CAREGIVERS' PERCEPTION OF HEALTH, BURDEN, SOCIAL SUPPORT, AND CARE RECEIVER PROBLEMS

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Caregivers' Perception of Health, Burden, Social Support, and Care Receiver Problems

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Abstract

A descriptive correlational study was designed to investigate perceptions of health status in a convenience sample of seventy-five primary caregivers waiting to place older adults in a nursing home. The relationships among sociodemographics, caregiving factors, burden, care receiver problems, social support, and caregiver health status was also explored. The conceptual framework for the study was based on the Stress Process Model (Pearlin, Mullan, Semple, & Skaff, 1990).

Most caregivers were adult children (66.7%), female (54.7%), living with care receivers (56.0%) in a rural area (61.3%), employed or looking for work (50.6%), and between 46 and 64 years of age (57.3%). Data were collected over a six-month period. The Revised Memory and Behavior Problems Checklist, Consequences of Care Index, Norbeck Social Support Questionnaire, and Descriptive Profile Form were administered during interviews with participants.

Study findings indicated that most caregivers were experiencing burden and adverse health effects. Caregiver burden was highest for personal and social restrictions, physical and emotional, and economic costs. The majority of participants rated their physical health good, and their mental health fair to good.

The findings also indicated that sociodemographics and caregiving factors, care receiver problems, and burden had a limited effect on caregiver health status. Care receiver memory and behavior problems, care receiver cognitive impairment, and caregiver overall burden were associated with poorer mental health. With regards to social support variables, only tangible support correlated with physical and mental health. During regression analysis, mental health and employment surfaced as predictors of physical health, and the physical and emotional dimension of burden and physical health as predictors of mental health.

The results of this study suggest that caregivers are experiencing negative health effects. The factors influencing the caregiving process are complex and require further research to clarify their prevalence and importance for caregivers. Although the results of the current study are not generalizable, they do support some of the findings from previous research and can be used to better inform nursing practice, education, and research.

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CHAPTER 1

Introduction

The anticipated and dramatic growth in the elderly population has been well documented. A recent Canadian survey projected an increase from the 10.6% reported in 1991 to 14.5% in 2011 and 21.8% in 2031 (Canadian Study of Health and Aging Working Group, 1994). Life expectancy has also increased bringing with it a greater risk for disabilities (Kahana, Biegel, & Wykle, 1994; Statistics Canada, 1994); consequently, a greater demand for informal supports and formal caregiving services.

One person usually assumes a primary role in informal caregiving while others take on secondary supportive roles. Research findings indicate that caregiving may be a source of burden for families, especially primary caregivers (Clark & Standard, 1996; Fink, 1995; Pearlin, Mullan, Semple, & Skaff, 1990; Russo & Vitaliano, 1995). When a critical juncture is reached in the caregiving process, the decision is often made to place the older adult within a nursing home.

Several studies have shown that caregiver burden is implicated in declining caregivers' health (Anthony-Bergstone, Zarit, & Gatz, 1988; Bull, 1990; Intrieri & Rapp, 1994; Kosberg, Cairl, & Keller, 1990; Robinson, 1990). Study findings also suggest that caregiver burden increases and health declines prior to the decision to seek institutional placement for older adults (Cohen, Gold, Shulman, Wortley, McDonald, & Wargon, 1993; McFall & Miller, 1992). However, there is a dearth of research on caregiver burden and health status during the critical period while waiting for placement (Chenier, 1997). The primary purpose of this study was to investigate the factors influencing primary caregivers health while caring for an older adult waiting placement in a nursing home within the western region of the province of Newfoundland.

Background and Rationale

The care of older adults by the family is becoming an increasingly normative practice (Pearlin & Zarit, 1993). At the same time, changes in societal values and demographics are affecting the caregiving role. It has been postulated that several factors are exerting a negative impact on caregiving: (a) fewer children to care for aging relatives (Hooyman & Gonyea, 1995), (b) families less geographically centered (Hooyman & Gonyea), (c) increased divorce rate (Uhlenberg, Cooney, & Brody,1990), (d) increased number of women in the labour force (Himes, 1992), and (e) overlap of child and elder care (Montgomery & Datwyler, 1990).

There is extensive research on factors influencing caregivers' burden and health. Despite the increasing knowledge base, the findings are inconsistent on whether social supports are related to caregiver burden and health (Bass, Noelker, & Rechlin, 1996; Bull, Maruyama, & Luo, 1995; Brown, Potter, & Foster, 1990; Jette, Tennstedt, & Crawford, 1995; McKinlay, Crawford, & Tennstedt, 1995; Penning, 1995; Pruchno, 1990; Robinson, 1990; Toseland, Rossiter, & Labrecque, 1989). Even though extensive consideration has been given to the influence of care receiver characteristics on caregiver burden and health, the findings remain inconclusive (Baumgarten, Battista, Infante-Rivard, Hanley, Becker, & Gauthier, 1992; Browning & Schwirian, 1994; Bull, 1990; Cattanach & Tebes, 1991; Clipp & George, 1993; Cohen et al., 1993; Draper, Poulos, Cole, Poulos, & Ehrlich, 1992; Dura, Haywood-Niler, & Kiecolt-Glaser, 1990; Intrieri & Rapp, 1994; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Neary, 1993; Neundorfer, 1991; O'Connor, Pollitt, Roth, Brook, & Reiss, 1990; Phillips, Morrison, Steffl, Chae, Cromwell, & Russell, 1995; Rabins, Fitting, Eastham, & Fetting, 1990; Zarit, Todd, & Zarit, 1986). Further, the studies dealing with the influence of sociodemographic and caregiving factors on burden and health also reflect conflicting findings (Barnes, Given, & Given, 1992; Elmstahl, Malmberg, & Annerstedt, 1996; Kramer & Kipnis, 1995; Mittelman et al., 1993; Pearson, Verma, Nellett, 1988; Stull, Bowman, & Smerglia, 1994; Yeatman, Bennetts, Allen, Ames, Flicker, & Waltrowicz, 1993). Finally, there are inconclusive findings on the relationship between caregiver burden and health status (Anthony-Bergstone et al., 1988; Bull, 1990; Kosberg et al., 1990; Pruchno, Kleban, Michaels, & Dempsey, 1990).

Because of the conflicting findings on factors exerting a significant effect on caregivers' health status, more research is obviously needed in this area. Most importantly, there is limited research on caregiver health status while waiting to place older adults in institutions. Several authors have noted that more research is needed to identify factors influencing caregiver health status during transitional periods (Anderson, Linto, & Stewart-Wynne, 1995; Chenier, 1997; Kahana et al., 1994).

Problem Statement

Caregiving involves both the psychological connection, caring about others, and the physical assistance, caring for others (Hooyman & Gonyea, 1995). Although many primary caregivers derive satisfaction from caring for family members, the experience is not without costs. When caring for older, dependent adults with disabilities, the burden may be so overwhelming that it has negative repercussions for caregivers' physical and mental health status.

Within the Newfoundland health care system, a Single Entry Model for Continuing Care is being used to assess the needs of older adults requiring formal support services. Consumers are offered a wide range of community and institution-based services based on the results of a needs assessment using a standardized form (National Health and Welfare, 1988; 1992). Older adults who require care in a nursing home have their names placed on an admission waiting list and are prioritized according to severity of disabilities and intensity of care requirements. The transitional period from home to institution can vary considerably depending on the availability of appropriate facilities.

With the focus primarily on care receivers' needs, less attention is given to the impact of caregiving on the physical and mental health status of caregivers. It is well documented in the literature that prolonged caregiving negatively influences caregivers health status. When the decision is made to seek placement for the older adult, caregivers are already feeling the stress of caregiving. It is somewhat surprising then that there is limited research investigating caregivers' health status during this transitional period.

The Stress Process Model (SPM) identifies a number of factors influencing the outcome of the caregiving process (Pearlin et al., 1990). Caregivers' health status is one outcome of the stress process. The factors influencing the outcome of caregiving are categorized as background and context, primary and secondary stressors, and mediators in the Model. Pearlin et al. suggest that more research is required to investigate the impact of these domain-factors on outcome. Although the SPM specifies multiple factors for each domain, this study only focused on select aspects. These factors are outlined in the research questions.

Research Questions

This study was designed to address the following research questions:

1. How do primary caregivers waiting to place older, dependent adults in a nursing home perceive their health status?
2. Is caregiver health status a function of select sociodemographic variables (gender, living arrangement, relationship, location, employment)?
3. Is there a significant relationship between caregiving factors (duration, tasks, and hours) and caregiver health status?
4. Is there a significant relationship between care receivers' characteristics and caregiver health status?
5. Is there a significant relationship between caregiver burden and health status?
6. Is there a significant relationship between social supports and caregiver health status?

CHAPTER 2

Literature Review

The purpose of this review is to examine the literature on caregiving for older adults within the community. The review is divided into five major sections. The first section presents an overview of theoretical and methodological trends in caregiving research. The second section summarizes research findings on key factors influencing caregivers' perception of the burden of caregiving. Special consideration is given to sociodemographic and caregiving factors, caregiver health status, care receiver characteristics, and social supports. The third section reviews research findings that focus on factors believed to influence health status as the outcome of caregiving. Special attention is given to sociodemographic and caregiving factors, care receiver characteristics, burden, and social supports. The fourth section presents a brief discussion on the limitations of study findings reported in the literature. The final section presents a brief overview of the conceptual framework for this study.

Theoretical and Methodological Trends in Caregiving

Early research on the impact of caregiving on family members was impeded by the absence of clearly articulated theoretical frameworks (Biegal & Blum, 1990; Kahana & Young, 1990) and lack of consensus on key concepts defining the caregiving experience. Conceptual overlap among key concepts (e.g., subjective and objective burden, health status, distress, stress, strain) and the resulting multiple and diverse measuring instruments make cross-study comparisons difficult (Braithwaite, 1992; Hooyman & Gonyea, 1995; Stephens & Kinney, 1989). In recent years, greater efforts have been directed towards developing and refining theoretical perspectives (Biegel, Sales, & Schulz, 1991; Shultz, 1990; Malonebeach & Zarit, 1991), clarifying the major components of burden, and designing psychometrically sound operational measures (Raveis, Siegel, & Sudit, 1990).

Burden, the dominant variable of interest to theorists and researchers, was traditionally defined as the negative impact of caregiving (Browning & Schwirian, 1994; George & Gwyther,1986; Stommel, Given, & Given, 1990; Max, Webber, & Fox, 1995; Zarit, Reever, & Bach-Peterson, 1980). As a result of the conceptual ambiguity and broad content domain (e.g., behavioral, social, affective, psychological, cognitive, financial, etc.), some researchers designed unidimensional instruments to produce a total burden score (e.g., Burden Interview - Zarit et al., 1980; Caregiver Strain Index - Robinson, 1983). Others relied on the theoretical insights of social interaction and role theory to treat burden as a multidimensional construct with mutually exclusive subjective and objective components (Montgomery, Gonyea, & Hooyman, 1985; Montgomery, Stull, & Borgatta, 1985; Rankin, Haut, Keefover, Franzen, 1994). The objective side of burden was defined in terms of the tangible effects of caregiving (e.g., number of tasks, hours of care, disruptions in routine, financial, etc.), and the subjective as caregivers' attitudes toward and feelings about performing caregiving responsibilities (i.e., distress, strained or positive relationships, anxiety, depression). Still others constructed multidimensional instruments capable of generating scores to reflect both total burden and its component parts (e.g., Cost of Care Index - Kosberg & Cairl, 1986). Kosberg et al. (1990) argued that researchers and clinicians would receive more insightful information on caregiver burden from considering both global and subscale scores.

With the refinement of transactional theory (i.e., interaction of person, event, and situational context), scholars reconceptualized the caregiving process and proposed theoretical models based on the major premises of this theory (Kinney & Stephens, 1989a, 1989b; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Poulshock & Deimling, 1984). In most cases, the stress of caregiving emerged as the dominant multidimensional construct (i.e., cognitive or emotional response to actual/potential stressors), and was separated from caregiving outcomes (i.e., burden and health status). Poulshock and Deimling theorized that subjective burden (i.e., reactions to physical and mental functioning of elder) performed a mediator role between elder impairment (i.e., physical and mental functioning) and caregiving impact (i.e., family, social and work activities, and health).

In contrast, Kinney and Stephens (1989a, 1989b) and Lawton et al. (1989) emphasized that equal attention should be given to the positive and negative aspects of caregiving. Kinney and Stephens viewed cognitive appraisal (i.e., caregivers' perception of stressors as hassels or uplifts) as a mediator between caregiver stress (i.e., behavioral, cognitive, practical/ logistical) and well-being (i.e., social, psychological, affective, and physical functioning). Lawton et al. differed from Kinney and Stephens by combining all appraisals of stress into one complex construct, caregiving appraisal (i.e., satisfaction, perceived impact, mastery, cognitive reappraisal), which integrates subjective and objective aspects of burden as well as caregiver well-being, satisfaction, and coping.

Another group of authors considered the positive and negative aspects of caregiving from the perspective of Stress Theory (Pearlin et al., 1990). They developed the Stress Process Model which depicts possible relationships between stressors, mediators, and outcomes. This model also separates objective (i.e., events) and subjective (i.e., burden) stressors of caregiving from health status. Coping and social support are identified as mediators between primary stressors (i.e., cognitive status and problematic behaviors of care receivers, caregiving factors), secondary stressors (i.e., role and intrapsychic strain), and caregiver well-being (i.e., physical, mental, and social).

The preceding paragraphs clearly capture the diverse pathways that scholars have taken in developing theoretical perspectives on the factors influencing caregiving, the perceived impact of caregiving, and the outcomes of the caregiving process. The sections that follow highlight the methodological differences that surfaced in response to variant conceptualizations, as well as the similarities and differences among study findings.

Burden: The Impact of Caregiving

The terms burden, strain, and stress have been used, sometimes interchangeably, to denote the negative impact of caregiving. The theoretical and research literature identified many significant factors affecting the caregiving process. The following section will highlight studies that address the influence of sociodemographic and caregiving factors, caregiver health status, care receiver characteristics, social support, and a combination of these and other factors on caregiver burden.

Sociodemographic and Caregiving Factors

The majority of studies identified from the literature explored the influence of sociodemographic variables and caregiving factors (i.e., duration of caregiving, care hours, and tasks) on caregiver burden. The following review highlights the inconsistent findings on select variables.

Miller and Cafasso (1992) applied meta-analysis techniques, as described by Hunter and Schmidt, to investigate gender differences in caregiver burden in fourteen descriptive studies published between 1983 and 1990. One significant finding was that female caregivers reported higher levels of burden than male caregivers in 10 of 14 studies. However, Miller and Cafasso concluded that gender differences may change with culture and with differing stages of caregiving. These findings on gender differences for burden were supported by Kosberg et al. (1990) in a sample of caregivers ($\underline{N}$ = 127) of relatives with Alzheimer's disease, but not by Strawbridge and Wallhagen (1991) in a sample of adult children caregivers ($\underline{N}$ = 100) for frail older adults.

Barnes et al. (1992) designed a longitudinal study to investigate caregiver perception of burden in a sample of spousal and children caregivers ($\underline{N}$ = 206). Burden was assessed with six subscales - financial impact (alpha = .72), impact on caregiver's physical health (alpha = .85), impact on schedule (alpha = .81), feelings of abandonment (alpha = . 87), role responsibility (alpha = .88), and negative reaction to caregiving (alpha = .88). Findings indicated that spousal caregivers reported greater burden than adult children caregivers in three areas: physical health, role responsibilities, and feelings of abandonment. The findings contrasted with those reported by Elmstahl et al.'s (1996) who also conducted a longitudinal investigation of burden with a sample ($\underline{N}$ = 35) of spouse and adult children caregivers.

Stull et al. (1994) investigated the effect of living arrangement on strain (burden) in a sample of women caregivers (N = 112). Strain was assessed with a researcher-developed multidimensional instrument (alpha = .55 to .85). Caregivers living with care receivers reported significantly higher levels of physical strain than those not living with care receivers, but no differences for social strain, time constraints, or care receiver provoking behaviors.

Using the Quebec Health Survey database, Jutras and Lavoie (1995) examined stress of caregivers living with physically or cognitively impaired elderly (n = 292) and nonimpaired older adults (n = 292), or not living with older adults (n = 292). All caregivers were matched for gender and age. Study findings indicated that caregivers living with an impaired elderly family member reported higher levels of stress than comparison groups. In contrast, Elmstahl et al. (1996) found that living arrangment was not associated with caregiver burden. Further, Pearson et al. (1988) reported no relationship between living arrangement and caregiver burden, as measured with the Relatives Stress Scale (alpha = .85), in a sample of primary caregivers (N = 56) for older adults referred to a geropsychiatric center with a variety of disorders.

Scharlach (1989) surveyed employed caregivers to investigate the influence of working on caregiving for older cogntivitely impaired adults (n = 106) and physically impaired adults (n = 226). Employees for cognitively impaired adults provided more assistance and reported higher levels of strain (i.e., physical, emotional, financial, personal, and social) than those caring for the physically impaired.

Draper et al. (1992) reported a positive association between burden and duration of caregiving and care tasks in a sample of caregivers for persons with dementia (n = 51) and persons with a stroke (n = 48). Similarly, Strawbridge and Wallhagen (1991) found caregiver burden and duration of caregiving and care tasks positively related in a sample of adult children (N = 100). In contrast, Kosberg et al. (1990) failed to find an association between care hours and tasks with overall burden or any of the components of burden.

Caregiver Health Status

There were a number of studies identified from the literature that explored the relationship between caregivers' perceptions of health status and burden. Studies have not consistently considered both the mental and physical components of health as predictors of burden. The three studies reviewed in this section suggest that caregivers' mental health status is negatively associated with burden. Conflicting findings still exist on the relationship between physical health status and burden.

Using a descriptive correlational design, Anthony-Bergstone et al. (1988) investigated emotional distress and burden in a convenience sample of primary caregivers (N = 184) for persons with dementia. The Brief Symptom Inventory

(BSI) measured emotional distress on nine dimensions (somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychotism). The Burden Interview assessed the overall impact of caregiving (i.e., perceived burden) in terms of financial status, physical health, emotional health, and social activities. The authors reported moderate to high internal consistency for the instruments within their sample. The findings demonstrated a significant, positive correlation between perceived burden and all dimensions of emotional distress. However, only interpersonal sensitivity and anxiety entered the regression equation to account for 36% of the explained variance in burden scores.

In a longitudinal study, Pruchno et al. (1990) explored the relationship between physical health, depression, and burden in a sample of spousal caregivers for persons with Alzheimer's disease. Data were collected during the initial interview ($\underline{N} = 315$), at six months ($\underline{N} = 198$), and one year ($\underline{N} = 152$). Caregiver physical health and burden were rated on single items ranging from 1 (poor) to 4 (excellent), and 1 (not at all burdened) to 5 (very greatly burdened), respectively; and caregiver depression with the Center for Epidemiologic Studies Depression Index. Path analysis identified caregiver depression at time1 and time2 as a strong predictor of burden at time2 but not time3. However, physical health failed to surface as a significant predictor of burden.

Kosberg et al. (1990) examined correlates of burden in a sample of caregivers ($\underline{N}$ = 127) of relatives with Alzheimer's disease. The Cost of Care Index (CCI) measured five dimensions of burden (personal and social restrictions, physical and emotional costs, economic costs, value of care, and care receiver as provocateur). Caregiver mental health was assessed with the Short Psychiatric Evaluation Schedule and the OARS instrument, and physical health with the OARS instrument. High reliability was reported for all instruments. The findings indicated that poorer caregiver mental health was correlated with increased overall burden and three burden dimensions (personal and social restrictions, physical and emotional costs, and care recipient as provocateur). When caregivers reported poorer physical health, they were also more likely to report greater overall burden and increased personal and social restrictions, and physical and emotional health problems.

Care Receiver Characteristics

Care receiver characteristics refer to caregivers' perceptions of the mental and physical functioning abilities of care receivers, as well as the documented health status of care receivers. In four of the five studies reviewed, it seems apparent that despite the use of different measuring instruments caregivers of cognitively impaired care receivers reported greater burden than those caring for persons with physical impairments.

Bull (1990) examined the impact of care receiver physical health and functional ability on caregiver burden in caregiver-recipient dyads (N = 47) at 2-weeks and 2-months following hospital discharge for a chronic debilitating disease. Care receiver physical health and functional status was measured with the Philadelphia Geriatric Center Multilevel Assessment Instrument, caregiver subjective burden with the Robinson's Strain Index, and objective burden in terms of time spent in the caregiving role and the actual tasks performed. High reliability scores were generated for the standardized instruments and objective measure of burden. Study findings demonstrated a strong, negative correlation between caregiver burden and the care receiver's physical health and functional ability at both time periods.

Kosberg et al. (1990) also examined the relationship of care receiver cognitive, behavioral, and functional impairments with burden in a sample of caregivers (N = 127) of relatives with Alzheimer's disease. Burden was assessed with the CCI, care receiver behaviors with the Memory and Behavior Problems Checklist, care receiver cognitive ability with the Mental Status Questionnaire, and care receiver functional status with physical and instrumental activities of daily living items (i.e, ADL and IADL) adapted from the OARS instrument. Significant, positive correlations were found between total burden and care receiver behavioral problems; physical and emotional health and care receiver behavioral and functional impairments; economic costs and care receiver behavioral impairment; personal and social restrictions and cognitive and behavioral impairments; and, provoking behaviors and care receiver behavioral problems.

O'Connor et al. (1990) compared a group of caregivers for persons who were cognitively alert but frail or physically impaired (n = 107) with caregivers for persons with dementia (n = 120). Caregivers were asked to rate the frequency of behaviors commonly associated with dementia and the intensity of their reactions to these behaviors. Caregivers also rated their perceived strain in five domains (i.e., frustration, anxiety, depression, sleep pattern, holidays, and finances). No information was provided about the instruments' reliability or validity. Caregivers of persons with dementia reported a greater number of care receiver behavioral problems, more intense reactions to care receiver behaviors, and greater strain than those caring for physically impaired persons.

Neary (1993) investigated burden in caregivers for physically (n = 96) and cognitively (n = 19) impaired elders. Caregivers had placed the care receiver in a long term care facility six months prior to the study. Objective burden was measured with a researcher-developed Caregiver Task Inventory and subjective burden with the Burden Interview. Both groups of caregivers reported objective and subjective burden, but there was no statistically significant difference in the level of burden. These findings should be interpreted cautiously given the large difference in sample sizes.

In a descriptive correlational study, Browning and Schwirian (1994) investigated the relationship between caregiver burden and care receiver physical and cognitive impairments in a sample of spousal caregivers (N = 102). Caregiver burden was measured with the Burden Interview; and physical and mental health in terms of the medical diagnosis listed on the agency's chart and Memory and Behavior Problems Checklist. Findings indicated that caregivers of cognitively impaired spouses were more burdened than caregivers of physically impaired spouses.

Social Support

Social support refers to the presence of both informal and formal support systems. In the six studies reviewed, inconsistent findings were noted regarding the effects of social supports on caregiver burden. The use of different instruments to measure social support could be partially responsible for this observation.

Using a quasi-experimental research design, Toseland et al. (1989) investigated the effects of different, formal social supports on caregiver burden in a sample (N = 56) of adult daughters and daughters-in-law who were the primary caregivers for parents. Caregivers were randomly assigned to one of three conditions: a professionally-led support group, a peer-led support group, or respite-only control group. The following variables were measured before and following the interventions: (a) caregiver burden - Burden Interview and Problems with Caregiving Scale, (b) changes in caregiving situation - Extent of Caregiving Scale, a 5-point health status scale, and hours of caregiving; and, (c) social support - Community Resource Scale and items on changes in knowledge, network size, extent of change, and satisfaction with support. No significant differences were detected in the caregiving situation or perceived burden among the three groups post-intervention.

In a longitudinal study, Pruchno (1990) examined the relationship between the availability of informal support for spouses (N = 315) of cognitively impaired persons, and caregiving burden. Support was assessed on a Likert-scale ranging from 3 (much) to 1 (none), and positive and negative aspects of caregiving with researcher developed Uplifts and Burden scales (alpha = .80, .89, respectively). Study findings indicated that a minimal amount of emotional and practical support was provided by children or other relatives, and did not significantly buffer caregiver burden.

In a longitudinal study of caregivers for older adults (N = 109), Brown et al. (1990) investigated the relationship between the use of long-term services and burden. Subjective burden was measured with the Burden Interview, and long term care use by questions posed during interviews at 6 and 12 months. Burden scores were higher on initial testing for those who later placed the older adult in an institution or increased home services. During follow-up, burden scores decreased substantially for caregivers who placed the older adult in an institution, but not for those who increased home service use.

Using longitudinal data from the National Long Term Care Survey and Informal Caregivers Survey, Miller and McFall (1991) investigated the relationship between formal supports and caregiver burden in a randomized subsample of caregiver-receiver dyads (N = 644). Data were collected on formal support use during the previous week, and the perceived impact of caregiving on personal actions and activities (Personal Burden Scale) and caregiver and care receiver relations (Interpersonal Burden Scale). The findings indicated that most caregivers (~ 67%) did not use formal supports at either time period. Further, greater use of formal supports was associated with less informal supports and greater personal burden.

Kramer and Kipnis (1995) examined caregiver resources and burden in a probability sample of employed, non-spousal caregivers for older adults (N = 512). Researcher-developed items measured caregiver resources (i.e., informal and formal supports) and burden (alpha = .74). Findings indicated that caregivers who had inadequate informal and formal resources were significantly more burdened than caregivers with adequate resources.

McKinlay et al. (1995) longitudinally investigated the effects of social support on caregiver burden in a stratified random subsample of caregivers and care recipients participating in the Massachusetts Elder Health Project. Subjects were interviewed at 15-month intervals over a 7-year period (time 1: N = 447; time 2: N = 359; time 3: N = 275). Social support was measured by hours of informal and formal support for personal care, housekeeping, meals, transportation, and financial management. Factor analysis of the data on changes in daily norms identified four major content domains of burden. The greatest impact occurred in the personal domain (61.1%), followed by job structure (20.3%), family relationships (17.6%), and employment (15.6%). Study findings indicated that assistance from family, friends, or professionals decreased the impact on personal factors (i.e., sleep, health, leisure, privacy, finances, and management of chores).

Interactive Factors

A number of studies explored the influence of several factors on caregiver burden. In the six studies reviewed in this section, caregiver emotional distress and the presence of cognitive and/or behavioral impairment in the care receiver were consistently correlated with higher caregiver burden, whereas social support evidenced an inconsistent relationship with burden. Other factors (e.g., coping skills, stressful life events, past marital relationship, etc.) also surfaced as significant predictors of burden.

Zarit et al. (1986) investigated factors affecting caregiver burden over a two-year period in spouses of persons with dementia (Time 1: N = 64; Time 2: N = 43). The Burden Interview, the Memory and Behavior Problems Checklist, and the frequency of informal and formal supports were used to assess study variables. Subjective ratings of social supports and the cross-product score for memory and behavior problems (i.e., frequency of problems x reactions to identified problems) were positively correlated with caregiver burden at initial testing, but only the cross-product score for memory and behavior problems maintained a significant correlation two years later.

Robinson (1990) investigated the effects of sociodemographic variables, caregiver physical health, well-being, social supports, and marital relationship to objective and subjective burden in wives caring for husbands with dementia (N = 78). Caregiver physical health was assessed on a 4-point Likert rating scale, functional health with the Louisville Health Scale, and overall physical well-being by combining the score obtained on both measures. A modified version of the Inventory of Socially Supportive Behaviors measured social supports: directive guidance (understanding and skill supports to improve caregivers performance), physical help, affection, and additional items assessing attitudes towards asking for support. In addition, the Marital Adjustment Test investigated past marital relationship, items adapted from scales by Montgomery, Gonyea, et al. (1985) measured objective burden, and items proposed by Zarit et al. (1980) assessed subjective burden. The findings indicated that caregiver physical well-being and directive guidance were negatively correlated with objective burden (i.e., better health and greater directive guidance, lower objective burden), whereas the desire for greater support was associated with greater subjective burden. During the regression analysis, only socioeconomic status and caregiver attitudes surfaced as significant predictors (i.e., accounting for 12% of the explained variance) of objective burden, and past marital adjustment as a significant predictor of subjective burden (i.e., accounting for 20% of the explained variance).

Intrieri and Rapp (1994) studied the relationship between coping skills, emotional distress, care receiver functioning, and burden in caregivers ($\underline{N} = 44$) for spouses with non-trauma induced cognitive impairment (eg., Alzheimer's, stroke, etc.). The Brief Symptom Inventory, Burden Interview, and Rosenbaum's Self-Control Schedule were used to measure emotional distress, burden, and self-control coping skills, respectively. Care receiver functioning was measured with the Memory and Behavior Problems Checklist. Study findings demonstrated significant, positive correlations between caregiver burden and memory and behavior problems of care receivers and the emotional distress of caregivers. Further, a strong, negative correlation was observed between self-control coping and burden. During regression analysis with caregiver burden as the outcome variable, care receiver memory and behavior problems accounted for 14.1% of the explained variance, emotional distress 20.4%, and self-control skills 22.1%. Given the large number of variables and the small sample size, these findings should be interpreted cautiously.

As part of a longitudinal design, Bull et al. (1995) examined factors influencing caregiver burden and health status in a sample of caregiver-care receiver dyads ($\underline{N}$ = 346) prior to hospital discharge, and at two weeks ($\underline{N}$ = 346) and two months ($\underline{N}$ = 316) following hospital discharge with a chronic illness. Caregiver physical health and functional health (i.e., ADL and IADL activities) were measured with the Philadelphia Center Multi-level Assessment Instrument (PGC-MAI); mental health with the Symptom Questionnaire; burden with an instrument developed by Given et al. (1990); coping with the Ways of Coping Checklist; discrepancy in actual and ideal emotional and practical support with the Significant Others Scale; and, several items measured hours and types of formal services and caregiving involvement. Care receiver health was measured with relevant subscales from the PGC-MAI, and the Symptom Questionnaire and Activities of Daily Living Scale. Study findings indicated that at two weeks caregiver burden depicted significant, negative correlations with care receiver health prior to hospital discharge, and caregiver coping, involvement, mental health status, and perception of informal support. Perception of informal support explained approximately 39% of the variance in caregiver burden. At two months, only caregiving involvement and perception of informal supports were related to burden.

Phillips et al. (1995) studied the effects of predictor variables on perceived burden in a convenience sample of caregivers for elders living in the community (N = 209 dyads). Life Event Questionnaire and Burden Interview assessed caregiver stress and burden. Norbeck Social Support Questionnaire measured availability of social support. Elder Image Scale operationalized caregivers' perception of the differences in the past and present image of care receivers, and Beliefs about Caregiving assessed beliefs and values on caregiving. Social Desirability Scale measured the amount of variance to be attributed to caregiver's desire to be viewed positively. All instruments were reported to have established reliabilities. Regression analysis identified social desirability (10% of the explained variance), stress of caregiver and cognitive function of care recipient (22% of the explained variance), and discrepancy between past and present image of elder (7% of the explained variance) as important predictors of burden. That is, higher social desirability and greater perceived caregiver stress, impaired cognitive functioning of the care recipient, and discrepancies between present and past images of elder were associated with higher burden.

Braithwaite (1996) investigated the relationship of caregiver burden and physical and mental health in a sample of caregivers (N = 144) for impaired elders (e.g., cardiovascular disorders, dementia, etc.). Burden was measured with 17 researcher-developed items which generated a global score. Personal resources was measured in terms of self-esteem (Rosenberg scale), mastery (modified Pearlin and Schooler scale), and coping (researcher developed scales on seeking solutions, reinterpretation and acceptance, avoidance, and withdraw). Physical health was measured on a Likert-type scale ranging from 1 (poor) to 3 (good), and mental health with the Delusions-Symptoms States Inventory and Four Neurotic Symptoms Index. All measures, except for the self-rating physical health scale, were found to have high reliabilities for the study sample. Study findings indicated that caregiver burden depicted low to moderate negative correlations with self-esteem, mastery, coping, and caregiver mental health.

Summary

It is apparent from the studies reviewed that researchers have conceptualized the impact of caregiving in different ways and investigated the effect of diverse factors on caregiver burden. The conceptual overlap between health status and burden was also evident from the studies reviewed. To complicate matters further, the use of multiple operational measures for the same factors (e.g., physical health, mental health, burden, social support, etc.) made cross-study comparisons difficult. The conflicting findings observed with respect to the influence of sociodemographic and caregiving factors, care receiver characteristics, caregiver health status, and social supports on burden may be due, in part, to the theoretical and methodological differences among the studies.

Health Status: The Outcome of Caregiving

The literature review identified many studies which investigated the factors affecting caregiver health as the outcome of caregiving. Studies highlighted in this section addressed the influence of sociodemographic and caregiving factors, caregiver burden, care receiver characteristics, social support, or a combination of these factors on caregivers' physical and mental health status.

Sociodemographic and Caregiving Factors

There were a number of studies identified from the literature that explored the influence of sociodemographic and caregiving factors (i.e., duration of caregiving, care hours, and tasks) on caregiver health status. The following review outlines some of the inconsistent findings on select variables pertinent to this study.

Jutras and Lavoie (1995) compared the physical and mental health of caregivers living with physically or cognitively impaired elderly ($\underline{n}$ = 292) and nonimpaired older adults (n = 292), or not living with older adults (n = 292). With regards to self-reported physical health problems, caregivers living with an impaired elderly family member reported significantly more disabilities and chronic conditions than those living with an unimpaired adult. From the perspective of psychological health, caregivers living with an impaired elderly family member scored lower on psychological well-being than those in both comparison groups. They also had more mental health problems than caregivers of unimpaired adults.

Stull et al. (1994) explored the effects of living arrangements and employment status on caregivers' well-being and mental health (i.e., depression) in a sample of women caregivers (N = 112). Depression was measured with the Center for Epidemiological Studies Depression Scale. Study findings failed to detect significant differences in caregivers well-being or levels of depression whether they were living with or separate from care receivers, and employed or unemployed.

In a cross-sectional study, Baumgarten et al. (1992) compared the health of spouse and children caregivers for persons with dementia (n = 103) with those for persons without dementia (n = 115) who underwent cataract surgery four months previously. The Centre for Epidemological Studies Depression (CESD) measured depression. The Aday and Anderson 24-item Checklist assessed physical symptoms, and the Older Americans Research and Services

(OARS) measured overall health and prescription and non-prescription drug use. Group differences on caregiver psychological and physical health were substantially larger for spouse versus children, and older versus younger caregivers.

Young and Kahana (1989) investigated gender differences in caregiver physical and mental health in patient-caregiver dyads (N = 183) six weeks after the older adults were discharged from the hospital for a confirmed heart attack. Female caregivers were found to have a greater decline in physical health and higher levels of mental health symptoms than male caregivers. However, Strawbridge and Wallhagen (1991) failed to find a relationship between gender and mental health in a sample of adult children caregivers (N = 100).

Scharlach (1989) surveyed employed caregivers to assess the influence of working and caregiving for older cogntivitely impaired adults (n = 106) and physically impaired adults (n = 226). Data were collected on sociodemographic variables, care receiver characteristics, caregiving involvement, and caregiver strains and health. Employees caring for cognitively impaired older adults provided more assistance, reported higher levels of strain (i.e., physical, emotional, financial, personal, and social), and reported lower levels of health than those caring for physically impaired adults.

Miller, McFall, and Montgomery (1991) investigated caregiver involvement and health in a sample of spouse and adult children (N = 940). Involvement measurements included the number of care hours and tasks, and items on physical and mental health. Caregiver involvement was negatively associated with caregiver health. Similarly, Draper et al. (1992) reported a negative relationship between caregiver mental health and duration of caregiving and care tasks in a sample of caregivers for persons with dementia (n = 51) and persons with a stroke (n = 48). However, Kiecolt-Glaser et al. (1991) examined the health of spouse caregivers (n = 69) for persons with dementia and matched control subjects (n = 69). The Hamilton Depression Rating Scale and the Structured Clinical Interview for DSM-III-R measured caregiver mental health status. Care hours and caregiver mental health were not found to be related.

Caregiver Burden

Bull (1990) examined the influence of caregiver burden on health status in a sample of caregiver-recipient dyads (N = 47) at 2-weeks and 2-months following hospital discharge for a chronic debilitating disease. The caregivers' physical health was assessed with the Philadelphia Geriatric Center Multilevel Assessment Instrument, and mental health with the Beck's Depression Inventory. Caregiver's subjective burden was measured with the Robinson's Strain Index, and objective burden in terms of time spent caregiving and tasks performed. Caregiver subjective and objective burden were not significant predictors of caregiver physical or functional ability. However, subjective burden did surface as a significant predictor of caregiver mental health at 2-weeks (i.e., 27% of explained variance) and 2-months (i.e., 17% of explained variance).

Care Receiver Characteristics

As noted in the previous section on caregiver burden, care receiver characteristics include caregivers' perceptions of the mental and physical functioning abilities of care receivers and medically diagnosed health problems. The eight studies reviewed which investigated the effects of care receiver characteristics on the mental and physical health status of caregivers evidenced conflicting findings. Study findings suggest that a decline in caregiver health was associated with some aspect of care receiver memory, depression, or behavior problems, and cognitive, functional, or physical health status. It was observed, however, that the smaller the sample size for certain groups, the greater the tendency for non-significant findings.

Neundorfer (1991) investigated caregiver health in a sample of spouse caregivers for persons with dementia ($\underline{N} = 60$). The frequency of care receiver problems and caregiver intensity of reactions to them was measured with the Memory and Behavior Problems Checklist. Caregiver physical and mental health were measured with the OARS, and the Brief Symptom Inventory, respectively. The frequency of problems and intensity of reactions were not significantly related to caregivers physical health, but depicted a low to moderate positive association with anxiety and depression.

As part of a longitudinal study, Pruchno and Potashnik (1989) investigated the impact of caregiving for persons with cognitive impairment on the mental and physical health of spouses (N = 315). Caregiver overall health was measured on a single item with a Likert-scale ranging from 1 (poor) to 4 (excellent). Additional measures of health status included the Hopkins Symptom Checklist, newly diagnosed physical health problems, recent use of psychotrophic drugs, the Centre for Epidemological Studies Depression (CESD), and the Affect Balance Scale. All instruments were reported to have strong reliability. Study findings were compared to those from matched control groups on age and gender from the general population. The findings indicated that caregivers in the current study rated their health as excellent less frequently, were more depressed, reported higher rates of physical health problems, and used psychotrophic drugs more frequently than the general population.

Kiecolt-Glaser et al. (1991) longitudinally examined the health of spouse caregivers (n = 69) for persons with dementia and sociodemographically matched control subjects (n = 69). The Hamilton Depression Rating Scale and the Structured Clinical Interview for DSM-III-R measured caregiver mental health status, and the Health Review Checklist illness symptoms. All instruments were reported to have strong reliability. Caregivers demonstrated more illness days and visits to the doctor, higher rates of syndromal depressive disorders, and poorer physical and mental health than controls.

In a longitudinal study, Rabins et al. (1990) compared the emotional impact of caregiving on caregivers for persons with Alzheimer's disease ($\underline{n}$ = 32) and persons with cancer ($\underline{n}$ = 30). The General Health Questionnaire and Affect Balance Scale were used to measure emotional distress. Findings indicated that emotional distress was similar for caregivers of persons with Alzheimer's disease and cancer. The small, convenience sample limits the generalizability of study findings.

In a cross-sectional study, Baumgarten et al. (1992) compared the health of spouse and adult children caregivers for persons with dementia ($\underline{n}$ = 103) with those for persons without dementia ($\underline{n}$ = 115) who had cataract surgery four months previously. The Centre for Epidemological Studies Depression (CESD) scale measured depression. The Aday and Anderson 24-item Checklist assessed physical symptoms, and the Older Americans Research and Services (OARS) measured overall health and prescription and non-prescription drug use. Caregivers for persons with dementia demonstrated lower levels of well-being than caregivers for persons without dementia on all measures of psychological and physical health.

Clipp and George (1993) studied caregiver well-being in spouses of persons with dementia ($\underline{n}$ = 272) or cancer ($\underline{n}$ = 30). Physical health was assessed with a number of indicators: the frequency of physician visits and hospital days in the past 6-months; rating of health on one item with a Likert-scale ranging from 1 (poor) to 4 (excellent); rating of interference with normal activities on one item with a Likert-scale ranging from 1 (never) to 4 (always); and, amount of drug use. Emotional health was measured with the Affect Balance Scale, Short Psychiatric Evaluation Schedule, Screening Scale, and three-items on life satisfaction. The findings indicated that both groups reported a decline in well-being. However, caregivers of persons with dementia reported greater negative impacts on physical and emotional health than those caring for persons with cancer. A major limitation of this study was the large discrepancy in sample sizes, especially the small number of subjects in the cancer group.

In a descriptive correlational study, Dura et al. (1990) investigated emotional distress in a sample of caregivers for spouses with Alzheimer's type dementia ($\underline{n}$ = 23) and Parkinson's Disease with dementia ($\underline{n}$ = 23), and a married control group matched for sex, age, and education ($\underline{n}$ = 23). The Hamilton Depression Rating Scale, Beck Depression Inventory, and Brief Symptom Inventory measured caregiver distress. The Blessed Dementia Scale, Memory and Behavior Problem Checklist, and Global Deterioration Scale assessed care recipient characteristics. All instruments were reported to be strongly reliable. Although the progression of cognitive and personality changes differed in care recipients with Parkinson's and Alzheimer's Diseases, no significant differences were observed between caregivers on levels of distress. However, both groups differed significantly from the control group. As the authors acknowledge, these results should be interpreted cautiously because of the small sample size.

Yeatman et al. (1993) compared the level of psychological health in caregivers for persons with dementia ($\underline{n} = 31$ dyads) with caregivers for persons with depression ($\underline{n} = 30$ dyads). The Geriatric Mental State examination, History and Aetiology Schedule, Cambridge Cognitive Examination, Hamilton Rating Scale for Depression, DSM-III-R, and Cambridge Examination for Mental Disorders in the Elderly measured care receiver depression and dementia. The General Health Questionnaire measured caregiver psychological health. Findings indicated that caregivers for persons with dementia and depression had higher psychological distress than the population norm. However, psychological distress was similar for both study groups.

Social Support

In this section, consideration is given to the influence of informal and formal supports on caregiver health status. In the three studies reviewed, informal and formal supports exerted either a mediating or direct effect on caregiver health status.

Fink (1995) examined the influence of family resources and demands on the well-being of caregivers for elderly parents ($\underline{N} = 65$). The Family Social Support Index, Personal Resources Questionnaire, and Family Hardiness Scale measured family resources. The Family Stressors Index and researcher-developed items on family involvement measured family demands. The Burden Interview and Family Strain Index assessed family strains. The Family Apgar, Affect Balance Scale, and 4-point Likert-scales measured individual and family well-being. Findings indicated that when informal and formal support resources were adequate, strains and burden did not affect caregiver well-being. The authors suggested that supports may buffer the effects of caregiving.

Toseland et al. (1989) also investigated the effects of different types of formal supports on mental, physical, and social functioning in adult children caregivers (N = 56). Caregivers were randomly assigned to one of the following treatment conditions: a professionally-led group, a peer-led group, or respite-only control group. The following variables were measured before and after the interventions: (a) psychological functioning - Bradburn Affect Balance Scale for wellness and Brief Symptom Inventory for psychiatric symptomatology; (b) social support - Community Resource Scale and items on changes in knowledge, network size, extent of change, and satisfaction with support; and, (c) personal problems - researcher-developed items on perceived changes. Both treatment groups reported increased persons in support networks, improved psychological functioning, greater knowledge of community resources, and less personal problems.

Bass et al. (1996) investigated the buffering effect of formal social support between care receiver characteristics and caregiver health status (i.e., physical and mental health, and emotional distress) in a sample of primary caregivers for older adults (N = 401). The Nagi Index measured care receiver physical disability, and researcher developed items assessed cognitive impairment (alpha = .86) and problem behaviors (alpha = .85). Researcher-developed items assessed personal care services (alpha = .78), escort services (alpha = .62), household services (alpha = .70), and health care services (alpha = .51). The Center for Epidemiological Study's Depression Scale measured caregiver depression. Researcher-developed items measured caregiver physical health (alpha = .89) and emotional distress (alpha = .85). Findings indicated that health care services consistently moderated the effect of care receivers' physical disability on caregiver distress, and the effect of care receivers' cognitive impairment on caregiver depression. Further, personal care services consistently modified the effect of problem behaviors on all aspects of caregiver distress, but only household services modified the effect of problem behaviors on depression.

Interactive Factors

A number of studies explored the influence of several factors on caregiver health status. The seven studies in this section viewed social support from diverse perspectives (i.e., emotional, utilization, numbers, and social activities, as well as informal, formal, or both) which partially contributed to the variable effects noted across the studies. Greater caregiver emotional distress was correlated with increased cognitive impairment and psychological distress in the care receiver, and greater caregiver burden.

Pruchno et al. (1990) explored the relationship between physical health and depression in a sample of spousal caregivers for persons with Alzheimer's disease at study entry (N = 315), six months (N = 198), and one year (N = 152). Caregiver physical health was rated on single items ranging from 1 (poor) to 4 (excellent), and depression with the Center for Epidemiologic Studies Depression Index. Path analysis identified caregiver depression at time1 and time2 as a strong predictor of declining physical health at later time periods. However, physical health failed to surface as significant predictor of depression.

In a longitudinal study, Speer (1993) investigated factors influencing adjustment (i.e., depression, distress, burden) in a sample of caregivers for persons with Parkinson's disease (N = 26 dyads). The following scales were completed for both caregivers and care receivers: the Appraisal and Belonging Social Support Scale (emotional and social activities), Interpersonal Support Evaluation List, short form of the Geriatric Depression Scale, and items measuring physical distress from the Duke-North Carolina Health Profile and Health and Daily Living Form. Caregivers also completed the Cost of Care

Index (i.e., burden), and care receivers the Perceived Stress Scale. Study findings at initial testing indicated that caregiver depression depicted moderate to strong, negative correlations with caregiver emotional support and social activities support; and strong, positive correlations with caregiver burden and physical distress. Caregiver depression also depicted strong, positive correlations with care receiver stress and depression.

Using a longitudinal design, Cohen et al. (1993) investigated the relationship between caregiver burden and health in a sample of caregivers for older adults with dementia (N = 196). Data were collected with the General Health Questionnaire, Burden Interview, Past Social Interaction Scale, Social Support Questionnaire, Memory and Behavior Problems Checklist, and ADL items. All instruments were shown to have good reliabilities. Data were collected at study inception and at 2-month intervals to document changes in caregiving. After eighteen months, caregivers (n = 100) who had placed the older adult in an institution reported lower levels of health, higher levels of burden, more use of community services, and more impaired care receivers than those who did not place the older adult.

Braithwaite (1996) also investigated the effect of a number of factors on caregiver mental health status in a convenience sample of caregivers (N = 144) for elders with a variety of disorders. Caregiver mental health status depicted moderate, positive correlations with self-esteem, mastery, and physical health; and, a low to moderate, positive correlation with coping.

Using data from the first wave of a longitudinal study, Stommel et al. (1990) investigated the relationship between caregiver health (i.e., mental and physical) and care receiver characteristics, social supports, and caregiver burden a sample of primary caregivers ($\underline{N} = 307$) for dependent elderly living in their own homes. A researcher-developed instrument measured burden in five areas: impact on finances, feelings of abandonment, impact on schedule, impact on health, and sense of entrapment (alpha = .72 to .87). The Center for Epidemiologic Studies Depression Scale assessed caregiver mental status. Care receiver physical and mental health were measured on Likert-type scales. The frequency of caregiver involvement with activities of daily living (ADL) and instrumental activities of daily living (IADL) was rated on a Likert-type scale ranging from 0 (no involvement) to 4 (several times a day). Support was assessed by the total number of informal support persons and utilization of formal services. Findings indicated that all components of caregiver burden depicted a strong, positive correlation with depression. Care receiver cognitive deficit and the extent of caregiver involvement also demonstrated a low to moderate, positive correlation with caregiver depression. Care receiver physical deficit or the number and type of social support were not significant correlates of caregiver depression.

In a descriptive correlation study, Cattanach and Tebes (1991) investigated the relationship between care receiver cognitive and functional abilities and caregiver health and social functioning in a sample of daughters and daughters-in-law for elders who were cognitively impaired (n = 39), functionally impaired (n = 30), or cognitively and functionally intact (n = 33). The Mini-Mental State and Older Americans Resources and Services (OARS) were used to measure care receiver characteristics. Caregiver health was assessed by the Center for Epidemiologic Studies Depression scale, General Health Questionnaire, Cohen-Hoberman Inventory of Physical Symptoms, Life Experience Survey, Perceived Stress Scale, Coping Strategies, and an item measuring control. Additional information was gathered on perceived usefulness of supports (Interpersonal Support Evaluation List) and use of health services. Analyses of variance did not reveal any significant group differences on caregiver health. Study findings should be interpreted cautiously because of the small sample size.

Draper et al. (1992) investigated factors affecting psychological morbidity in a sample of caregivers for persons with dementia (n = 51) and persons with a stroke (n = 48). Caregiver psychological distress was measured with the General Health Questionnaire and Chronic General Health Questionnaire (CGHQ); caregiver burden with Relatives Stress Scale; social participation and satisfaction with Quality of Life Questionnaire and Life Satisfaction

Questionnaire; caregiver self-ratings of health status on one item with a 4-point Likert-scale; and, caregiver perception of care receiver's mental functioning with the Behavior and Mood Disturbance Questionnaire. The findings indicated that caregiver health status was negatively correlated with burden and psychological distress in the dementia group. In addition, a stronger positive correlation was observed between care receiver mental and behavioral problems and caregiver psychological distress and a stronger negative correlation between quality of life and psychological distress for caregivers of persons with dementia than those caring for persons with stroke. Finally, life satisfaction depicted a strong, negative correlation with psychological distress for both groups.

Summary

As noted in the previous section on the impact of caregiving, the inconsistent findings on the influence of social supports, caregiver burden, and care receiver characteristics on health status may be attributed in part to the theoretical and methodological variations among studies and ratio of sample sizes to the number of variables investigated. Despite these limitations, most of the evidence suggested that a decline in caregiver mental health was associated with burden and aspects of care receiver characteristics (i.e., degree of physical, cognitive, and functional impairment). Several studies reported that social support was more likely to have a buffering or mediating effect.

Discussion

The conceptual overlap between burden and health status is problematic. In some instances, physical and emotional health are treated as aspects of burden; but in other cases burden is used to predict health status, or health status is used to predict burden. The ambiguity with conceptual definitions, and restricted agreement on valid and reliable operational measures for burden, supports, health, and others must be reduced if meaningful conclusions are to be reached on the key factors influencing caregiver health status.

While a number of different factors affect caregivers' perceptions of health, the influence tends to vary in terms of the cognitive and physical limitations of the care receiver, caregiver burden, and the caregiving situation (e.g., availability of and the perceived need for informal or formal supports, etc.). Conflicting findings exist on the extent to which social supports (informal and formal) influence caregiver burden and negative changes in health status. Observed discrepancies in study findings on factors influencing caregiver health status suggest the need for more research in this area.

Conceptual Framework

The conceptual framework for this study is based on the Stress Process Model (Pearlin, et al., 1990). The model evolved from conceptual themes generated from in-depth interviews with primary caregivers (N = 555) of a spouse or parent with cognitive impairments (Aneshensel, Pearlin, & Schuler, 1993). The major theoretical constructs of the model endeavor to capture the interactions between primary caregivers and the caregiving environment through a comprehensive, evolving process (see Figure 1).

The Stress Process Model consists of four interrelated domains: background and stress context, stressors (primary, secondary), mediators of stress, and stress outcomes. Pearlin et al. (1990) postulate that the outcome of caregiving stress (i.e., health status) results from changing conditions in background and contextual factors, primary and secondary stressors, and mediators of stress. For the purposes of this study, the focus will be restricted to the direct effects of background and context factors, primary and secondary stressors, and interpersonal relationships on outcome.

The background and context consists of caregiver sociodemographic characteristics (i.e., age, gender, length of caregiving, relationship, living arrangements, urban/rural location, economic status). Primary and secondary stressors comprise the second domain of the Stress Process Model. Primary stressors are problems encountered during caregiving, and include daily dependencies, problematic behaviors and cognitive status of the care receiver. Secondary stressors, generated by primary stressors, include caregiver psychological and role strains. They are multidimensional and equally as powerful as primary stressors.

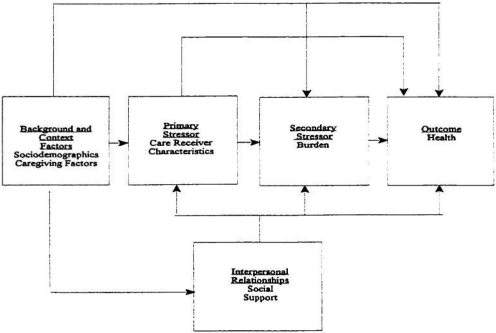

Figure 1. Proposed relationship among study variables.

Note. Modified Version of the Stress Process Model as outlined in "Caregiving and the stress process: An overview of concepts and their measures." by L.I. Pearlin, J.T. Mullan, S.J. Semple, & M.M. Skaff, 1990, The Gerontologist, 30 (5), p. 586.

Mediators, the third domain of the Model, decrease the impact of caregiving and constrain the outcomes. Pearlin et al. (1990) identified social support and coping as important mediators. Social support has both instrumental and expressive components. Coping processes are conceptualized as behaviors and practices employed to manage the stress situation and stress symptoms, and to reduce the perceived threat. The final domain is outcome or effects of stress. Caregiver well-being, physical and mental health, and social functioning are considered outcomes. According to Pearlin et al., stress first affects caregiver physical health, then psychological health, and finally yielding of the caregiver role.

This model is sufficiently general to facilitate comparisons across care receivers' diagnoses, and relationships among caregivers and care receivers. Although the proposed study is cross-sectional and not longitudinal as suggested by the model, data will be collected at a crucial time in the caregiving process. The SPM model has several modifications in the proposed study. Secondary stressors are considered the consequences or impact of caregiving (i.e, burden) as defined by Kosberg et al. (1990). As well, social support was defined as the effects of the quantity and quality of interpersonal relationships on health status rather than a mediator as identified in the Stress Process Model.

Definitions

Caregiver self-ratings of physical and mental health status were the outcome variables investigated in this study. Physical and mental health were rated on Likert-type scales ranging from 1 (poor) to 4 (excellent). The use of single items with this type of format has been reported in the literature as a valid way to elicit health perceptions (Frank-Stromborg, Pender, Walker, & Sechrist, 1990).

Care receiver characteristics were used to represent primary stressors. Care receiver characteristics refer to caregiver perception of memory problems, disruptive behaviors, and depression problems of the care receiver. The secondary stressor component of the model was restricted to caregiver burden as defined by Kosberg et al. (1990). Burden was defined as the impact of caregiving (i.e., subjective) in terms of personal and social, physical and emotional, value of caregiving, care receiver as provocateur, and economic dimensions. Background and context factors reflect select attributes of the caregiver and care receiver. Consideration was given to sociodemographic factors (gender, relationship, living arrangement, location, and employment status) and caregiving factors (tasks, hours, and duration of caregiving).

Social support was defined as the effects of the quantity and quality of interpersonal relationships. The structural (network size, source of support, duration of supportive relationships, frequency of contact, and loss of relationships) and functional (emotional and tangible) aspects of social support were addressed.

CHAPTER 3

Methodology

A descriptive correlational design was used in this study to investigate factors influencing perception of health status in a sample of primary caregivers waiting to place an older adult in a nursing home within the western region of the Newfoundland health care system. Consideration was also given to the relationships among sociodemographic variables, caregiving factors, care receiver characteristics, burden, social support, and caregiver health status; and, to the most significant predictors of caregiver health status. This chapter provides an overview of the sample, setting, instruments, procedure, ethical considerations, data analysis, and study limitations.

Population and Sample

The target population was all primary caregivers of older, dependent adults waiting for placement in a nursing home within the western region of the province of Newfoundland. All applications for nursing home entry are reviewed by the Regional Assessment and Placement Committee for eligibility, level of care required and priority. Subsequently, the names of those who are eligible for admission are placed on a waiting list (L. Hoddinott, personal communication, February 11, 1998). A non-probability convenience sample was obtained from the accessible population registered with Community Health Western, a regional health board within the western region of the province of Newfoundland. Subjects eligible for inclusion in the sample had to meet the following criteria: 1) listed as primary caregivers on the application form of an older adult (65 years of age and over) waiting for placement in a nursing home within the western region of Newfoundland; 2) mentally competent - able to understand the study purpose and give written, informed consent; 3) living within a three-hour drive of Corner Brook; and, 4) nineteen years of age and older.

One hundred and five subjects meeting the study criteria were contacted by the Continuing Care Coordinator for Community Health Western. Seventy-five agreed to participate, giving a 71.4% response rate. The number was slightly lower than the desired sample size. Using a power of .80, alpha of .05, and an estimated medium to large effect, a sample size between 159 and 66 was projected. Due to the smaller than expected number of older adults on the registry for nursing homes, a sufficient sample size to attain a medium effect was not possible within the allotted time frame.

Setting

The majority of participants ($\underline{n}$ = 72) preferred to be interviewed in their homes. Three participants requested that the interview take place outside their homes, and chose the researcher's office. The interviews were conducted in private in order to facilitate a freer discussion of experiences and concerns.

Procedure

The questionnaires were pretested in face-to-face interviews with five caregivers prior to the data collection process. No problems were encountered with item clarity of the instruments. It was also determined that the interviews would take approximately one and one-half hours.

Data were collected from September 1996 to March 1997. All study participants were initially contacted by the Continuing Care Coordinator from Community Health Western. In a letter to potential participants, the Coordinator provided a brief description of the study, an informed consent form, a form to indicate consent for researcher contact, a self-addressed and stamped envelope, and her telephone number if additional information was needed prior to researcher contact. After a two week waiting period, follow-up telephone calls were made by the Coordinator to those who had not responded to the initial mailout.

Participants who agreed to be contacted were telephoned by the researcher. Any questions and concerns were addressed at this time. Interviews were then arranged at a time and place convenient for participants.

A consistent format was followed during the interviews to ensure voluntary, informed consent and to reduce the potential for bias. Informed, written consent was obtained following a detailed explanation of the study and any participant questions addressed (see Appendix A). An interview format was used with all participants. Each instrument was administered in the same order following a brief description of standardized instructions. Interviews took approximately one and one-half hours to complete.

Instruments

Data were collected with four instruments. Three of the instruments were identified from the literature review. Permission for instrument use was requested and received from relevant authors. The fourth instrument was developed by the researcher for use in the current study.

Revised Memory and Behavior Problems Checklist (RMBPC)

The RMBPC, developed by Teri, Truax, Logsdon, Uomoto, Zarit, and Vitaliano (1992), assessed caregivers' perception of memory problems, depression, and disruptive behaviors of care receivers (see Appendix B). Most items were taken from the original Memory and Behavior Problems Checklist developed by Zarit et al. (1980). Additional items were added to measure behaviors associated with dementia and designed for clinical and research practice.

The RMBPC consists of twenty-four items in three subscales: memory-related problems, depression, and disruptive behaviors. Frequency ratings are used to assess the occurrence of care receiver's problems, and reaction ratings evaluate the impact of these problems on caregivers. The data are collected using a five-point rating scale. It is possible to calculate a global summary score and subscores for both the frequency and reaction ratings.

Teri et al. (1992) reported on the reliability and validity of the RMBPC. Internal consistency of the subscales ranged from an alpha of .67 to .84 for frequency ratings, and from .84 to .90 for reaction ratings. Construct validity was established by using principle factor analysis with varimax rotation. Criterion-related validity of the frequency ratings was established by correlating the Depression subscale with the Hamilton Depression Rating Scale, and the Memory subscale with the Mini-Mental State Exam. Criterion-related validity of the reaction scale was established by correlating ratings with the Center for Epidemiological Studies Depression Scale and the Caregiver Stress Scale. Further confirmation of criterion-related validity was obtained for the Depression subscale by comparing differences between a depressed group of subjects with a non-depressed group, $\underline{t}$ (155) = 5.1, $\underline{p} < .001$, and for the Memory subscale by comparing a group of subjects with dementia and a group without dementia, $\underline{t}$ (33) = 5.56, $\underline{p} < .001$. Validity of the Disruptive Behaviors subscale was not evaluated since no similar measures were available.

Norbeck Social Support Questionnaire (NSSQ)

The NSSQ, a multidimensional instrument developed by Norbeck, Lindsey, and Carrieri (1981), was used to measure caregiver perception of social support (see Appendix C). Content validity of the NSSQ was based on the conceptualization of social support by Kahn (1979). Studies (O'Brien, 1993; Primomo, Yates, & Woods, 1990) describe Kahn's definition of support as affect (expression of liking, admiration, respect or love of one person toward another), affirmation (expression of agreement, acknowledgement or endorsement of another person's behaviors, perceptions, or expressed views), and aid (giving of direct assistance to another by providing resources, money, information, or time).

The NSSQ is designed to measure two functional aspects of support (emotional support and aid) and five structural properties which include network size, source of support, duration of the relationships, frequency of contact, and recent losses of persons from the support network (Norbeck, 1995). Subjects are asked to list people who provide personal support, formally or informally, and to indicate the relationship of that person. Each identified person in the network is rated on a five-point rating scale in terms of structural and functional contributions.

Concurrent validity of the NSSQ was demonstrated with the Social Support Questionnaire, an instrument with established high internal consistency (Norbeck et al., 1981), and the Personal Resource Questionnaire (Brandt & Weinert, 1981). The NSSQ has a reported test-retest reliability of .85 to .92 for function and network properties, and a Kendall Tau B correlation coefficient of .83 for persons loss, and .71 for support loss (Norbeck et al., 1981). High internal consistency has also been established with scores ranging from .72 to .97 (Hirth & Stewart, 1994; Norbeck et al., 1981; Norbeck, Lindsey, & Carriere, 1983). Construct validity was established initially by correlating the NSSQ with the Profile of Mood States (Norbeck et al., 1981). The revised version of the NSSQ (i.e., combining of affect and affirmation subscales to create one subscale on emotional support) was based on the two factor solution results of principal axes factor analysis (Norbeck, 1995).

Consequences (Cost) of Care Index (CCI)

The CCI, a multidimensional instrument, measured caregiver perception of burden (Kosberg & Cairl, 1986; Kosberg et al., 1990). The CCI is a twenty-item instrument that addresses five content dimensions: Personal and Social Restrictions, Physical and Emotional Health, Economic cost, Value Investment in Caregiving, and Perception of the Older Person as Provocateur (see Appendix D). Items are rated on a four-point Likert-scale ranging from 1 (strongly disagree) to 4 (strongly agree). Total scale scores range from 20 to 80 with higher scores indicating greater adverse consequences of caregiving.

Content validity of the CCI was confirmed by the research of Zarit et al. (1980) on caregiver burden, Lau and Kosberg (1979) on elder abuse, and clinical experiences of professionals working with caregivers. The reported alpha coefficient of .91 (Kosberg & Cairl, 1986) indicates that the CCI has a high degree of internal consistency. Factor analysis was used to establish construct validity.

Descriptive Profile Form

The Descriptive Profile Form was developed to collect data on the caregiver and care receiver's medical health, caregiver perception of physical and mental health, caregiver and care receiver sociodemographic factors, caregiving factors (care hours, tasks, and duration), and placement decision-making (see Appendix E).

Perceptions of physical and mental health were rated on a four-point scale ranging from 1 (poor) to 4 (excellent). The health perception items and scale formats are consistent with what has been reported in the literature as a reliable and valid way to elicit health perceptions (Frank-Stromberg et al., 1990).

Individual items collected data on sociodemographic and caregiving factors. Contextual or situational variables (i.e., gender, relationship, employment, living arrangements, location, caregiving factors) can contribute to caregiving outcomes, and should be addressed in caregiving research (Biegel, Sales, & Schulz, 1991). In studies, involvement in caregiving activities (care hours and tasks) have been conceptualized in various ways: characteristics of the caregiving situation, care receiver characteristics, and objective burden (Stommel et al., 1990). The data on the number of care hours each day was collected with a continuous variable, ranging from 0 to 24, and number of care tasks was based on the caregiver's perception of the number of tasks associated with caregiving. This is consistent with other studies (Coward & Dwyer, 1990: Miller et al., 1991; Stommel et al., 1990) which have attempted to quantify the magnitude of the caregiver involvement in caregiving activities.

Ethical Considerations

Ethical considerations were addressed in a number of ways. The study was approved by the Human Investigations Committee, Memorial University of Newfoundland (see Appendix F). Approval to access subjects was sought and received from Dr. Minnie Weismier, Executive Director, Community Health Western (see Appendix G).

Strict measures were also taken to protect participants' rights. The Continuing Care Coordinator of Community Health Western acted as an intermediary between caregivers and the researcher. Immediately prior to data collection, a complete explanation of the study was given and an informed, written consent obtained. Potential participants were assured that their involvement was entirely voluntary and that they could withdraw from the study at any time.

Confidentiality of all data and anonymity of participants were maintained throughout the study. Each subject was given a file number on entry into the study, which was entered on each questionnaire. The master form identifying subjects name and numbers was kept in a locked filing cabinet accessible only to the researcher.

Data Analysis

Descriptive statistics (e.g., frequencies, histograms, means, and standard deviations) were used to generate a descriptive profile of the sociodemographic variables, and subscales of the NSSQ, RMBPC, and CCI. The t-test or ANOVA was used to test for effects of select sociodemographic variables on the independent and dependent variables of interest. The appropriate non-parametric test was used if the assumptions of the t-test or ANOVA were not met. Pearson's r correlation coefficients, and where applicable chi-square, were used to investigate relationships variables. The alpha level was set at .05 for statistical significance.

Multiple Regression was used to predict and explain the interrelationships among select independent variables and health status of caregivers. The independent variables were entered in a Forward Stepwise Method based on the strength of correlation with health status. Internal consistency and intercorrelations among subscale and global scores were also calculated for the Consequences of Care instrument, Revised Memory and Behavior Problems Checklist, and Norbeck Social Support Questionnaire.

Limitations

The use of a small, non-probability sample limits the generalizability of study findings. Further, the use of subjective measures without objective data may decrease the reliability and validity of the findings. For example, the credibility of the findings would have been enhanced if standardized measures had been used to assess caregiver burden and health status.

CHAPTER 4

Results

Study findings are presented in four sections. The first section presents a descriptive profile of the sample and key variables. The second section summarizes the relationships among variables, and the third section describes predictors of health status. The final section discusses the reliability and validity of the instruments based on study findings.

Descriptive Profile

This section presents an overview of key sociodemographic and caregiving factors. Descriptive findings are also presented on major study variables - caregiver burden, health status, social support, and care receiver memory problems, depression, and disruptive behaviors.

Sociodemographic Characteristics

Table 1 summarizes key sociodemographic characteristics of study participants ($\underline{N} = 75$). Most caregivers were adult children (66.7%), female (54.7%), living with care receivers (56.0%) in a rural area (61.3%), employed or

Table 1

Characteristics of Caregivers (N = 75)

Variable	n	%
Relationship		
Spouse	12	16.0
Son	21	28.0
Daughter	29	38.7
Other	13	17.3
Gender		
Male	34	45.3
Female	41	54.7
Living Arrangement		
Living Together	42	56.0
Living in Own Home	13	17.3
Living in Manor	20	26.7
Age of Caregiver		
< 45 years	9	12.0
46 - 54 years	25	33.3
55 - 64 years	18	24.0
≥ 65 years	23	30.7
Employment		
Employed	28	37.3
Available for Work	10	13.3
Retired	37	49.3
Location		
Rural	46	61.3
Urban	29	38.7

looking for work (50.6%), and between 46 and 64 years of age (57.3%). The mean age was 58.3, ranging from 36 to 84 years. Most care receivers were female (62.7%), and aged 67.0 to 101.0 years (M = 82.8).

Caregiving Factors

Caregiving factors have been conceptualized in numerous ways across studies (i.e., objective burden, environmental or situational characteristics). In the current study, caregiving factors were assessed in terms of duration, hours and tasks. A summary of the findings on caregiving factors is presented in Table 2.

A large number of participants had been involved in caregiving for more than five years (46.7%). Caregivers reported an average of 10.9 hours of caregiving and 8.3 tasks per day. In a comparable study of caregivers for persons with a variety of chronic disorders, Bull (1990) found that most averaged 5 hours and 7 tasks per day.

Caregiver Burden

The Consequences of Care Index (CCI) measured caregivers' perception of burden (see Appendix D). Items were rated on a Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). The possible range for the total score

Table 2

<u>Caregiving Factors</u> (<u>N</u> = 75)

Variable	**<u>N</u>**	**%**
Number of Daily Tasks		
< 4 tasks	17	22.7
5 to 8 tasks	23	30.7
9 to 14 tasks	35	46.7
Time Spent Caregiving		
< 5 hours	21	28.0
5 to 9 hours	17	22.6
≥ 10 hours	37	49.3
Duration of Caregiving		
< 1 year	6	8.0
1 to 5 years	34	45.3
> 5 years	35	46.7

was 20 to 80, and subscales 4 to 16. The higher the total and subscale scores (i.e., personal and social restrictions, physical and emotional costs, provoking behavior, value of care, and economic costs), the greater the adverse effects of caregiving. The mean scores for the subscales and total scale are summarized in Table 3.

The findings suggest that most participants agreed that they were experiencing burden from caregiving activities (M = 58.11). This was above the normative values obtained at six month intervals (M = 42.5, 40.9, and 44.0, respectively) for caregivers of persons with Parkinson's disease, and at three month intervals (M = 38.0 and 42.0, respectively) for caregivers of older adults with mental disorders (D. Speer, personal communication, November 7, 1997).

Participants scored highest on personal and social restrictions (M = 13.40) and lowest on value of care (M = 8.47). The greatest consequences of caregiving were the psychosocial implications (i.e., decreased amount of time for self, strain with family members, disruption of household routine, and increased demands). The lower score obtained for value of care suggests that most participants felt that caregiving was worth the effort (i.e., feeling wanted and important, and meeting daily, health, and social needs). Because previous studies did not report subscale means (e.g., Kosberg et al., 1990; Speer, 1993), it was not possible to compare this study's findings with normative values.

Table 3

Consequence of Care Index Results (N = 75)

Subscales	**M**	**SD**
Personal/Social	13.40	2.42
Physical/Emotional	12.37	2.60
Value of Care	8.47	3.06
Provocateur	11.52	2.97
Economics	12.35	3.96
Total Score	58.11	10.51

Caregiver Health Status

Caregivers rated their physical and mental health (see Appendix E) on a Likert-scale ranging from 1 (poor) to 4 (excellent). The majority of caregivers rated their physical health (M = 2.95, SD = .84) better than their mental health (M = 2.61, SD = .79), despite most (56%) reporting the presence of some type of chronic physical condition (e.g., heart disease, diabetes, etc.). The moderate to strong, positive correlation between the two measures of health r = .54, p = .000) suggests that 29.2% of the observed variance in physical health was explained by caregivers ratings of their mental health.

Care Receiver Characteristics

Caregivers were asked their perception of care receivers' cognitive and physical problems. The data indicated that 52.0% had physical impairments only. The remaining care receivers either were cognitively impaired (22.7%) or had some combination of physical and cognitive impairments (25.3%).

The Revised Memory and Behavior Problems Checklist (RMBPC) measured caregiver perceptions of care receivers' memory problems, depression, and disruptive behaviors, and caregivers' reactions to them. Frequency items were rated on Likert-type scales ranging from 0 (never occurred) to 4 (daily or more often), and reaction items from 0 (not at all) to 4 (extremely). The higher the score, the greater the frequency of problems and reactions to them (see Appendix B).

Table 4 illustrates the means and standard deviations for frequency of care receiver problems and caregivers' reactions to them. Care receiver memory problems ($\underline{M}$ = 15.36) were reported most frequently and disruptive behaviors ($\underline{M}$ = 9.77) least frequently by caregivers. The normative values reported by Teri et al. (1992), in a sample of 201 patient/caregiver dyads accessing geriatric services, were lower for depression ($\underline{M}$ = 11.4) and disruptive behavior problems ($\underline{M}$ = 5.64), and higher for memory problems ($\underline{M}$ = 18.33).

In the current study, caregivers tended to react stronger to more frequent problems, but reacted stronger to memory ($\underline{M}$ = 12.79) and depression problems ($\underline{M}$ = 15.97) than disruptive behaviors ($\underline{M}$ = 10.11). The findings indicate that caregivers were moderately upset by memory problems which occurred once or twice in the past week, and only a little upset with disruptive behaviors that were less likely to surface in the past week. In contrast, Teri et al. (1992) found that caregivers did not necessarily depict stronger reactions to the most frequently occurring problems. Further, these authors reported stronger mean reaction scores for depression ($\underline{M}$ = 18.73) and disruptive behaviors ($\underline{M}$ = 14.85) than memory problems ($\underline{M}$ = 11.12).

Table 4

Revised Memory and Behavior Problems Checklist Results (N = 75)

Subscales	Frequency of Problems M (SD)	Caregivers Reaction M (SD)	Possible Range
Memory	15.36 (9.85)	12.79 (9.79)	0 - 28
Depression	15.09 (8.41)	15.97 (8.59)	0 - 36
Disruption	9.77 (7.74)	10.11 (8.61)	0 - 32
Total Score	40.23 (18.92)	38.87 (21.19)	0 - 96

Social Support

The Norbeck Social Support Questionnaire (NSSQ) measured informal and formal social supports over two dimensions: (i) functional support includes emotional (affect and affirmation) and tangible (aid) and, (ii) structural support refers to network size, sources of support, duration of supportive relationships, frequency of contacts, and loss of support persons.

Structural support. Descriptive data on the structural aspects of support are presented in Table 5. The number of support persons listed by caregivers ranged from 4 to 29 ($\underline{M}$ = 13.5). Males identified slightly more support persons ($\underline{M}$ = 14.65) than females ($\underline{M}$ = 12.51), although the difference was not statistically significant ($\underline{t}$ = 1.39, $\underline{p}$ = .17). Network size is above the normative values for males ($\underline{M}$ = 10.6) and females ($\underline{M}$ = 10. 9) reported by Norbeck (1995).

Out of the total numbers in support networks, caregiving by relatives was dominant (73.1%). Additional supports included friends (15.1%), health care providers (6.1%), minister/priest (1.9%), and others (3.8%). A significant number of caregivers (44.0%) reported using health care services, with 18.7% having two or more and 10.7% three or more supports. Home support workers were the most utilized service (68.8%), followed by social workers (28.1%), nurses (21.9%), doctors (6.2%), and daycare services (3.1%).

Table 5

Norbeck Social Support Questionnaire Results (N = 75)

Variable	M	SD	Range
Total Network Support	*126.1*	*59.9*	*35 - 274*
Number Listed	13.5	6.6	4 - 29
Frequency	47.7	23.4	11 - 108
Duration	64.8	32.9	20 - 145
Total Functional Support	203.9	123.4	23 - 564
Emotional	172.8	101.9	21 - 464
Tangible	31.1	26.5	1 - 149
Total Loss	3.4	3.4	0 - 15

Most caregivers (61.3%) felt that no additional supports could prevent or delay placement of the older adult. Affordable assistance from home support workers (24.0%), group and professional supports (2.6%), payment for elder-kin care (5.3%), and greater information on care (6.7%) were identified by the caregivers who felt that placement could be prevented or delayed.

Frequency of contact (i.e., personal, telephone, or letter) was rated on a Likert-scale ranging from 5 (daily) to 1 (once a year or less). Cumulative scores ranged from 11 to 108 (M = 47.7), with higher scores indicating more frequent contact. This is slightly above the average (M = 42.77) reported by Norbeck et al. (1981) in a sample of graduate nursing students (N = 75). Because frequency of contact scores do not reflect actual time periods, they were divided by the total number of supports listed for each caregiver to generate a mean score. The mean score (M = 3.6) indicates that caregivers had weekly to monthly contact with support persons. The average number of contacts with support persons for male caregivers (M = 3.4) was slightly below those reported by female caregivers (M = 3.8) although the difference was not statistically significant (t = 1.64, p = .10).

Duration of relationships was measured on a Likert-scale ranging from 5 (five years) to 1 (less than six months). Cumulative scores ranged from 20 to

145 (M = 64.8), with higher scores suggesting longer supportive relationships. This is slightly above the value (M = 55.87) reported by Norbeck et al. (1981). Because these scores do not reflect actual time periods, they were divided by the total number of support persons listed for each caregiver. The mean score (M = 4.8) suggests that relationships with supportive persons were present for more than five years. Males (M = 4.7) and females (M = 4.9) were fairly equal in terms of duration of supportive relationships.

The total network support is a composite of the number listed, duration of the relationships, and frequency of contact. Cumulative scores ranged from 35 to 274 (M = 126.1). The observed gender differences in average scores suggest that males (M = 133.4) perceived their support network to be larger than females (M = 120.0). However, the differences did not reach statistical significance (t = .95, p = .35). The normative values for total network support for males (M = 95.0) and females (M = 98.5) reported by Norbeck (1995) are opposite to and higher than those found in the current study.

Total loss involved the number of support persons lost (quantity) and the amount (quality) over the last year. This may be loss of informal support due to death, move, or divorce of informal support persons or loss of formal support services for numerous reasons. Approximately one-half (56%) of the caregivers lost one relationship over the past year, including a spouse (12%), family member (34.7%), friend (20.0%), neighbor (6.7%), health care professional (2.7%), and minister/priest (1.3%). Caregivers perceived these relationships as providing a little to moderate level of support (M = 1.7). Males and females had an equal number of losses which was different from the normative values for males (36.3%) and females (44.1%) reported by Norbeck (1995).

Functional support. Descriptive data on the functional aspects of support are also summarized in Table 5. Emotional and tangible support were rated on Likert-scales ranging from 4 (great deal) to 0 (not at all). Higher scores indicate greater perceived emotional and tangible support from persons in the network.

The emotional support variable measured the degree to which support persons made the caregiver feel liked/loved, respected/admired, served as confidants, and agreed with the caregiver's actions and thoughts. Emotional support for caregivers ranged from 21 to 464.0 (M = 172.8). Male caregivers reported receiving more emotional support (M = 183.8) than female caregivers (M = 163.8), although the difference was not statistically significant (t = .84, p = .40). These findings were higher than and opposite to normative values for emotional support for males (M = 119.3) and females (M = 127.2) reported by Norbeck (1995).

Tangible support measured caregivers' perceptions of the availability of informal and formal supports. Cumulative scores ranged from 1 to 149 (M = 31.1), with higher scores indicating more available supports. Male (M = 31.6) and female (M = 30.6) caregivers reported similar amounts of tangible support. This average was much lower than the normative values for males (M = 55.3) and females (M = 53.1) reported by Norbeck (1995).

In order to create a meaningful context for emotional and tangible support, total scores for each caregiver were divided by the number of support persons listed. The findings suggest that most caregivers felt that support persons provided quite a bit of emotional support (M = 3.1) and a moderate amount of tangible support (M = 2.3).

Total functional support, a composite of emotional and tangible support, ranged from 23 to 564 (M = 203.9). This finding was similar to normative values (M = 201.9) reported by Norbeck (1995). Since higher scores suggest more perceived support, males (M = 215.4) indicated that they received more functional support than females (M = 194.4), although not statistically significant (t = .72, p = .48). Normative values for total functional support are also lower than, and opposite to, those reported by Norbeck for males (M = 173.6) and females (M = 179.4).

Interrelationships Among Study Variables

This section examines the effect of key variables on caregiver burden and health status. Consideration is also given to the interrelationship among sociodemographic variables, caregiving factors, caregiver perception of care receiver characteristics, and social support.

Caregiver Burden

The findings are summarized according to major groupings. Pearson's r and analysis of variance, as well as appropriate non-parametric tests, were used to identify variables exerting a significant impact on burden.

Sociodemographic and caregiving factors. The findings did not show any significant difference in caregiver burden for location, employment, age, or gender. Living arrangements ($F = 6.73$, $p = .002$) and duration of caregiving ($F = 5.17$, $p = .008$) affected caregivers' perception of economic burden. That is, those who had been caregiving for more than five years or living with care receivers reported significantly greater economic costs than those providing care for less than one year or living separate from care receivers. Spouses indicated significantly more economic burden than daughters and other caregivers, but not sons ($F = 5.44$, $p = .002$). As well, spouses placed more value on care than other caregivers only ($F = 4.45$, $p = .006$). These results should be interpreted cautiously given the small numbers in certain groups.

The findings indicated that the greater the caregiving tasks, the greater the overall burden $r = .36$, $p = .002$), personal and social restrictions $r = .30$, $p = .01$), physical and emotional costs $r = .44$, $p = .000$), and economic costs $r = .48$, $p = .000$). Also, the higher the number of hours, the greater the physical and emotional costs $r = .28$, $p = .02$) and economic costs $r = .43$, $p = .000$). Care hours and tasks were highly correlated $r = .73$, $p = .000$).

Care receiver characteristics. Table 6 summarizes the correlation findings between the total and subscale scores of the CCI and the RMBPC. There was a statistically, significant positive relationship between the total burden score and care receiver memory problems $r = .43$, $p = .000$), depression $r = .41$, $p = .000$), and disruptive behaviors $r = .54$, $p = .000$). Comparative findings are evident for caregiver reactions. These findings suggest that as the frequency of care receiver problems and caregiver reactions increase, there is a corresponsing increase in overall caregiver burden.

The findings also suggest that increased frequency of and reaction to care receiver problems were significantly associated with greater personal and social restrictions, physical and emotional costs, and perception of care receiver as provocateur. In addition, more frequent disruptive behaviors and caregivers reactions to memory and disruptive behavior problems were associated with greater economic costs and less value placed on caregiving.

Table 6

Correlations of CCI with RMBPC (N = 75)

	CCI Scale and Subscales					
Variable	**CCI**	**CCI-1**	**CCI-2**	**CCI-3**	**CCI-4**	**CCI-5**
	r	**r**	**r**	**r**	**r**	**r**
	(p)	**(p)**	**(p)**	**(p)**	**(p)**	**(p)**
Frequency						
Memory	.43*** (.000)	.48*** (.000)	.40*** (.000)	.17 (.14)	.28** (.01)	.23 (.05)
Depression	.41*** (.000)	.39*** (.001)	.36** (.002)	.17 (.14)	.37*** (.001)	.20 (.09)
Disruptive	.54*** (.000)	.41*** (.000)	.48*** (.000)	.32** (.006)	.41*** (.000)	.30** (.008)
Reactions						
Memory	.47*** (.000)	.43*** (.000)	.38*** (.001)	.30** (.008)	.33** (.003)	.24* (.04)
Depression	.41*** (.000)	.40*** (.001)	.39*** (.001)	.19 (.10)	.32** (.006)	.21 (.07)
Disruptive	.51*** (.000)	.35** (.002)	.46*** (.000)	.36*** (.001)	.37*** (.001)	.27* (.02)

* p < .05 ** p <.01 *** p <.001

Note: Consequences of Care Index total (CCI) and subscales: Personal and Social Restrictions (CCI-1), Physical and Emotional Health (CCI-2), Value of Care (CCI-3), Provocateur (CCI-4), and Economic (CCI-5).

Social support. Table 7 summarizes the correlations between social support and caregiver burden. Overall caregiver burden depicted significant, negative correlations with frequency of contact (r = -.27, p = .02), total functional support (r = -.36, p = .001), emotional support (r = -.34, p = .003), and tangible support (r = -.40, p = .000). The findings suggest that greater burden was associated with less contact with and functional support from persons comprising the total network. Comparable findings were observed for personal and social restrictions and provoking care receiver behaviors.

Caregiver physical and emotional dimension of burden depicted significant, negative correlations with total network support (r = -.26, p = .02), frequency of contact (r = -.29, p = .01), number of support persons (r = -.24, p = .04), total functional support (r = -.38, p = .001), emotional support (r = -.35, p .002), and tangible support (r = -.40, p = .000). The findings suggest that caregivers with weaker structural and functional support systems were more likely to experience greater burden.

No significant differences were observed between caregivers with formal supports and those without such services on overall and most components of burden. The only exception was the reporting of greater economic costs by caregivers with formal supports (t = 2.07, p = .04).

Table 7

Correlations Among Social Support and Caregiver Burden (N = 75)

	CCI Scales and Subscales					
Variable	**CCI**	**CCI-1**	**CCI-2**	**CCI-3**	**CCI-4**	**CCI-5**
	r	**r**	**r**	**r**	**r**	**r**
	(p)	**(p)**	**(p)**	**(p)**	**(p)**	**(p)**
Total Network Support	-.21	-.20	-.26*	-.05	-.22	-.07
	(.06)	(.09)	(.02)	(.66)	(.05)	(.56)
Number Listed	-.17	-.15	-.24*	-.05	-.17	-.04
	(.14)	(.19)	(.04)	(.70)	(.16)	(.74)
Frequency	-.27*	-.24*	-.29**	-.09	-.30**	-.09
	(.02)	(.04)	(.01)	(.44)	(.009)	(.44)
Duration	-.16	-.16	-.22	-.02	-.16	-.05
	(.16)	(.17)	(.06)	(.86)	(.17)	(.65)
Total Functional Support	-.36***	-.32**	-.38***	-.11	-.35**	-.18
	(.001)	(.005)	(.001)	(.37)	(.002)	(.13)
Emotional Support	-.34**	-.28*	-.35**	-.10	-.33***	-.17
	(.003)	(.02)	(.002)	(.40)	(.003)	(.15)
Tangible Support	-.40***	-.43***	-.40***	-.11	-.35**	-.19
	(.000)	(.000)	(.000)	(.33)	(.002)	(.11)

* p < .05 ** p <.01 *** p <.001

Note: Consequences of Care Index (CCI) total and subscales: Personal and Social Restrictions (CCI-1), Physical and Emotional Health (CCI-2), Value of Care (CCI-3), Provocateur (CCI-4), and Economic (CCI-5).

Caregiver Health Status

The findings are summarized according to major groupings. Pearson's r and analysis of variance, as well as appropriate non-parametric tests, were used to identify variables exerting a significant impact on caregiver health status.

Sociodemographic and caregiving factors. There were no statistically, significant differences in caregiver physical health in terms of gender, location, duration of caregiving, living arrangements, care hours, or care tasks. However, employed caregivers reported significantly better physical health than those retired (F = 9.29, p = .000). Spouse caregivers reported significantly poorer physical health than sons and daughters (F = 6.00, p = .000). Younger caregivers reported significantly better health than older caregivers (F =15.01, p = .000). No significant differences in mental health were observed for any sociodemographic or caregiving factors.

Care receiver characteristics. Table 8 summarizes the correlation findings for the total and subscale scores of the RMBPC and mental and physical health. The findings suggest that poorer mental health was associated with a greater number of care receiver memory problems (r = -.24, p = .04) and disruptive behaviors (r = -.31, p = .007). Poorer mental health was also associated with increased caregiver reactions to disruptive behaviors (r = -.28, p =.01). Caregiver physical health failed to depict a significant association with total or subscale scores for the frequency or reaction scales.

Table 8

Correlations Between RMBPC and Caregiver Health Status (N = 75)

Variable	Physical Health r (p)	Mental Health r (p)
Frequency		
Memory	-.07 (.57)	-.24* (.04)
Depression	-.11 (.35)	-.10 (.39)
Disruptive	-.10 (.37)	-.31** (.007)
Reactions		
Memory	-.03 (.82)	-.21 (.07)
Depression	-.01 (.95)	-.13 (.29)
Disruptive	-.13 (.29)	-.28** (.01)

* $p < .05$ ** $p < .01$ *** $p < .001$

There were no statistically, significant differences noted in caregivers physical health based on care receivers cognitive ($M = 2.9$) or physical ($M = 3.0$) functioning. However, caregivers rated their mental health significantly higher when caring for care receivers who were physically ($M = 2.8$) as opposed to *cognitively* ($M = 2.4$) *impaired* ($t = 2.13$, $p = .04$).

Social support. Table 9 summarizes the correlations between social support (i.e., formal and informal) and caregiver health. The findings suggest that greater tangible support was associated with better physical ($r = .26$, $p = .02$) and mental ($r = .31$, p .006) health.

The sample was divided with regard to caregivers with and without formal supports. No significant differences were observed in the physical and mental health of caregivers with and without formal supports.

Caregiver burden. Table 10 summarizes the correlation results for burden and health status. Greater overall burden was associated with poorer mental health ($r = -.29$, $p = .01$). Only one component of burden, the physical and emotional subscale, depicted a significant, negative correlation with physical ($r = -.25$, $p = .03$) and mental ($r = -.50$, $p = .000$) health.

Social Support

This section provides a summary of the findings on the observed associations and differences between sociodemographic and caregiving

Table 9

Correlations Among Social Supports and Caregiver Health Status (N=75)

Variable	Physical Health r (p)	Mental Health r (p)
Total Network Support	.07 (.52)	.11 (.31)
Number Listed	.03 (.82)	.05 (.63)
Frequency	.10 (.41)	.22 (.05)
Duration	.06 (.60)	.05 (.70)
Total Functional Support	.15 (.21)	.21 (.06)
Emotional Support	.11 (.35)	.18 (.12)
Tangible Support	.26* (.02)	.31** (.006)

* $p < .05$ ** $p < .01$ *** $p < .001$

Table 10

Correlations Among Caregiver Burden and Health Status (N = 75)

Variable	Physical Health	Mental Health
	r	r
	(p)	(p)
Total Burden	-.07	-.29**
	(.53)	(.01)
Personal/Social	.04	-.16
	(.75)	(.17)
Physical/Emotional	-.25*	-.50***
	(.03)	(.000)
Value of Caregiving	.05	-.04
	(.66)	(.76)
Provocateur	.05	-.19
	(.67)	(.10)
Economic	-.13	-.17
	(.26)	(.14)

* $p < .05$ ** $p < .01$ *** $p < .001$

factors, care receiver characteristics, and social support. Pearson's r was used for the correlational analysis, and the t-test and analysis of variance (ANOVA) to detect differences.

Sociodemographic and caregiving factors. Caregivers in rural areas indicated significantly longer supportive relationships than those in urban areas ($\underline{t} = -2.04$, $\underline{p} = .04$). Daughter caregivers reported significantly less ($\underline{F} = 3.34$, $\underline{p} = .02$) support persons than sons and other caregivers. Daughters also reported less duration of supportive relationships than sons and other caregivers ($\underline{F} = 2.98$, $\underline{p} = .04$) and less contact with supports than other caregivers ($\underline{F} = 2.89$, $\underline{p} = .04$). As well, employed caregivers reported fewer persons in their support system than retired caregivers ($\underline{F} = 3.35$, $\underline{p} = .04$).

Only care hours and tasks influenced social support variables. Study participants with longer supportive relationships reported fewer care hours ($\underline{r} = -.25$, $\underline{p}$ .03) and tasks ($\underline{r} = -.25$, $\underline{p} = .02$). Further, greater emotional support was associated with fewer care hours ($\underline{r} = -.27$, $\underline{p} = .02$). Duration of caregiving did not influence structural or functional support.

There was a greater tendency for caregivers in urban areas (60%) to use health care services than those in rural areas. Supportive relationships were also significantly shorter for health care providers than other support persons (t = -3.01, p = .005). The findings also indicated that health care personnel provided significantly less emotional (t = -2.20, p = .03) and tangible (t = -2.46, p = .02) support than other persons comprising social networks. There were no significant differences in caregiving hours, tasks, or duration for the formal and informal systems.

Care receiver characteristics. There were no statistically, significant differences detected in social support variables based on care receivers cognitive or physical functioning. In addition, only care receiver depression problems significantly correlated with support variables. Frequency of contact with support persons was negatively associated with caregiver ratings of the frequency of (r = -. 25, p = .03) and reaction to (r = -.23, p = .04) care receiver depression problems. Tangible support also negatively correlated with caregiver ratings of the frequency of (r = -.32, p = .004) and reaction to (r = -.33, p = .004) care receiver depression problems. The findings suggest that caregivers who reported a greater number of care receiver depression problems and stronger reactions to them had less frequent contact with network members and received less tangible support. Greater emotional support was also associated with less intense caregiver reactions to care receiver depression problems ($\underline{r} = -.27$, $\underline{p} = .02$).

Care Receiver Characteristics

Tests of difference (e.g., t-test and ANOVA) and association (e.g., *Pearson's r) were computed to determine whether care receiver* characteristics were a function of sociodemographic and caregiving factors. Only employment status surfaced as a significant factor. Employed caregivers reported significantly more care receiver depression problems than retired caregivers ($\underline{F} = 3.54$, $\underline{p} = .03$).

Predictors of Caregiver Health Status

This section explores the relationship between predictor and outcome variables. Forward step-wise multiple regression was used to determine the predictors of caregiver health status. Only those variables which were not strongly associated but depicted a significant correlation with physical and mental health were used in the analysis.

Physical Health Status

Caregiver mental and physical health were strongly correlated. Only a limited number of sociodemographic (employment, relationship), social support (tangible), and burden (physical and emotional) variables were associated with caregiver physical health. Table 11 summarizes the multiple regression results obtained for the physical health model.

Mental health entered into the equation first accounting for 29.5% of the variance, F = 30.6, p = .000. This variable was followed by employment accounting for an additional 5.4% of the variance, F = 19.3, p = .000. Relationship, tangible support, and physical and emotional dimension of burden failed to enter the regression equation.

Mental Health Status

As was observed with physical health, only a few social support (tangible), care receiver characteristics (frequency of memory and disruptive behavior problems, reaction to disruptive behavior problems), and burden (total burden, physical and emotional dimension) variables were associated with caregiver mental health. Due to the high intercorrelations among frequency and reaction problems, only frequency of disruptive behaviors was entered into the regression model with other predictor variables. Table 11 summarizes the multiple regression results obtained for the model of best fit for mental health.

Table 11

Stepwise Multiple Regression on Caregiver Health Status

	Multiple R	**Adjusted R^2**	**R^2 Change**	***F***	***p***
Variable		**Caregiver**	**Physical**	**Health**	
Mental Health	.543	.285	.295	30.6	.000
Employment	.591	.331	.054	19.3	.000
		Caregiver	**Mental**	**Health**	
Physical Health	.543	.285	.295	30.6	.000
Physical/Emotional	.664	.425	.146	28.4	.000
	Physical and Emotional Burden				
Mental Health	.504	.243	.254	24.8	.000
Disruptive Behaviors	.608	.352	.116	13.3	.001
Care Tasks	.663	.416	.070	8.9	.004
Tangible	.689	.444	.034	4.6	.036

Physical health entered into the equation first accounting for 28.5% of the variance, F = 30.6, p = .000. This variable was followed by the physical and emotional dimension of burden which accounted for an additional 14.6% of the variance, F = 28.4, p = .000. Tangible support, total burden, and the frequency of disruptive behaviors failed to enter the regression equation.

Physical and Emotional Dimension of Burden

The literature review demonstrated that the concepts of burden and health have been intertwined in studies. In the present study, physical and emotional health was also measured as a dimension of burden. Given the restricted measures of physical and mental health used in this study, the decision was made to also treat the physical and emotional dimension of burden as an outcome variable.

A number of social support measures (tangible and emotional, number of and frequency of contact with network members), care receiver characteristics (frequency of and reaction to memory, depression and behavior problems), burden (total and all components), caregiving factors (hours, tasks), and health status (mental, physical) variables were associated with the physical and emotional dimension of burden. Due to the high intercorrelations among many of these variables, only frequency of disruptive behaviors, tangible support, and tasks was entered into the final regression model with other predictor variables. Table 11 summarizes the multiple regression results obtained for the model of best fit for physical and emotional dimension of burden.

Mental health entered into the regression equation first to account for 25.4% of the variance. This was followed by the frequency of disruptive behaviors, care tasks, and tangible support which accounted for 11.6%, 7.0%, and 3.4%, respectively. Physical health failed to enter the regression equation.

Reliability and Validity of Study Instruments

The reliability and validity of the Consequences of Care (CCI), Revised Memory and Behavior Problems Checklist (RMBPC), and Norbeck Social Support Questionnaire (NSSQ) were also examined for the study population. Cronbach's alpha was used to assess internal consistency. The intercorrelations among subscale and total scores were used to determine construct validity.

Consequences of Care Index

Cronbach's alpha was used for internal consistency. Alpha coefficients ranged from .90 for the total scale to .76 and .96 for the five subscales: personal and social (.76), physical and emotional (.79), value of care (.93), provocateur (.78), and economic (.96). These findings indicate that the total scale and subscales have good internal consistency.

One way to determine the suitability of dimensions for defining a construct is to assess the intercorrelations among them. Pearson's r coefficient was used to identify the relationships among the subscales and total scale scores of the CCI (see Table 12). The subscales depicted a moderate to strong, positive correlation with the total scale. The value subscale ($\underline{r} = .50$, $\underline{p} = .000$) had the lowest correlation with the total scale and physical/emotional the strongest ($\underline{r} = .82$, $\underline{p} = .000$). These findings suggest that all of the subscales are measuring some aspect of burden.

The intercorrelations among the subscales were also examined. Seven of the ten correlations reached statistical significance and fell within the moderate range. The value subscale was the only outlier, depicting a significant correlation with the provocateur subscale. The findings suggest that the subscales reflect distinct dimensions of consequences of care or burden - good discriminatory power.

In summary, the moderate to strong correlations between the total scale and subscales, and the moderate intercorrelations among the subscales suggest that the CCI has construct validity.

Table 12

Intercorrelations Among CCI Subscales

Variable	*Provocater*	*Physical/ Emotional*	*Personal/ Social*	Economic	Total
Value	$.51^{***}$	.16	.10	.004	$.50^{***}$
Provocateur		$.55^{***}$	$.53^{***}$	$.28^{*}$	$.80^{***}$
Physical/ Emotional			$.66^{***}$	$.57^{***}$	$.82^{***}$
Personal/ Social				$.40^{***}$	$.72^{***}$
Economic					$.69^{***}$

Revised Memory and Behavior Problems Checklist

Alpha coefficients were generated for the Frequency and Reaction components of the RMBPC and their subscales. The alpha coefficients for the Frequency and Reaction scales were .88 and .91, respectively. For both the Frequency and Reaction subscales, alpha coefficients were greater than .70 (see Table 13). These findings suggest that the total Reaction and Frequency scales and subscales have good internal consistency.

The Frequency and Reaction subscales depicted a moderate, positive correlation with total scale scores. The depression subscales (r = .41, p =000) had the lowest correlation with total scores, and the disruption subscales the strongest (r = .51, .54, p = .000). These findings suggest that the subscales may be measuring some aspect of memory problems, depression, and disruptive behaviors.

The intercorrelations among the Frequency and Reaction scales, and subscale to total scores were used to examine validity (see Table 13). The extremely high correlations obtained between common Frequency and Reaction subscales (r = .92, 91, .95, p = .000) imply that these two scales did not perform a discriminatory function in this sample. For the most part, the correlations among the Frequency subscales did not achieve statistical significance. The

Table 13

Correlations and Internal Consistency of RMBPC

Scale	Alpha	Depression	Memory	Disruption
		Frequency		
Frequency				
Depression	.84			
Memory	.92	.08		
Disruption	.79	.06	.71***	
Total Score	.88	.41***	.43***	.54***
		Reaction		
Reaction				
Depression	.83			
Memory	.93	.26*		
Disruption	.85	.21	.77***	
Total Score	.91	.41***	.47***	.51***
		Reaction		
Frequency				
Depression		.92***	.14	.04
Memory		.18	.91***	.70***
Disruption		.15	.72***	.95***

* p < .05 ** p < .01 *** p < .001

only exception was the strong, positive correlation between the memory and disruption subscales ($r = .71$, $p = .000$). A similar pattern was observed with the Reaction subscales. Again a strong, positive correlation was obtained between the memory and disruption subscales ($r = .77$, $p = .000$), as well as a low, positive correlation between the memory and depression subscales ($r = .26$, $p = .022$).

The findings on the Frequency and Reaction scales may be interpreted as follows: (a) the subscales probably should not be combined to generate a composite score, (b) the subscales do not reflect distinct dimensions of memory and behavior problems or, (c) the items on the depression subscale were not relevant for the particular group of care receivers being rated by caregivers. In summary, the validity of the RMBPC for the study sample is questionable and findings on these variables must be interpreted cautiously.

Norbeck Social Support Questionnaire

Alpha coefficients were generated for the total functional support scale and its subscales. The alpha coefficient for the functional scale was .96, the tangible support subscale .83, and the emotional support subscale .99. The high alpha values suggest that this scale and its subscales have good internal consistency.

The correlation between the structural and functional components of the NSSQ ($r = .92$, $p = .000$) was high. For the structural and functional component, the correlation of subscales to total scale were also high (i.e., range of values between .93 and .97 for structural, and .85 to 99 for functional). The average intercorrelations between the structural subscales ranged between .81 and .98, and .77 for the functional subscales. The findings suggest that items comprising the structural support and functional support components of the NSSQ, and most of the subscales, are redundant. This does not detract, however, from the fact that the items are valid measures of social support.

Summary

Most caregivers rated their physical health as good or excellent, and mental health as fair to good. Sociodemographic factors (employment, relationship), social support (tangible), mental health status, and physical and emotional dimension of burden were found to influence caregiver physical health. Social support (tangible), overall burden, physical and emotional dimension of burden, physical health status, and care receiver characteristics (frequency of memory and disruptive behavior problems, reaction to disruptive behaviors) were associated with caregiver mental health.

Caregivers reported that caregiving had adversely affected different aspects of their lives. Personal and social restrictions, physical and emotional burden, and economic costs emerged as the greatest impact areas. Care receiver characteristics (frequency of and reaction to problems), and social support (structural, functional) were associated with overall burden, personal and social restrictions, physical and emotional burden, and perception of care receiver as provocateur. Sociodemographic variables (living arrangement, relationship), caregiving factors (tasks, hours, duration), and care receiver characteristics (frequency of disruptive behaviors, reaction to memory and behavior problems) were associated with economic costs.

Mental health and employment status emerged as significant predictors of physical health during regression analysis; and, physical health and the physical and emotional dimension of burden as significant predictors of mental health. Finally, caregiver mental health, disruptive care receiver behaviors, care tasks, and tangible support surfaced as significant predictors of the physical and emotional dimension of burden.

CHAPTER 5

Discussion

The Stress Process Model (Pearlin et al., 1990) provided the conceptual framework for this study. Pearlin et al. postulate that the outcome of caregiving stress is the result of changing conditions in three domains (i.e., background and contextual factors, primary and secondary stressors, and mediators of stress). The discussion of the findings is organized around the major premises of the model.

The modified Stress Process Model (SPM) proposes that background and context factors, primary and secondary stressors, and interpersonal relationships exert a direct effect on each other, as well as health outcomes. Aspects of background and context (i.e., sociodemographic variables and caregiving factors), primary stressors (i.e., care receiver problems with memory, depression, and disruptive behaviors), secondary stressors (i.e., caregiver burden), interpersonal relationships (i.e., structural and functional supports), and the outcome of caregiving stress (i.e., caregiver physical and mental health status) were selected for investigation in this study.

Health Status: Outcome of Caregiving

One of the research questions investigated in this study was caregivers' perceptions of their health status. Most caregivers rated their physical health as good, and mental health as fair to good. Caregivers' tendency to rate physical health more positively than mental health is consistent with Pearlin et al.'s (1990) assumption that caregivers are more likely to experience a decline in mental before physical health.

Significantly, studies which used a variety of self-report measures for health status found that caregivers tended to rate their physical and mental health poorer than matched controls from the general population (Kiecolt-Glaser et al., 1991; Pruchno & Potashnik, 1989; Yeatman et al., 1993). There is also evidence to support the assumption that caregiving negatively affects mental health (Barnes et al., 1992; Bull, 1990; Clipp & George, 1993; Draper et al., 1992; Kosberg et al., 1990; Neundorfer, 1991) and physical health (Bull, 1990; Clipp & George; Kosberg et al.).

Factors Influencing Health Status

Several research questions investigated the impact of sociodemographic variables, caregiving factors, care receiver problems, burden, and social supports on caregiver health status. The present discussion compares study findings with those reported in the literature.

Background and Context

Study findings provide minimal support for the modified SPM assumption that background and context factors affect caregiver health status. Caregiver physical health but not mental health varied for relationship, employment, and age. Spouse, older, and employed caregivers reported poorer physical health than adult children, younger, and retired caregivers. Previous studies have also documented poorer physical health for spouse (Baumgarten et al., 1992; Barnes et al., 1992) and older caregivers (Baumgarten et al.). No other recent studies have considered the effects of employment on caregiver health status. In a review of studies focusing on caregivers for the elderly, Tennstedt and Gonyea (1994) found conflicting findings on whether or not employment influenced caregiver well-being.

Caregivers' ratings of their physical and mental health status failed to depict significant correlations with caregiving factors. Similarly, Kiecolt-Glaser et al. (1991) found no relationship between caregiver mental health and care hours. In contrast, other researchers documented a significant association between poorer caregiver mental health and increased care tasks (Braithwaite, 1996; Strawbridge & Wallhagen, 1991) and longer duration of caregiving (Draper et al., 1992). Further, Robinson (1990) found a significant relationship between diminished physical well-being and increased caregiving activities and hours of care.

Interestingly, this study did document an increase in physical and emotional burden in response to greater caregiving tasks and hours. Comparatively, Miller et al. (1991) found that poorer caregiver well-being (i.e., mental and physical health) was associated with increased caregiving tasks and hours. In contrast, Kosberg et al. (1990) failed to document a significant association between the physical and emotional dimension of burden and caregiving hours and tasks.

Primary Stressors

Study findings provide partial support for the modified SPM assumption that primary stressors influence caregiving outcomes. There were no significant relationships identified between caregiver physical health and the frequency of care receiver problems (i.e., memory, depression, and behavior) or the intensity of caregiver reactions to them. However, caregiver mental health did depict a significant negative correlation with frequency of care receiver memory and disruptive behaviors problems, and intensity of caregiver reactions to disruptive behaviors. Neundorfer (1991) reported comparable findings on the implications of care receiver problems for caregiver physical and mental health. The negative effect of care receiver problems on caregiver mental health has also been reported by Speer (1993) and Draper et al. (1992).

Additionally, increased physical and emotional burden was associated with more frequent care receiver problems and more intense caregiver reactions to them. These findings concur with those reported by Kosberg et al. (1990).

Secondary Stressors

Study findings provide limited support for the modified SPM assumption that secondary stressors influence health outcomes. Overall burden depicted significant relationships with caregiver mental health but not physical health. This finding is not surprising given that participants rated their physical health more positively than mental health. Strong support for the relationship between greater overall burden and poorer mental health has been frequently documented (Anthony-Bergstone et al., 1988; Braithwaite, 1996; Bull, 1990; Bull et al.,1995; Draper et al., 1992; Kosberg et al., 1990; Intrieri & Rapp, 1994; Speer, 1993; Stommel et al., 1990; Strawbridge & Wallhagen, 1991). Similarly, studies have failed to document a relationship between overall burden and caregiver physical health (Braithwaite, 1996; Bull), while others have found that greater burden was aligned with poorer physical health (Kosberg et al.; Speer).

There were also significant correlations observed between greater physical and emotional burden and poorer caregiver physical and mental health in this study. Comparatively, Kosberg et al. (1990) documented a significant correlation between poorer mental health and physical and emotional burden.

Interpersonal Relationships

Study findings provide little evidence for the modified SPM assumption that social support directly influences stress outcomes. The only measure of social support to correlate significantly with health status was tangible support. That is, greater tangible support was associated with more positive ratings of physical and mental health. Other studies also failed to document a direct relationship between social support variables and caregiver well-being (Spaid & Barusch, 1994; Stull et al., 1994).

The findings were somewhat different for the physical and emotional dimension of burden. Greater physical and emotional burden was significantly associated with fewer support persons, less contact with network members, and less emotional and tangible supports. In contrast, Kosberg et al. (1990) failed to find an association between physical and emotional burden and social support variables. No additional studies were identified that examined the relationship between social supports and physical and emotional burden.

Although the original SPM (Pearlin et al., 1990) postulates that social supports exert a direct effect on stress outcomes, greater emphasis is placed on the buffering or mediating role between stressors and outcome. It was not possible to investigate the mediating effects of social support in this study because the sample size was small in relation to the number of stressor variables. Other studies have examined the buffering effect of formal supports on caregiver well-being. Bass et al. (1996), Fink (1995), Toseland et al. (1989), and Stommel et al. (1990) found that formal supports modified the impact of primary and secondary stressors on caregiver well-being (i.e., mental, physical, or overall health).

Predictors of Health Status

The primary purpose of this study was to identify which components of the modified SPM correlated with health status. During data analysis, consideration was also given to the interrelationships among independent variables and the best predictor models of outcome (i.e., physical and mental health status, and the physical and emotional dimension of burden).

Interactive Effects

For the most part, background and context factors (i.e., sociodemographic and caregiving) did not interact with care receiver problems (i.e., memory, depression, and disruptive behaviors). The only significant difference observed was the reporting of more care receiver depression problems by employed caregivers than retirees. Other studies have also failed to find a significant effect for caregiver gender (Elmstahl et al., 1996) and duration of caregiving (Clipp & George, 1993). In contrast to this study, significant associations have been reported for greater care hours (Dura et al.'s, 1990; Miller et al. 1991; Scharlach, 1989) and tasks (Miller et al.).

Background and context had differing effects on caregiver burden. Longer periods of caregiving, increased caregiving tasks and hours, spouse caregivers, and those living with care receivers reported greater economic burden. Increased caregiving tasks were also associated with greater overall burden, as well as personal and social restrictions. In contrast to this study, the literature does provide some support for higher burden levels for females than males (Braithwaite, 1996; Kosberg et al, 1990; Kramer & Kipnis, 1995; Miller et al., 1991; Miller & Cafasso, 1992). Greater overall burden has also been correlated with longer periods of caregiving (Draper et al., 1992), increased tasks (Draper et al.; Strawbridge & Wallhagen, 1991), and increased hours and tasks (Bull et al., 1995; Miller et al.).

Study findings also indicated that background and context factors interact with social supports. Structural supports (i.e., number of persons, frequency of contact, duration of support) varied according to select sociodemographic factors (i.e., employment, relationship, and location). Less caregiving hours and tasks were associated with longer supportive relations with network members, and less hours with greater emotional support. In contrast, some authors failed to detect any differences in structural supports based on relationship (Baille, Norbeck, & Barnes, 1988; Horowitz, 1985) or caregiving factors (Baille et al.). Further, Orbell and Gillies (1993) failed to document a significant association between caregiving factors and functional support.

Significant relationships were observed between care receiver problems and overall caregiver burden as well as various dimensions of burden. More frequent care receiver problems and more intense caregiver reactions to them correlated with greater overall burden, personal and social restrictions, and provoking behavior. Further, more frequent disruptive behaviors and more intense caregiver reactions to memory and disruptive behavior problems were associated with greater economic costs and diminished caregiving value. Other researchers also reported a relationship between total burden and increased frequency of care receiver problems (Kosberg et al., 1990; Pearson et al., 1988) and between the total score for frequency of care receiver problems and the intensity of caregiver reactions to them (Intrieri & Rapp, 1994). In addition, Kosberg et al. found that more frequent care receiver problems correlated with personal and social restrictions, economic costs, and care receiver provoking behavior.

There were few significant correlations observed between social supports and care receiver problems. Decreased contact with and tangible support from network members were associated with more frequent care receiver problems. Decreased contact with support persons and less tangible and emotional support were correlated with more intense caregiver reactions to care receiver depression problems. In a previous study Orbell and Gillies (1993) also documented a negative association between emotional and tangible support and the frequency of care receiver disruptive behaviors.

In the current study, several social support variables correlated with burden. Less contact with network members, emotional support, and tangible support were associated with greater overall burden, personal and social restrictions, and provoking behavior. Other studies give conflicting reports on the relationship between social support and burden. For example, Stull et al. (1994) found that the number of support persons did not influence burden, but Bull (1990) reported that both decreased numbers and contact accompanied increased burden. Although Spaid and Barusch (1994) and Zarit et al. (1986) found that less emotional support was associated with increased burden, Pruncho (1990) failed to document such a relationship.

Study findings indicated that caregivers with formal supports did not differ from those without services on overall burden or most of its components. The only exception was the greater economic costs for caregivers with formal supports. Similarly, other studies have failed to document a significant effect for formal supports (Brown et al., 1990; Kosberg et al., 1990; Penning, 1995; Toseland et al., 1989).

Predictors of Physical and Mental Health

A number of different combinations of independent or predictor variables was attempted during regression analysis to obtain the model-of-best-fit for physical health status. Although several variables depicted moderate to strong correlations with physical health (i.e., employment, relationship, tangible support, physical and emotional dimension of burden, and mental health), only mental health and employment entered the regression equation. Mental health emerged as the strongest predictor, accounting for 29.5% of the total explained variance (33.1%) in physical health.

Only a limited number of previous studies treated caregiver physical health as an outcome variable. Pruchno et al. (1990) found that caregiver mental health (depression) was a significant predictor of physical health over time. Neundorfer (1991) regressed a number of variables (i.e., frequency of care receiver memory and behavior problems, caregiver gender and age, coping strategies, and stress) on physical health but only gender and wishing-emotive coping emerged as significant predictors.

Several different combinations of variables were also used to identify the model-of-best-fit for mental health status. A number of variables depicted moderate to strong correlations with mental health (i.e., frequency of disruptive behaviors and memory problems, reaction to disruptive behaviors, tangible support, total burden, physical and emotional dimension of burden, and physical health). However, only physical health and the physical and emotional dimension of burden entered the regression equation to explain 28.5% and 14.6% of the observed variance in mental health, respectively.

Neundorfer (1991) found that caregiver stress, wishing-emotive coping, and frequency of care receiver problems were the best predictors of mental health (i.e., depression). Braithwaite (1996) found that stressors (i.e., increased care supervisory activities), personal resources (i.e., low self-esteem, passive coping, poor physical health, and restricted social network), and greater burden were significant predictors of poorer mental health (i.e., depression and anxiety). Significant for the current study is the high predictive value of physical health for mental health documented by Braithwaite (1996). In contrast, Pruchno et al. (1990) did not find physical health to be a significant predictor of mental health (i.e., depression), whereas burden was a significant predictor.

Predictors of Physical and Emotional Burden

The literature review demonstrated that the concepts of burden and health have been used interchangeably across studies. In the present study, caregiver physical and emotional costs represented a dimension of burden. The decision was made to also treat this aspect of burden as an outcome variable.

As noted previously with mental and physical health, different combinations of variables depicting significant correlations with physical and emotional burden were used during regression analysis to identify the model-of-best-fit. The variables demonstrating moderate to strong correlations with physical and emotional burden included: care hours and tasks, the frequency of care receiver depression, memory, and disruptive problems, emotional support, tangible support, and mental and physical health status. Mental health emerged as the strongest predictor of physical and emotional burden, accounting for 25.4% of the explained variance. Mental health was followed by the frequency of disruptive behaviors, care tasks, and tangible support, accounting for 11.6%, 7.0%, and 3.4% of the explained variance, respectively.

Comparatively, Kosberg et al. (1990) found that mental health and the frequency of care receiver disruptive behaviors were significant predictors of physical and emotional burden. In contrast to the current study's findings, caregiver physical health and care receiver functional impairment were also found to be significant predictors of physical and emotional burden by Kosberg et al.

Implications of Findings for the SPM (Modified)

Data from the current study provided partial support for some of the major assumptions of the modified SPM. It was postulated that the outcome of caregiving is the way that stress is expressed (e.g., health changes). The shift from burden to overall health status as outcome is also supported by other researchers (Braithwaite, 1996; Kinney & Stephens, 1989a, 1989b; Lawton et al., 1989; Neundorfer, 1991). Since the current study used a cross-sectional design, it was not possible to determine whether health changes were the result of caregiving. However, study findings do provide strong support for the assumptions that physical and mental health are interrelated, and mental health declines before physical health as noted earlier.

The modified SPM assumes that background and context factors exert a direct effect on primary and secondary stressors, interpersonal relationships, and stress outcomes. The current study found limited support for the assumption that background and context factors influence primary stressors and outcome, and partial support for their impact on secondary stressors and interpersonal relationships. Unfortunately, most of the literature in this area examined the effects of sociodemographic and caregiving factors on burden or outcome. Given the variant effects observed in the current study and the conflicting findings reported in the literature, it is obvious that further research with path analysis is required to examine the validity of this assumption.

The modified SPM postulates that a direct relationship exists between primary and secondary stressors. That is, secondary stressors surface in response to the increasing intensity of primary stressors. The current study's findings provide strong support for this assumption. Despite the use of different measurement instruments and composite versus individual component scores for burden and care receiver problems, most previous studies also support the influence of primary stressors on secondary stressors. It seems that there is strong support for this particular assumption.

The influence of primary stressors on stress outcomes was another important assumption of the modified SPM investigated in the current study. Study findings provide limited support for this assumption. That is, primary stressors were found to influence caregiver mental but not physical health. Additional support for this assumption is found in the literature (Draper et al., 1992;

Neundorfer, 1991; Speer, 1993). There are a couple of possible reasons for the reduced significance of the current study's findings. First, as discussed in the previous chapter, the RMBPC has questionable validity for the study population. Second, the data from the RMBPC reflects caregivers' perceptions of care receiver problems for the past week. Vitaliano, Young, and Russo (1991) argue that limiting responses to a time frame may increase measurement error. Thus, measurement problems could be responsible for variant support for the proposed effect of primary stressors on the outcomes of caregiving. Further, testing of this model should consider both the most recent and cumulative effects of primary stressors as suggested by Pearlin et al. (1990) and Vitaliano et al. (1991)

The modified SPM proposes that secondary stressors (i.e., burden) impact stress outcomes. The current study only found partial support for the effects of secondary stressors on health status. Although the physical and emotional dimension of burden depicted a significant negative correlation with physical and mental health, overall burden failed to demonstrate a significant relationship with physical health. Similarly, other studies failed to document a significant relationship between overall burden and physical health (Braithwaite, 1996; Bull, 1990; Speer, 1993), but did support the presence of a strong association between burden and mental health (Anthony-Bergstone et al., 1988; Braithwaite, 1996; Bull; Bull et al.,1995; Draper et al., 1992; Kosberg et al., 1990; Intrieri & Rapp, 1994; Speer, 1993; Stommel et al., 1990; Strawbridge & Wallhagen, 1991). Kosberg et al. also reported a significant relationship between physical and emotional dimension of burden with physical and mental health. Further research is needed to fully understand the relationship between burden as a strain and health status.

The modified SPM also proposes a direct effect for interpersonal relationships on primary and secondary stressors, and stress outcomes. The current study found limited support for the assumption that interpersonal relationships directly influence primary stressors and outcome, and partial support for their impact on secondary stressors. In contrast, Speer (1993) reported that social support (i.e., emotional and actual) depicted a strong association with primary stressors and outcome (i.e., mental but not physical health), but was not related to burden. Braithwaite (1996) also found that social support correlated with mental health but not burden. This assumption also requires further testing with both perceived and actual measures of social support.

Summary

The primary purpose of this study was to investigate primary caregivers' perception of health status while waiting to place an older, dependent adult in a nursing home. A second purpose was to examine the relationship of select factors (i.e., sociodemographic and caregiving factors, caregiver perception of care receiver characteristics, social supports, and caregiver burden) on health status. The Stress Process Model provided the conceptual framework for the study.

Findings demonstrated that caregivers waiting to place the older dependent adult in a nursing home are experiencing moderate to high burden, and poorer mental than physical health. The level of burden was influenced by frequency of care receiver problems, greater caregiving hours and tasks, and weaker support systems. Although employment, relationship, tangible supports, caregiver mental health, and the physical and emotional dimension of burden were associated with physical health, only mental health and employment emerged as significant predictors. Caregiver mental health was influenced by tangible supports, overall burden, physical and emotional dimension of burden, physical health, frequency of care receiver memory problems and disruptive behaviors, and caregiver reaction to disruptive behaviors. Physical health and the physical and emotional dimension of burden emerged as the strongest predictors of mental health.

Chapter 6

Limitations and Implications

In this chapter, the limitations of the study will be discussed. Implications for nursing practice, education, and research will also be presented.

Limitations

The small, non-probability sample limits the generalizability of study findings, and thus the findings should be interpreted with caution. The use of a cross-sectional design for data collection could have diminished the comprehensiveness and conclusiveness of the findings and testing of the Stress Process Model. Further, self-report measures may generate less reliable data than more objective measures.

The use of the RMBPC to measure care receiver problems and caregiver reaction to them is another limitation of this study. The low intercorrelations among the subscales of both the frequency and reaction scales suggest that the RMBPC may not have been a valid measure of care receiver problems for the current study population. It is possible that the use of standardized instruments would have provided a more indepth, accurate picture of care receiver cognitive and functional problems (e.g., Mental Status Questionnaire, Philadelphia Geriatic Center Multilevel Assessment, etc.).

Although study findings suggest that the NSSQ is a valid measure of social support, the extremely high intercorrelations between the structural and functional scales provide limited insight into the variant effects of these different components on caregiver health status. A further limitation of the NSSQ is that it does not allow differentiation between actual and perceived support. Assessment of caregivers actual support may have generated different study findings.

A final limitation is the use of single items to measure mental and physical health. It is acknowledged that this may have resulted in restrictive findings on caregiver health status.

Implications

The results of this study have implications for nursing practice, education, and research.

Nursing Practice

Study findings suggest that factors influencing burden may differ from those affecting health. If this is the case, then nurses working in institutional and community settings must be made aware of the importance of assessing both the burden level and health status of caregivers. Awareness is only one side of the coin, however. Nurses must also possess the necessary knowledge about important risk factors, and develop the required competencies and skills to complete accurate assessments of caregivers burden and health status.

The findings also indicate that physical and mental health are strongly associated with each other, and mental health is rated less positively than physical health. In addition, the findings suggest that the frequency of care receiver problems and the intensity of caregivers' reactions to them can have negative repercussions for caregiver burden and mental health status. Nurses involved with caregivers of older, dependent adults should conduct detailed assessments of caregivers health status, the scope and severity of care receiver problems, and caregivers ability to cope with and manage caregiving activities. This is especially important when caregivers are seeking placement of family members in nursing homes.

Study findings also suggest that greater tangible support can lessen the impact of caregiving on caregivers physical and mental health. These findings stress the importance of monitoring the adequacy of informal supports. It is reasonable to assume that accurate, detailed assessments will alert health care providers to caregivers at greatest health-risk. When deficiencies are detected, steps should be taken to ensure that caregivers have access to appropriate formal supports. Such measures may be beneficial in preventing a further decline in caregiver health status, especially during the transitional period to nursing homes.

Nursing Education

It is imperative that nursing curriculum include gerontological nursing with a family focus. This is especially important with the increasing proportion of elderly in the population. Nursing students must be cognizant of the multiple factors influencing the caregiving process. Practicing nurses must keep abreast of current knowledge and recommended clinical approaches in gerontological nursing through self study, continuing education programs, and conferences.

Educational programs have to ensure that nursing students are given an opportunity to work with families caring for older adults in community settings; to develop beginning competencies in assessing the impact of caregiving on health; and to become advocates for older adults and their caregivers. Nursing students, as well as practicing nurses, must understand the importance of forging collaborative relations with professional and non-professional groups, communities, and the public. This level of collaboration is needed in order to ensure that both care receivers and caregivers are aware of available supports and know how to access them.

Nurse educators use of conceptual frameworks, both nursing and non-nursing, will not only facilitate student understanding of caregiver needs but also help them provide more comprehensive nursing care. The SPM highlights a broad range of factors that exert independent and interactive effects on caregiving outcomes. Application and testing of models, such as the SPM, in nursing practice situations have the potential to not only enhance the quality of nursing practice, but also help refine and modify model assumptions.

Nursing Research

Although there has been extensive research on the caregiving process, few studies have been completed by nurses. Further, conflicting findings continue to plague progress in identifying the most important factors influencing caregiving outcomes. Future research should be directed towards examining the applicability and usefulness of different theoretical models for guiding nursing practice. Equally as important is the development and refinement of measuring instruments that are capable of generating reliable and valid data for testing theoretical models and assessing the caregiving environment.

Given the conflicting findings in the literature on the influence of different factors on caregiving outcomes, it would probably be more beneficial to use triangulated approaches during data collection. The problems with methodological limitations (e.g., sample size, instruments, cross-sectional designs) would be reduced somewhat if future studies also included a qualitative component to explore caregivers' perceptions of factors that are having the most significant impact on their lives and well-being. The insights provided by these data could prove to be quite useful in identifying strengths and health needs, as well as important areas for nursing interventions. Further, more longitudinal studies need to be conducted to monitor changes in the caregiving environment and evaluate the effectiveness and efficacy of formal support services, especially nursing care. As well, further study is needed on caregivers health status as the outcome of caregiving measured as a separate entity and as a component of burden.

Summary

The results of this study suggest that caregivers for older dependent adults waiting placement in a nursing home are experiencing burden and negative health effects. The factors influencing the caregiving process are complex, but include those from the caregiving environment, care receiver characteristics, and social support. Although the results of the current study are not generalizable, they support some of the findings of previous research and have the potential to better inform nursing practice, education, and research.

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Appendix A
Consent Form

School of Nursing, Memorial University of Newfoundland,
St. John's, Newfoundland A1B 3V6

CONSENT TO PARTICIPATE IN HEALTH CARE RESEARCH

TITLE: Caregivers' Perception of Burden and the Institualization of Older Dependent Adults

INVESTIGATOR: Elizabeth Spracklin, B.N., R.N.
Telephone: 634-5712

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time **without affecting your application for placement in continuing care.**

Confidentiality of information concerning participants will be maintained by the investigator. The investigator will be available during the study at all times should you have any problems or questions about the study.

Purpose of the Study: You are being asked to participate in a research study of primary caregivers waiting to place an older, dependent adult in a continuing care facility within the western region. The purpose of this study is to develop a greater appreciation of the burden experienced by caregivers, and factors that may influence perceptions of burden and health.

Description of Procedures and Tests: You are being asked to participate in one interview which will be conducted at a time and place convenient for you. During the interview, you will be asked questions about your health, demands of caregiving, the health of your care receiver, and available social supports. Personal health questions will involve rating your overall health, and the demands of caregiving. Questions on the health of your family member will involve rating his/her memory and behavior problems. The social support questions will ask you to identify members of your social network and comment on your relationships with each of these people.

Duration of Participation: The interview will take 1 to 1 1/2 hours of your time.

Foreseeable Risks, Discomforts or Inconveniences: There are no expected risks from participating in this study. You may refuse to answer any questions which make you feel uncomfortable, and terminate the interview at any time. The investigator may make a referral to available counselling services if you feel that you could benefit from additional supports. All information that you provide will be kept strictly confidential, secured in a locked file, and accessible only to the principal investigator.

Benefits: You may not derive any direct benefits from participating in this study. However, the information that you provide may help health care workers in continuing care plan more appropriate supports for caregivers waiting to place family members.

Other Information: Findings of this study will be available to you and health care professionals upon request. Although study findings will be published or presented, your name will not appear anywhere in the report. The investigator will be available during the study at all times should you have any questions or concerns about your continued participation.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities.

I,______________________________, the undersigned, agree to my

participation in the research study described.

Any questions have been answered and I understand what is involved in the study. I realize that participation is voluntary and that there is no guarantee that I will benefit from my involvement. I acknowledge that a copy of this form has been given to me.

______________________ ____________
Signature of Participant Date

______________________ ____________
Signature of Witness Date

To the best of my ability, I have fully explained the nature of this study to the participant. I have invited questions and provided answers. I believe that the participant fully understands the implications and voluntary nature of the study.

______________________ ____________
Signature of Interviewer Date

____
Phone Number

Appendix B
RMBPC and Letter of Permission

Revised Memory and Behavior Problems Checklist

ID Code: ______________

The following is a list of problems patients sometimes have. Please indicate if any of these problems have occurred <u>during the past week</u>. If so, how much has this bothered or upset you when it happened? Use the following scales for the frequency of the problem and your reaction to it. Please read the description of the ratings carefully

<u>Frequency Ratings</u>	<u>Reactions Ratings</u>
0 = never occurred	**0 = not at all**
1 = not in the past week	**1 = a little**
2 = 1 to 2 times in the past week	**2 = moderately**
3 = 3 to 6 times in the past week	**3 = very much**
4 = daily or more often	**4 = extremely**
9 = don't know/not applicable	**9 = don't know/not applicable**

L. Teri Ph D
Professor and Dean
Office of the Dean
School of Nursing
University of California
San Francisco
94143-0604

Revised Memory and Behavior Problems Checklist

Please answer all the questions below. Please circle a number from 0 - 9 for <u>both</u> frequency *and reaction.*

Item	Frequency	Reaction
1. Asking the same question over and over.	0 1 2 3 4 9	0 1 2 3 4 9
2. Trouble remembering recent events (e.g. *items in the newspaper or on TV).*	0 1 2 3 4 9	0 1 2 3 4 9
3. Trouble remembering significant past events.	0 1 2 3 4 9	0 1 2 3 4 9
4. Losing or misplacing things.	0 1 2 3 4 9	0 1 2 3 4 9
5. Forgetting what day it is.	0 1 2 3 4 9	0 1 2 3 4 9
6. Starting, but not finishing things.	0 1 2 3 4 9	0 1 2 3 4 9
7. Difficulty concentrating on a task.	0 1 2 3 4 9	0 1 2 3 4 9
8. Destroying property.	0 1 2 3 4 9	0 1 2 3 4 9
9. Doing things that embarrass you.	0 1 2 3 4 9	0 1 2 3 4 9
10. Waking you or other family members up at *night.*	0 1 2 3 4 9	0 1 2 3 4 9
11. Talking loudly and rapidly.	0 1 2 3 4 9	0 1 2 3 4 9
12. Appears anxious or worried.	0 1 2 3 4 9	0 1 2 3 4 9
***13. Engaging in behavior that is potentially* dangerous to self or others.**	0 1 2 3 4 9	0 1 2 3 4 9

Item	Frequency	Reaction
14. Threats to hurt onself.	0 1 2 3 4 9	0 1 2 3 4 9
15. Threats to hurt others.	0 1 2 3 4 9	0 1 2 3 4 9
16. Aggressive to others verbally.	0 1 2 3 4 9	0 1 2 3 4 9
17. Appears sad or depressed.	0 1 2 3 4 9	0 1 2 3 4 9
18. Expressing feelings of hopelessness or sadness about the future (e.g. "Nothing worthwhile ever happens. "I nver do anything right".).	0 1 2 3 4 9	0 1 2 3 4 9
19. Crying and tearfulness.	0 1 2 3 4 9	0 1 2 3 4 9
20. Commenting about deal of self or others (e.g. "Life isn't worth living." "I'd be better off dead".).	0 1 2 3 4 9	0 1 2 3 4 9
21. Talking about feeling lonely.	0 1 2 3 4 9	0 1 2 3 4 9
22. Comments about feeling worthless or being a burden to others.	0 1 2 3 4 9	0 1 2 3 4 9
23. Comments about feeling like a failure or about not having any worthwhile accomplishments in life.	0 1 2 3 4 9	0 1 2 3 4 9
24. Arguing, irritability, and/or complaining.	0 1 2 3 4 9	0 1 2 3 4 9

10 Ingrid Avenue
Corner Brook, NF
Canada
A2H 6P2
February 8, 1996

Dr. Linda Teri
University of Washington School of Medicine
Department of Psychiatry and Behavioral Sciences
RP-10, Seattle, Washington. 98195

Dear Dr. Teri

This letter requests your permission to use the Revised Memory and Behavior Problems Checklist for data collection with a sample of caregivers within my Province. I am a graduate student in the School of Nursing, Memorial University of Newfoundland, Canada, and the proposed research fulfills the the thesis requirement for the Masters of Nursing program.

The purpose of the study will be to investigate perception of burden and the predictors of burden in caregivers of older adults who are waiting placemnt in a continuing care facility. Some studies have shown a relationship between care receiver characteristics and caregiver burden. The findings of the study will assist in developing the appropriate programs to lower the burden of the caregivers. The programs may be able to prevent or delay placement and keep older adults with families in the community.

I am aware of the extensive use of the instrument through the articles written by you and your colleagues. Is there a manual to aid with the use of the instrument in data collection and analysis? I appreciate your sharing any information on the use of the instrument and the data analysis. I also appreciate any specific forms or protocols that you feel may benefit the study.

I can be reached at the above address, or 709-634-5712 (home), 709-637-5585 (office), 709-637-5161 (Fax) if you require further information. Thank-you for your assistance, and I look forward to a favourable reply.

Sincerely

Elizabeth Spracklin B.N. R.N.

You have my permission. Let me know how it works for you.

L Teri

Appendix C
NSSQ and Letter of Permission

SOCIAL SUPPORT QUESTIONNAIRE

PLEASE READ ALL DIRECTIONS
ON THIS PAGE BEFORE STARTING

Please list each significant person in your life on the right. Consider all the persons who provide personal support for you or who are important to you.

Use only first names or initials, and then indicate the relationship, as in *the following example:*

Example:

	First Name or Initials	Relationship
1.	MARY T.	FRIEND
2.	BOB	BROTHER
3.	M.T.	MOTHER
4.	SAM	FRIEND
5.	MRS. R.	NEIGHBOR

etc.

Use the following list to help you think of the people important to you, and list as many people as apply in your case.

- spouse or partner
- family members or relatives
- friends
- work or school associates
- neighbors
- health care providers
- counselor or therapist
- minister/priest/rabbi
- other

You do not have to use all 24 spaces. Use as many spaces as you have important persons in your life.

WHEN YOU HAVE FINISHED YOUR LIST, PLEASE TURN TO PAGE 2.

Note: Before use, pages 1-4 should be cut along the dashed center line to allow the response lines for Questions 1-6 to align with the Personal Network list on page 5.

For each person you listed, please answer the following questions by writing in the number that applies.

0 = not at all
1 = a little
2 = moderately
3 = quite a bit
4 = a great deal

Question 1:

How much does this person make you feel liked or loved?

1. ____________
2. ____________
3. ____________
4. ____________
5. ____________
6. ____________
7. ____________
8. ____________
9. ____________
10. ____________
11. ____________
12. ____________
13. ____________
14. ____________
15. ____________
16. ____________
17. ____________
18. ____________
19. ____________
20. ____________
21. ____________
22. ____________
23. ____________
24. ____________

[EMO1]

Question 2:

How much does this person make you feel respected or admired?

1. ____________
2. ____________
3. ____________
4. ____________
5. ____________
6. ____________
7. ____________
8. ____________
9. ____________
10. ____________
11. ____________
12. ____________
13. ____________
14. ____________
15. ____________
16. ____________
17. ____________
18. ____________
19. ____________
20. ____________
21. ____________
22. ____________
23. ____________
24. ____________

[EMO2]

GO ON TO NEXT PAGE

Note: Before use, pages 1-4 should be cut along the dashed center line to allow the response lines for Questions 1-6 to align with the Personal Network list on page 5.

0 = not at all
1 = a little
2 = moderately
3 = quite a bit
4 = a great deal

Question 3:

How much can you confide in this person?

1. ________
2. ________
3. ________
4. ________
5. ________
6. ________
7. ________
8. ________
9. ________
10. ________
11. ________
12. ________
13. ________
14. ________
15. ________
16. ________
17. ________
18. ________
19. ________
20. ________
21. ________
22. ________
23. ________
24. ________

[EMO3]

Question 4:

How much does this person agree with or support your actions or thoughts?

1. ________
2. ________
3. ________
4. ________
5. ________
6. ________
7. ________
8. ________
9. ________
10. ________
11. ________
12. ________
13. ________
14. ________
15. ________
16. ________
17. ________
18. ________
19. ________
20. ________
21. ________
22. ________
23. ________
24. ________

[EMO4]

GO ON TO NEXT PAGE

Note: Before use, pages 1-4 should be cut along the dashed center line to allow the response lines for Questions 1-6 to align with the Personal Network list on page 5.

0 = not at all
1 = a little
2 = moderately
3 = quite a bit
4 = a great deal

Question 5:

If you needed to borrow $10, a ride to the doctor, or some other immediate help, how much could this person usually help?

1. ________________
2. ________________
3. ________________
4. ________________
5. ________________
6. ________________
7. ________________
8. ________________
9. ________________
10. ________________
11. ________________
12. ________________
13. ________________
14. ________________
15. ________________
16. ________________
17. ________________
18. ________________
19. ________________
20. ________________
21. ________________
22. ________________
23. ________________
24. ________________

[AID5]

Question 6:

If you were confined to bed for several weeks, how much could this person help you?

1. ________________
2. ________________
3. ________________
4. ________________
5. ________________
6. ________________
7. ________________
8. ________________
9. ________________
10. ________________
11. ________________
12. ________________
13. ________________
14. ________________
15. ________________
16. ________________
17. ________________
18. ________________
19. ________________
20. ________________
21. ________________
22. ________________
23. ________________
24. ________________

[AID6]

GO ON TO NEXT PAGE

Note: Before use, pages 1-4 should be cut along the dashed center line to allow the response lines for Questions 1-6 to align with the Personal Network list on page 5.

Question 7:

How long have you known this person?

1 = less than 6 months
2 = 6 to 12 months
3 = 1 to 2 years
4 = 2 to 5 years
5 = more than 5 years

1. ____________
2. ____________
3. ____________
4. ____________
5. ____________
6. ____________
7. ____________
8. ____________
9. ____________
10. ____________
11. ____________
12. ____________
13. ____________
14. ____________
15. ____________
16. ____________
17. ____________
18. ____________
19. ____________
20. ____________
21. ____________
22. ____________
23. ____________
24. ____________

[DURATION]

Question 8:

How frequently do you usually have contact with this person? (Phone calls, visits, or letters)

5 = daily
4 = weekly
3 = monthly
2 = a few times a year
1 = once a year or less

1. ____________
2. ____________
3. ____________
4. ____________
5. ____________
6. ____________
7. ____________
8. ____________
9. ____________
10. ____________
11. ____________
12. ____________
13. ____________
14. ____________
15. ____________
16. ____________
17. ____________
18. ____________
19. ____________
20. ____________
21. ____________
22. ____________
23. ____________
24. ____________

[FREQCON]

PLEASE BE SURE YOU HAVE RATED EACH PERSON ON EVERY QUESTIONS. GO ON TO THE LAST PAGE.

Number ____________ [IDNO]

Date ____________

PERSONAL NETWORK

	First Name or Initials	Relationship
1.		[SOU1]
2.		[SOU2]
3.		[SOU3]
4.		[SOU4]
5.		[SOU5]
6.		[SOU6]
7.		[SOU7]
8.		[SOU8]
9.		[SOU9]
10.		[SOU10]
11.		[SOU11]
12.		[SOU12]
13.		[SOU13]
14.		[SOU14]
15.		[SOU15]
16.		[SOU16]
17.		[SOU17]
18.		[SOU18]
19.		[SOU19]
20.		[SOU20]
21.		[SOU21]
22.		[SOU22]
23.		[SOU23]
24.		[SOU24]

Appendix D
CCI and Letter of Permission

The Consequences of Care Index

ID Code: ____________

The following items permit you to indicate the experienced consequence (or the anticipated consequence) from caring for an elderly relative. We all realize that though we may wish to meet the needs of our relative, often providing care and assistance has its impact on family members. This is only normal.

Your honest response to the following items will aid others to assist you in the event that you are (or will be) providing such care to an elderly relative.

There are no right or wrong answers, only truthful feelings. For each item, circle the appropriate number for Strongly Disagree, Disagree, Agree, or Strongly Agree. Your responses will remain confidential. It is important that you respond to all the items.

Note: The use and interpretation of this Index requires special instructions.

Not to be duplicated without permission

* formerly referred to as the Cost of Care Index

Jordan I. Kosberg, PhD., ACSW
School of Social Work
Florida International University
North Miami, Florida 33181

The Consequence of Care Index

Item	Strongly Disagree	Disagree	Agree	Strongly Agree
1. I feel that meeting the psychological needs of my elderly relative for feeling wanted and important is not (will not be) worth the effort.	1	2	3	4
2. I feel that my elderly relative is (will be) an overly demanding person to care for.	1	2	3	4
3. I feel that caring for my elderly relative has negatively affected (will negatively affect) my family's or my physical health.	1	2	3	4
4. I feel that as a result of caring for my elderly relative I do not (will not) have enough time for myself.	1	2	3	4
5. I feel that caring for my elderly relative is causing me (will cause me) to dip into savings meant for other things.	1	2	3	4
6. I feel that meeting the health needs of my elderly relative is not (will not be) worth the effort.	1	2	3	4
7. I feel that my elderly relative tries (will try) to manipulate me.	1	2	3	4
8. I feel that caring for my elderly relative has negatively affected (will negatively affect) my appetite.	1	2	3	4
9. I feel that caring for my elderly relative puts (will put) a strain on family relationships.	1	2	3	4
10. I feel that my family and I must give up (will have to give up) necessities because of the expense to care for my elderly relative.	1	2	3	4
11. I feel that caring for my elderly relative disrupts (will disrupt) my routine in my home.	1	2	3	4

Item	Strongly Disagree	Disagree	Agree	Strongly Agree
12. I feel that caring for my elderly relative has caused (will cause) my family and me much aggravation.	1	2	3	4
13. I feel that meeting the daily needs of my elderly relative is not (will not be) worth the effort.	1	2	3	4
14. I feel that caring for my elderly relative has caused me (will cause me) to be physically fatigued.	1	2	3	4
15. I feel that my family and I cannot (will not be able to) afford those little extras because of the expense to care for my elderly relative.	1	2	3	4
16. I feel that my elderly relative makes (will make) unnecessary requests of me for care.	1	2	3	4
17. I feel that meeting the social needs of my elderly relative for companionship is not (will not be) worth the effort.	1	2	3	4
18. I feel that caring for my elderly relative has caused me (will cause me) to become anxious.	1	2	3	4
19. I feel that caring for my elderly relative interfers (will interfere) with my friends or friends of my family coming to my home.	1	2	3	4
20. I feel that caring for my elderly relative is (will be) too expensive.	1	2	3	4

Appendix E
Descriptive Profile Form

IV. Placement Decision:

Perceived reason (s) for placement: ____________________________________
____
____

Are there any additional health care services that could prevent/delay placement of your family member in a continuing care facility? ☐ yes ☐ No

Could you identify these health care services:
____
____
____

V. Demands of Caregiving

Approximate number of tasks associated with caregiving each week: __________

Approximate number of hours associated with caregiving each week: __________

Appendix F
Letter of Permission from Human Investigation Committee

Memorial
University of Newfoundland

Human Investigation Committee
Research and Graduate Studies
Faculty of Medicine
The Health Sciences Centre

11 June 1996

<u>**Reference #96.80**</u>

Ms. Elizabeth Spracklin
c/o Dr. Christine Way
School of Nursing

Dear Ms. Spracklin:

This will acknowledge receipt of your correspondence dated **June 5, 1996**, wherein you clarify issues and provide revised copies of appendices A, M, and N, as well as correspondence from Ms. M. Fleming for the research application entitled **"Caregivers' Perception of Burden and the Institualization of Older Dependent Adults"**.

I have reviewed the information provided and am recommending full approval of this application. This decision will be ratified at the HIC meeting scheduled for **June 20, 1996**.

We take this opportunity to wish you every success with your research study.

Sincerely yours,

H.B. Younghusband, Ph.D.
Chairman
Human Investigation Committee

cc Dr. K.M.W. Keough, Vice-President, Research
Dr. Eric Parsons, Vice-President, Medical Services, HCC
Dr. Christine Way, Supervisor

St. John's, NF, Canada A1B 3V6 • Tel.: (709) 737-6974 • Fax: (709) 737-5033

Appendix G
Letter of Permission from Community Health Western