in poverty, be less educated, receive support primarily from informal services, and have less access to services (Bedard, Koivuranta & Stuckey, 2004; Tryssenar & Tremblay, 2002; U.S. Department of Agriculture Economic Research Service, 2007). Other studies have found improved caregiving relationships among rural caregivers due to increased leisure time and physical activity (Bedard et al., 2004; Parris-Stephens, Townsend, Martire & Druley, 2001).

If future studies validate the finding that disrupted schedule is the primary concern for rural caregivers, it may impact the direction of healthcare to best support families in this role. Program design that reflects the concerns of its consumers will facilitate family centered care. If further studies determine hours spent traveling and increased distances for health appointments as a key factor in caregiving burden, interventions such as multidisciplinary services that can be arranged to meet multiple health needs in one trip may be investigated.

Facilitating understanding of variables influencing rural caregiving serves to promote culturally sensitive care. The advanced practice nurse can use these findings to advocate for families through barrier identification, education and resource allocation.

Table 3
Sample Demographics (n=92)

	Frequency	%
Elder Cared For		
Mother	38	41.3
Father	6	6.5
Parent in-law	5	5.4
Spouse	32	34.8
Other	7	7.6
Caregiver Characteristics		
Sex		
Male	19	21.1
Female	71	78.9
Race		
Caucasian	83	92.2
Native American	7	7.8
Marital Status		
Married / Partner	68	75.5
Single	22	24.4
Education		
Less than High School	4	4.3
High School Grad/GED	25	27.2
Some College	24	26.1
College Degree	23	25.0
Advanced Degree	14	15.2
Amount of Years Caring		
<3 years	47	52.8
>3 years	42	47.2
Income		
<\$ 40,000	48	54.5
>\$40,000	27	30.7
Declined	13	14.8
Proximity to care-recipient		
Live in my home	50	54.9
Live in their home	11	12.1
<1 mile	6	6.6
1-10 miles	10	11
11-40 miles	10	11
>40 miles	4	4.4
Other sources of support		
Your Brother	13	14.1
Your Sister	23	25.0
Your Spouse	29	31.5
Your Children	35	38.0
Elders Spouse	3	3.3
Elders Siblings	5	5.4
Other Family	21	22.8
Friends	14	15.2
Other	22	23.9

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APPENDIX

Appendix A: Introduction Letter to Participants

November 27, 2007

Rural Caregiving Project
PMB 130
29 Taft Corners Shopping Ctr
Williston, VT 05495-2023
megan.jones@uvm.edu

Title: Perception of Burden in Rural Caregivers

Dear Caregiver:

My name is Megan O'Brien. I am a graduate nursing student at the University of Vermont. As part of my studies I want to learn what it is like to care for an elder who needs help caring for themselves. Filling out this short survey will help me know what this has been like for you, and give me information that might help others with caring.

[Name of agency contact] and [Agency] have approved this project and feel your input could be useful to this study. For your privacy, [name of agency contact] has offered to give you this survey for me. I do not have your name or address and will not contact you again. Your answers will be grouped together with surveys from around the state. Filling out and returning the survey is voluntary and implies you agree to take part in this project, there is no penalty for not returning the survey. There is no risk of harm from answering these questions, but they may produce strong feelings. When done, please place in the provided envelope and put in the U.S. mail. I will write a report about my findings for school and hope to publish a summary of this research in a nursing journal for other nurses to learn from.

If you have any questions please contact me at (802) 316-1231. If you have any questions about your rights as a participant contact Nancy Stalnaker, Program Director of the Institutional Review Board at the University of Vermont, 245 South Park/Suite 900, University of Vermont, (802) 656-5040.

Thank you,



Megan L. O'Brien, BS, RNC

Appendix B: Participant Survey

Perception of Burden in Rural Caregivers

Thank you for choosing to take part in this survey. The purpose of this survey is to gather information about the feelings and experience of being the main caregiver of an elder who needs help caring for themselves. Your responses will stay anonymous, do not put your name or address on any of these forms. Please seal completed survey in the addressed, stamped envelope provided and return via U.S mail no later than January 4, 2008.

Please Check ONE box for each question

1. The elder I am the primary care provider for is my:
- Mother Father Mother-in-law Father-in-law
- Spouse Sibling Child Other _____

2. Please fill out the next two pages about your care for the elder you have identified in Question 1. You DO NOT need to fill in the blanks for each question. Please do not put the name of the person you provide care for on the survey.

	SELECT ONE				
	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
I feel privileged to care for _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others have dumped caring for _____ onto me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My financial services are adequate to pay for things that are required for caregiving	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My activities are centered around care for _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Since caring for _____, it seems like I'm tired all of the time	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I resent having to take care of _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have to stop in the middle of work or activities to provide care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
My health has gotten worse since I've been caring for _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I will never be able to do enough caregiving to repay _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family works together to care for _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have eliminated things from my schedule since caring for _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have enough physical strength to care for _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Since caring for _____ I feel my family has abandoned me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caring for _____ makes me feel good	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The constant interruptions make it difficult to find time for relaxation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am healthy enough to care for _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caring for _____ is important to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caring for _____ has put a financial strain on the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My family (brothers, sisters, and children) left me alone to care for _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I enjoy caring for _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Its difficult to pay for _____ health needs and services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**All of the following questions are about YOU.
Please check or fill in your answers.**

I am a:

- Male
- Female

My age is: _____

I am:

- Caucasian
- Hispanic
- African-American
- Native American
- Asian-Pacific
- Other _____

I am:

- Married
- Living as Married
- Single

I have children under the
age of 18 who live with me:

- Yes
- No

I think my health is:

- Excellent
- Very Good
- Good
- Fair
- Poor

The most schooling/education

I have is:

- Less than High School
- Some High School
- High school graduate or GED
- Some College
- College Degree
- Advanced Degree

I have been providing care for:

- Less than 1 year
- 1-3 years
- 3-5 years
- Over 5 years

I have another job other than
this caregiving job:

- Yes
- No

I work for pay:

- Less than half time
- More than half time

My total household income is:

- Less than \$10,000
- \$10,000-\$20,000
- \$21,000-\$30,000
- \$31,000-\$40,000
- \$41,000-\$50,000
- \$51,000-\$60,000
- \$61,000-\$70,000
- Over \$71,000
- Decline

What is the zip-code for the person you are caring for?

How close do you live to the person you are caring for?

- Live with them in my home
- Live with them in their home
- Less than 1 mile
- 1-10 miles
- 11-20 miles
- 21-40 miles
- Greater than 40 miles

The closest hospital is _____miles

On average, I travel _____miles (round trip) to take the person I care for to health appointments

Check all of the people who help you provide care:

- Your brother
- Your sister
- Your spouse
- Your children
- The elders' spouse
- The elders' siblings
- Other family members _____
- Family Friends
- Other _____

Now that you have finished this survey, place it in the envelope addressed to "Megan O'Brien" and mail as soon as you can.

Thank you for participating