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THE RELATIONSHIP BETWEEN IMPACT ON SCHEDULE AND
DEPRESSION IN CAREGIVER DAUGHTERS, OF ELDERLY MOTHERS,
WITH DIFFERING EMPLOYMENT STATUS

presented by

Patricia M. Kemmer De Vries

has been accepted towards fulfillment
of the requirements for

MASTER OF SCIENCE degree in IN NURSING

Carla L. Barnes

Major professor

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THE RELATIONSHIP BETWEEN IMPACT ON SCHEDULE AND
DEPRESSION IN CAREGIVER DAUGHTERS, OF ELDERLY MOTHERS,
WITH DIFFERING EMPLOYMENT STATUS

By

Patricia M. Kemmer DeVries

A THESIS

Submitted to
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ABSTRACT

THE RELATIONSHIP BETWEEN IMPACT ON SCHEDULE AND DEPRESSION IN CAREGIVER DAUGHTERS, OF ELDERLY MOTHERS, WITH DIFFERING EMPLOYMENT STATUS

By

Patricia M. Kemmer DeVries

This study examined the impact on schedule of 120 caregiver daughters, of elderly mothers, who were employed, unemployed, or had terminated employment during the first 2 through 4 weeks of caregiving and the relationship between impact on schedule and depression. No significant differences on impact on schedule were found in the three different employment groups by using analysis. Significant Pearson correlation were found between impact on schedule and depression in employed and unemployed caregiver daughters. However, there was no significant relationship between impact on schedule and depression in daughters who terminated employment. Implications for advanced practice nurses were based on role theory and include adequate preparation of the new caregiver regarding expected tasks, time involvement, and community resources.

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The Problem

Introduction

In contemporary society, it is common for women to have multiple roles including wife, mother, career woman, and caregiver of elderly parents. Sometimes referred to as the "sandwich generation", middle-aged women are finding themselves caring for both their children and their parents. Daughters are more frequently involved in caregiving activities for elderly disabled family members comprising 29% of family caregivers, compared to sons who make up less than 10% of family caregivers (Gallagher, Rose, Rivera, Lovett, & Thompson, 1989).

As a result of advanced technology in health care, people are living longer but the quality of life is not equally extended. Presently, persons 85 years and older constitute the age group that is experiencing the most rapid growth rate in America (Longino, 1988). In 1963, 25% of people over the age of 45 had a surviving parent and by 1980, 40% of people in their late fifties had at least one surviving parent (National Retired Teachers Association - American Association of Retired Persons, 1984). It is estimated that by the year 2000, the population over 85 years will reach 5.4 million compared to 2.3 million in 1980 (Longino, 1988).

Hence, society must make provisions to maintain the

fundamental requirements of the elderly who are unable to perform independent activities of daily living. An estimated 70% of individuals 85 years and older require assistance with one or more activities of daily living (Johnson & Hoover, 1982; Soldo & Longino, 1989; Suzman & Riley, 1985). It was predicted that many elderly people will be women who are disabled and in need of caregivers (Lamphere-Thorpe & Blendon, 1991; Manton & Soldo, 1985). An estimated 70% of the oldest Americans are female (Longino, 1988) and widowed females account for the majority of persons 85 years and older (Serow & Sly, 1987). Since women are surviving longer than their spouses, the responsibility of caregiving generally falls upon their daughters. The Census Bureau estimates that by the year 2030, 7 of 10 baby boom women will outlive their husbands to live approximately 15 years alone (Beck, 1990), generating a cycle of perpetual need for caregiver daughters. More elderly widows will depend on their daughters as a result of advanced technology prolonging their lives; caregiver daughters can expect to spend more years caring for an aging parent than for a dependent child (Wisensale, 1993).

Thus, caregiver daughters will persistently experience the demands of role accumulation and new stressors as they combine the modern role of employment with the traditional role of caregiving. A considerable number of daughters provide care for their elderly parents, particularly their mothers, while employed (Brody & Schoonover, 1986; Pohl, Given, & Given, 1991; Stoller, 1983; Wisensale, 1993). Approximately 75% of all women 18 to 44 years

of age are in the labor force, as are 62% of all women between 45 and 54, and 42% of those between the age of 53 and 64 (Wisensale, 1993). The Family and Medical Leave Act of 1993 provides unpaid leave for caregivers who are employed by private companies with 50 or more employees. Many workers and particularly low income individuals cannot afford time off work without pay. Caregiver daughters who work for companies with less than 50 employees may be forced to terminate employment to care for their elderly parents.

Caregiver daughters who continue to work may experience role strain including emotional distress and schedule disruptions (Walker, Martin, & Jones, 1992). In general, female caregivers report higher levels of strain than do male caregivers (Cantor, 1983; Fitting, Rabins, Lucas, & Eastham, 1986; Horowitz, 1985). This susceptibility may be attributed to the finding that female caregivers are typically younger than male caregivers (Fitting & Rabins, 1985). At a younger age, women may be in the work force and raising children, in addition to providing care to an elderly mother. Moreover, caregiver daughters with multiple roles may experience emotional strain when they protect their families and work, but not their personal interests (Cantor, 1983). Hence, working women with multiple roles may find that caregiving decreases time for meeting personal needs, engaging in other relationships, and focusing on career goals (Archbold, 1982).

Particularly, a lack of personal time to concentrate on one's own physical and emotional needs may lead to a loss of sense of self and eventually to depression (Barusch & Spaid, 1989). An estimated 50% of all caregivers suffer from depression (Cohen & Eisdorfer,

1988; Shields, 1992). Caregiver depression may be due to a lack of support, respite, and confidence in performing care activities. As a result, caregivers may experience loneliness, anger, guilt, and longing for a lost lifestyle (Sommers & Shields, 1987). Furthermore, depression has been found to interfere with daily functioning and to impede the ability to provide care (Clayton, 1982). Also, it has been shown that high levels of depression cause vulnerability to physical health problems over time (Given, Given, & Stommel, 1991). It is typical for modern women to have multiple roles; however, the addition of parent caregiver to these roles may result in a significant impact on schedule and have possible deleterious psychological effects.

In the primary care setting, it is not uncommon for individuals to seek medical attention for vague and ill-defined symptoms. Caregiver daughters may seek medical attention for symptoms triggered by role strain associated with the transition to caregiving. It is also likely that caregiver daughters will accompany their parent to health care visits, so advanced practice nurses (APN) need to attend not only to the patient but also to the caregiver. As primary care providers, APNs often must determine the origin of presenting symptoms and contributing factors, such as multiple roles. In order to detect a potentially health threatening situation and provide early intervention the APN must be aware of caregiving-related stressors, impact on schedule, and potential depression.

Much of the current literature examines seasoned caregivers who have been involved in caregiving activities on average 3 to 5

years (Brody, Litvin, Hoffman, & Kleban, 1992; Dellasega, 1990; Pohl, Given, Collins, & Given, 1991). Relatively few studies have looked at the effect of caregiving during the transition phase or in first 3 months of caregiving. Franklin, Ames, and King (1994) studied employed female caregivers ($N = 119$) who responded to telephone interviews and self-report questionnaires after 3 months of caregiving. They found that women employed full-time or part-time before caregiving used short-term work adjustments during the first 3 months of caregiving. These work adjustments did not influence the probability of the caregiver taking a leave of absence or terminating employment in the next 3 months.

Archbold, Stewart, Greenlick, and Harvath (1990) interviewed caregivers ($N = 78$) after 6 weeks using the Family Caregiving Inventory (Archbold & Stewart, 1986). They found caregiver competence may have been a stronger predictor of role strain at the end of 6 weeks rather than during periods of more stability. The transition period is a critical time when caregivers may experience the most difficulty adjusting to the role. Moreover, Barusch and Spaid (1989) interviewed caregivers ($N = 131$) after 3 months using a coping inventory, Milardo's Social Support Inventory (1983), and a caregiver burden scale (Zarit, Reever, & Back-Peterson, 1980). They found that the care recipient's cognitive and behavioral difficulties predicted burden. Other factors may predict burden prior to the 3 month mark, such as employment status.

Overall, the current caregiver literature has focused on individuals who have been caregivers for an extended period of time.

Little attention has been given to daughters as caregivers. In addition to further research on caregiver daughters, more studies are necessary to determine the effect of caregiving during transition to the role. New caregivers in transition have been overlooked as a sample and may produce different data regarding the effect of caregiving than seasoned caregivers. This study is unique because it examines an inception cohort during the first month of caregiving rather than after long term adaptation.

Research Questions

Two questions were posed by this study: (a) what is the impact on schedule in caregiver daughters who are unemployed, employed, or have terminated employment during the early part of caregiving? and (b) is there a relationship between impact on schedule and level of depression in caregiver daughters by level of employment?

Definition of Concepts

In this section the concepts of impact on schedule and depression will be defined.

Impact on Schedule

In this study, impact on schedule was defined as a lack of personal time which affects an individual's sense of self and freedom as a result of caregiving. This definition includes not having enough time for self, family/friends, or leisure. The Impact on Schedule subscale of the Caregiver Reaction Assessment (CRA) (Given, Given, Stommel, Collins, King, & Franklin, 1992) was used to measure impact on schedule. This study defined impact on schedule according

to the CRA, as a lack of personal time, elimination of scheduled activities, and/or constant interruptions. Examples of caregiving tasks that may interfere with personal activities include: providing transportation, helping with household tasks, assisting with personal finances, running errands, and providing emotional support (Robinson & Thurner, 1979).

A decrease in personal time may be reflected by a lack of time for leisure activities, vacation, socialization with friends, and management of one's own home (Cantor, 1983). Moreover, impact on schedule is evident in the amount of privacy, personal space, freedom, and family time available and may subsequently lead to sleep disturbances and exhaustion (Archbold, 1982). The changes that are imposed on one's lifestyle are reflected in activities, income, relationships, and habits (Archbold, 1982).

As involvement in caregiving tasks of communication, food preparation, administration of medication, mobility, hygiene, dressing, and feeding occurs, impact on schedule may become more noticeable (Barusch & Spaid, 1989; Dwyer & Coward, 1991). The amount of time necessary to complete numerous caregiving tasks may leave an individual who has additional responsibilities, little time for family, career, and self. Long term effects may include depression, guilt, and anger toward the care recipient.

Depression

Depression may be measured and categorized many different ways. It may be defined according to clinical criteria, mood, or depressive symptomatology. For the purpose of this study,

depressive symptomatology is defined as an emotional condition which may be a cumulative response to life processes, such as caregiving. It may be characterized by feeling blue, depressed, lonely, tearful, sad, disliked, bothered, unable to concentrate, unmotivated, that people are unfriendly, lacking appetite, and/or sleeping restlessly.

A common approach for defining depression focuses on the diagnosis of clinical depression as defined by the DSM-IV (American Psychiatric Association, 1994). The DSM-IV defines major depression as depressed mood or loss of interest or pleasure lasting for at least 2 weeks. At least 5 of the following symptoms must be experienced most of the day, nearly every day to conclude major depression: (a) depressed mood, (b) diminished interest or pleasure in almost all activities, (c) significant weight loss without dieting or weight gain of 5% of body weight or increase/decrease in appetite, (d) insomnia or hypersomnia, (e) observable psychomotor agitation or retardation (not merely subjective feelings of restlessness or being slowed down), (f) fatigue or loss of energy, (g) feelings of worthlessness or excessive/ inappropriate guilt, (h) diminished ability to think/concentrate or indecisiveness, or (i) recurrent thoughts of death, recurrent suicidal ideation without a specific plan, suicide attempt, or specific plan for committing suicide. These symptoms must cause significant distress or impairment in social, occupational, or other important areas of functioning to be considered major depression and do not result from a substance/medication or general medical condition, such as

hypothyroidism.

Mood states may also be used in defining depression. For example, the Profile of Mood States (POMS) (McNair, Lorr, & Droppleman, 1971) describes depression as including feelings of hopelessness and discouragement. Depression may be depicted as a trait or mood, such as pessimism, loss of social interest, work difficulty, fatigue or somatic preoccupation.

Another approach to defining depression is based on depressive symptomatology. The Beck Depression Inventory (BDI) (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), Center for Epidemiologic Studies - Depression Scale (CES-D) (Radloff, 1977), and Zung self-rating Depression Scale (Zung, 1965) are examples of tools that define depression according to symptoms. For example, the BDI considers specific cognitive, behavioral, or vegetative symptoms and attitudes to be manifestations of depression.

Rather than diagnosing depression according to clinical criteria, the CES-D identifies depression as evidenced by depressive symptoms (Barnes & Prosen, 1984). The CES-D is based on similar symptomatology as the DSM-IV. Barnes and Prosen (1984) stated that depressive symptoms depend on the time available to sleep/read, the ability to be efficient, to have fun/laugh, or to have a meaningful life. According to the Radloff (1977), depressed affect manifests itself as the blues, depression, loneliness, crying and/or sadness. The author of the CES-D states that depression may include depressed mood, feelings of guilt, worthlessness, helplessness, hopelessness, and psychomotor retardation as perceived by the

individual. As a result, depression may adversely effect physical health by causing a poor appetite, restless sleep, irritability, inability to concentrate, lack of motivation, and/or not being talkative. Moreover, Radloff defines depression as psychological distress as evidenced by the helplessness and hopelessness that often accompanies depression. This study used the CES-D to measure depression in caregiver daughters since it incorporated mood, affect, and depressive symptomatology. For the purpose of this study, depression was defined as depressive symptomatology because clinical depression was an unlikely manifestation during the 2 through 4 week transition period to caregiving.

Literature Review

The literature reviewed on caregiver daughters focused on the impact of caregiving on schedule, caregiver depression, and caregiving and employment. Depression and burden have been investigated, but few people have looked at the relationship between impact on schedule and depression.

Impact of Caregiving on Schedule

This section compared the literature on impact on schedule in caregiver daughters with that in spouses and other caregivers. It also looked at employment status and impact on schedule. For many people, caregiving means they must sacrifice something in order to provide time to socialize with or care for a homebound elderly person. Unfortunately, sacrifices are usually made in the area of personal time. The following studies reviewed caregivers who were caregivers from a few weeks to over 5 years.

Caregiver Daughters

The literature found that caregiver daughters experienced a considerable impact on schedule. Cantor (1983) studied impact on schedule in a sample of caregivers, including daughters, using a questionnaire ($N = 111$). Caregivers provided care following an acute medical episode and were assessed before and after 12 weeks of care. Cantor reported two-thirds of her sample of caregiver children lived in separate households from their parents and lost personal time by duplicating household responsibilities. In addition to providing assistance to a dependent parent, caregiver children had to carry out their own activities of daily living. Impact on schedule was indicated by a lack of personal time. Cantor's study showed that children lost more personal time than other relatives or friends. Cantor did not specifically examine caregiver daughters.

Franklin et al. (1994) found that caregiver daughters with full and part time employment made substantial adjustments during the initial 3 months of caregiving. Time for caregiving, work, and family had to be carefully balanced in order to avoid role overload. The authors found that the time of role acquisition was the time most caregiver daughters needed help. Franklin et al. (1994) found that caregiver daughters who were employed particularly experienced impact on schedule. Franklin et al. (1994) focused on the transition period of caregiving rather than long term impact on schedule.

Archbold (1982) looked at the changes in lifestyle that parentcaring daughters ($N = 30$) made as a result of caregiving. Archbold (1984) found that caregiver daughters experienced impact

on schedule on a daily basis by a loss of freedom and inability to make long range life plans. Two thirds of her sample had provided care for five years or longer. Her data were based on interviews, participant observation, and the OARS Multidimensional Functional Assessment (Pfeiffer, 1976). Some caregivers postponed plans of traveling or relocating in order to be near the care recipient, while other caregivers rearranged their daily schedules to provide care, especially if they were employed. Archbold's sample was small and completely Caucasian; therefore, her findings may not apply to the general population. Nevertheless, these studies showed impact on schedule is a common experience among caregiver daughters.

Caregiver Spouses

In comparison, the literature on other caregivers showed that spouses experienced more impact on schedule than daughters. Cantor (1983) studied a sample of caregiver spouses, children, other relatives and friends/neighbors ($N = 111$) using a questionnaire to assess worry, strain and impact of caregiving on private life during the first 12 weeks of care. She found that after spouses, the lives of children were next most severely affected by caregiving. Cantor's study showed the most severe impact was in the areas of free time for oneself and opportunities to socialize with friends, take vacations, have leisure time pursuits, and run one's own house. Furthermore, Cantor (1983) found the impact of caregiving was most severe for spouses, all of whom lived in the same house as the care recipient.

Employment Status of Caregivers

Stone and Short (1990) compared employed and unemployed caregivers ($N = 1003$) in a caregiver survey that estimated the personal characteristics and use of health-related services by disabled non-institutionalized elderly persons in the United States. They found that primary caregivers (individuals with major care responsibility) were about 19% more likely to alter their schedules than secondary caregivers, regardless of employment status. However, Stone and Short (1990) also showed that employed caregivers devoted less time to free time, household and leisure activities. Hence, employed caregivers may experience greater impact on schedule because they do not give up any responsibilities. Stone and Short (1990) focused on caregivers in general, rather than on daughters, and did not explore the effect of caregiving on long range plans.

Summary

Impact on schedule was defined similarly across the studies reviewed. Most of the literature defines impact on schedule as a loss of personal time and freedom as evidenced by alterations in short and long term plans. Although the literature on caregiver impact on schedule does not emphasize daughters, it does show that they are the second most vulnerable group after spouses.

The majority of research has not differentiated daughters as a population that is especially vulnerable to a loss of personal time as a result of caregiving. The literature shows that caregiver daughters experience the second highest impact on schedule after spouses. In a

society where it is virtually required of women to manage many aspects of family care, in addition to providing an income, it is necessary to examine the relationship between multiple roles and impact on schedule. Caregiver daughters may experience impact on schedule because they do not eliminate activities from their schedules as they acquire new responsibilities. As a result, they may lose personal time. An individual subjected to the unrelenting demands of life without reprieve may develop physical symptoms in response to role overload.

Caregiver Depression

Depression has been defined differently throughout the literature according to clinical criteria, mood states, and depressive symptomatology. The studies reviewed were based on depressive symptomatology and clinical criteria since they were the most common approaches to measuring depression in caregivers. In this section, the literature on depression in caregiver daughters was compared with that in spouses and other caregivers.

Caregiver Daughters

Depressive Symptomatology. Some authors of the literature on depression in caregiver daughters based their definition of depression on depressive symptomatology (Brody, Litvin, Hoffman, & Kleban, 1992; Young & Kahana, 1989). Brody et al. (1992) interviewed 492 caregiver daughters of elderly parents using the Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977). The CES-D focuses on depressive symptoms and psychological distress to signify depression. Brody et al. (1992) found that marital

status of caregiver daughters was associated with differences in the caregiving experience. The study reported married caregiver daughters tended to receive more socioemotional and instrumental support, have less financial strain due to higher incomes, and be less depressed. Married daughters experienced more family conflict due to caregiving, but the positive aspects of marriage outweighed the negative aspects of caregiving. Brody et al. (1992) found that more depression in caregiver daughters who were widowed or divorced may have been related to a recent change in marital status. Therefore, marital status may influence the risk of depression in caregiver daughters. Brody et al. (1992) did not report the severity of depression.

Young and Kahana (1989) conducted another study that looked at depressive symptomatology in caregiver daughters. They held in-home interviews using the Symptom Checklist (Derogatis, Lipman & Covi, 1973) to assess depression in 183 caregivers of post-myocardial infarction patients. The authors found more symptoms reported by daughters than wives, but did not report the prevalence of depression. Caregiver daughters tended to adapt over time but experienced more depressive symptoms than other caregivers. Moreover, female caregivers reported higher levels of depression than males, with a significantly greater mental distress reported by daughters (Young & Kahana, 1989). Wives and daughters provided similar amounts of care and both experienced negative outcomes, but they did not suffer the same uniform effects. Young and Kahana (1989) found that spouses provided a different range of services

than child providers and reported very different caregiver outcomes related to burden and role conflict. They also found that caring for an ill spouse may be a normative expectation for older couples who may perceive less burden. Hence, marital status and types of services provided may influence whether a caregiver daughter experiences depressive symptoms.

Clinical Criteria. Rivera et al. (1991) looked at depression in caregiver daughters according to clinical criteria. They used the Research Diagnostic Criteria (RDC) (Spitzer, Endicott, & Robins, 1978) to assess depression in 165 women caring for frail family members with similar levels of disability. The RDC were designed to identify and classify individuals with psychiatric disorders. Based on the diagnostic categories of major and minor depressive disorder, the RDC may aid in the diagnosis of clinical depression. Rivera et al. (1991) reported 44.8% ($\underline{n} = 39$) of caregiver daughters was depressed compared to 52.8% ($\underline{n} = 46$) wives. The authors found caregivers with more frequent general social contact were not depressed because they adapted more readily to stressors. Both depressed and nondepressed caregivers had equal access to social support, but nondepressed caregivers used resources more. Whereas, depressed caregivers reported more negative interactions with others. The study by Rivera et al. (1991) was limited to a sample of Caucasians with relatively high income and education. Clinical depression in caregiver daughters seemed to be dependent on social support.

Spouse Caregivers

Depressive Symptomatology. In comparison to caregiver daughters, studies on spousal caregivers determined depression according to depressive symptomatology. Boss et al. (1990) studied dementia patients and their caregivers ($N = 70$) using a semi-structured 2 hour interview and the Zung Depression Scale (Zung, 1965) to measure depressive symptoms in the caregivers. The Zung Depression Scale determines depression according to the frequency of 20 depressive symptoms in the past week. Their study showed a sense of control and mastery in managing stressful caregiving situations was associated with less depression. Whereas, patient behavioral problems caused caregiver uncertainty about their relationship with the patient and subsequent depression. Boss et al. (1990) found that ambiguity and preoccupation created more burden than the severity of the patient's illness. Caregiver perception of an event determined whether caregiving had a negative impact. The number of symptoms and severity of depression were not reported.

Robinson (1989) interviewed spousal caregivers ($N = 78$) using the CES-D. Robinson found caregiver health was the best predictor of depression with caregiver attitude being the second most reliable predictor. Her study showed that caregiver spouses in better health and with positive attitudes had less depression. Robinson (1989) found that caregiver spouses generally believe caregiving is their own responsibility and that they should be able to take care of their spouses independently. She also found that an unmet desire for support results in more stress and depression.

Stommel et al. (1990) used the CES-D to measure caregiver depression in 307 patient-caregiver dyads. Stommel et al. (1990) found that depression may be the cumulative outcome of caregiving processes. Stommel et al. (1990) found that their sample was depressed, but felt that depression may have existed prior to caregiving.

Given et al. (1993) studied 196 caregivers of cancer patients, of whom 80% were spouses, using the CES-D. It was found that patient dependencies in activities of daily living (ADL) were directly related to depressive symptomatology in the caregiver. Moreover, patient dependencies in ADLs, symptom distress, and immobility were directly related to impact of caring on caregiver schedule. Given et al. (1993) found that the level of caregiver optimism was an important predictor of variations in caregiver depression and perceived impact of caregiving on health. Caregiver optimism predicted impact of caregiving on daily schedule. Once again, a relationship between depression and impact on schedule was cited in the literature.

Macera, Eaker, Jannarone, Davis, and Stoskopf (1993) interviewed 82 family caregivers with 53% being spouses. Using the CES-D, Macera et al. (1993) found that depressive symptomatology was inversely related to having enough time to sleep, read, etc., being efficient, having fun and laughing, and having meaningful lives. The most important factor was getting enough rest or sleep. In summary, spouses experienced depressive symptoms when they were unable to master stressful caregiving situations, had poor

health and negative attitudes, had little personal time, and their partners had many dependencies. The severity and extent of depression were not reported.

Clinical Criteria. Other studies used clinical criteria to define depression in spousal caregivers. Drinka, Smith, and Drinka (1987) found that 83% of 117 spousal caregivers of Alzheimer patients met DSM-III-R criteria for major depression. Furthermore, Coppel et al. (1985) reported that 41% of spousal caregivers ($N = 68$) met Research Diagnostic Criteria (Spitzer et al., 1978) for depression. It was also found in a sample of Alzheimer patients that 46% of related caregivers seeking help met criteria for depression according to the BDI (Gallagher, Wrabetz, Lovett, Del Maestro, & Rose, 1989).

Summary

In the current literature, the finding of depression varies widely according to the conceptual definition of depression, including clinical depression, depressed mood, and depressive symptomatology. Much of the existing literature on caregiver depression, with the exception of Brody et al. (1992) and Young and Kahana (1989), fails to differentiate daughters from other caregivers.

Spouses are generally older and in poorer health at the inception of caregiving which may increase their risk of depression. However, a caregiver daughter may have more outside obligations and roles to fulfill than a caregiver spouse because of the differences in age and developmental life stages at the time of caregiving. Thus, caregiver daughters may be at greater risk for depression than spouses. Caregiver daughters are also more likely to be employed

than caregiver spouses, since spouses are usually older.

Caregiver Daughters and Employment

The American Association of Retired Persons (1989) conducted telephone interviews ($N = 754$) nationally and found almost one-third of full and part time workers spend 21 or more hours per week providing care. Therefore, caregivers spent a significant amount of time providing care while employed. Hence, there were two themes in the current literature: employment as a buffer and as a precursor to role overload.

Employment as a Buffer

One perspective suggests that employment may act as a buffer on caregivers (Baruch & Barnett, 1986; Barusch & Spaid, 1989; Froberg, Gjerdingen, & Preston, 1986; Pohl, Given, Collins, & Given, 1991; Scharlach, 1989; Stoller & Pugliesi, 1989; Tiedje, Wortman, Downey, Emmons, Biernat, & Lang, 1990; Waldron & Jacobs, 1989). As a buffer, employment provides the caregiver with outside social contacts and the opportunity to be productive. Studies including caregiver daughters have demonstrated that roles outside of the family are associated with improved caregiver well-being by providing the opportunity for social interaction and respite from the pressures of caregiving (Baruch & Barnett, 1986; Pohl et al., 1991; Scharlach, 1989; Stoller & Pugliesi, 1989). Supporting research has determined that employment also provides caregiver daughters with a sense of competence at work which enhances self-esteem (Baruch & Barnett, 1986; Froberg et al., 1986; Stoller & Pugliesi, 1989; Tiedje et al., 1990; Waldron & Jacobs, 1989).

Pohl et al. (1991) studied a sample of caregiver daughters ($N = 159$) who were interviewed using the Social Provisions Scale (Russel, Altmaier, and VanVelzen, 1984) and the Caregiver Reaction Assessment Scale (Given et al., 1992; Stommel, Given, & Given, 1990). Pohl et al. (1990) found that employment buffered the effects of more difficult roles and possibly enhanced well-being during the transition to caregiving by providing social support and increasing self-esteem. This is of principal importance when considering that women may choose to terminate employment, and lose the associated benefits, in order to perform caregiving duties. Furthermore, women who forego employment and personally sacrifice to provide care to elderly mothers may become isolated, depressed, and resentful (Brody, 1981). Despite their findings, Pohl et al. (1991) did not explore the prevalence of depression in their sample of caregivers.

Scharlach (1989) used questionnaires regarding impact of caregiving on work to study employed caregivers ($N = 332$). Twenty-seven percent of his sample reported that their overall caregiving situation was less stressful as a result of their working. Barusch and Spaid (1989) interviewed 131 caregivers using a coping inventory and found employment offered the most effective protection against engulfment by the caregiving role.

Role Overload

Several studies have reported negative effects of caregiving on employment, such as role overload (Barr et al., 1992; Brody, 1981; Brody, Kleban, Johnson, Hoffman, & Schoonover, 1987; Brody et al.,

1992; Gibeau & Anastas, 1989; Green, 1991; Orodener, 1990; Scharlach & Boyd, 1989). Employed daughters who become caregivers of elderly parents lose leisure and personal time (Brody et al., 1987). Moreover, many caregivers take leaves of absence from work, leave work early, or are so tired on the job that they cannot work effectively (Scharlach & Boyd, 1989; Stone & Short, 1990). Stone and Short (1990) found that females were about 12% more likely to take time off without pay. They also reported 29% of their sample of caregivers ($N = 1003$) either quit their jobs or had to accommodate their work schedules to assume care responsibilities and considered employment "just a job" instead of a career. No personal rewards were associated with their work. Other studies found that daughters experienced more job conflicts related to caregiving than sons (Stoller, 1983). Stoller (1983) found that unlike daughters, sons reduced hours of caregiving when employed.

Barnes, Given, and Given (1995) looked at a sample of caregiver daughters ($N = 118$) from a longitudinal study which used interviews and questionnaires to compare employed and unemployed caregiver daughters. They found caregiver daughters who terminated employment reported a greater impact on schedule due to caregiving activities than those who were unemployed. Furthermore, Brody (1981) found that women who forego employment and sacrifice personally to provide care to elderly parents often feel resentful and become depressed and isolated.

Gibeau and Anastas (1989) found that most caregiver daughters with full-time employment experienced role conflict

between work and caregiving responsibilities. Therefore, some caregiver daughters choose to continue employment and purchase care while others limit or terminate work in order to provide more care. Orodnenker (1990) interviewed a sample of female caregivers ($N = 1168$) and found that employed caregiver daughters experienced significantly more stress when they were unable to balance the demands of two roles and were forced to adjust work schedules in order to perform caregiving duties. Orodnenker's study is limited by the cross-sectional data which may cause attitudes to be misinterpreted as ongoing when they may actually be temporary.

Another study showed 22% of caregiver daughters terminated employment due to family care obligations (Enright, 1991). Boyd and Treck (1989) found that women who quit working were placed in jeopardy by losing salary, benefits, social networks, and a sense of job satisfaction that employment offered. Others found that unemployed caregivers were economically vulnerable due to inadequate social security and pension benefits (Atchley, 1990; Doty, 1986; Holden, 1989; Stone, 1989).

Summary

Eight of the studies found that employment was a buffer, while eight found employment contributed to role overload. Positive social interaction and personal rewards seemed to suggest employment would be a buffer rather than cause overload in the studies cited. As a buffer, employment offers the opportunity for social interaction and respite from caregiving. It also promotes competence, enhances self-esteem, and provides financial security. On the other hand,

individuals may experience role overload when combining employment with caregiving. For example, employment may exacerbate job-family conflict and distress in the context of caregiving. Frequently, women occupy more roles than men since they tend to be the primary caregivers of both children and elderly parents.

Little attention has been given to the effect of role accumulation on daughters in the current caregiver literature. While the literature concerning employment as a buffer is compelling, the data regarding employment leading to role overload is more substantive. Therefore, this study focused on employment and role overload data to support the hypotheses.

Theoretical Framework

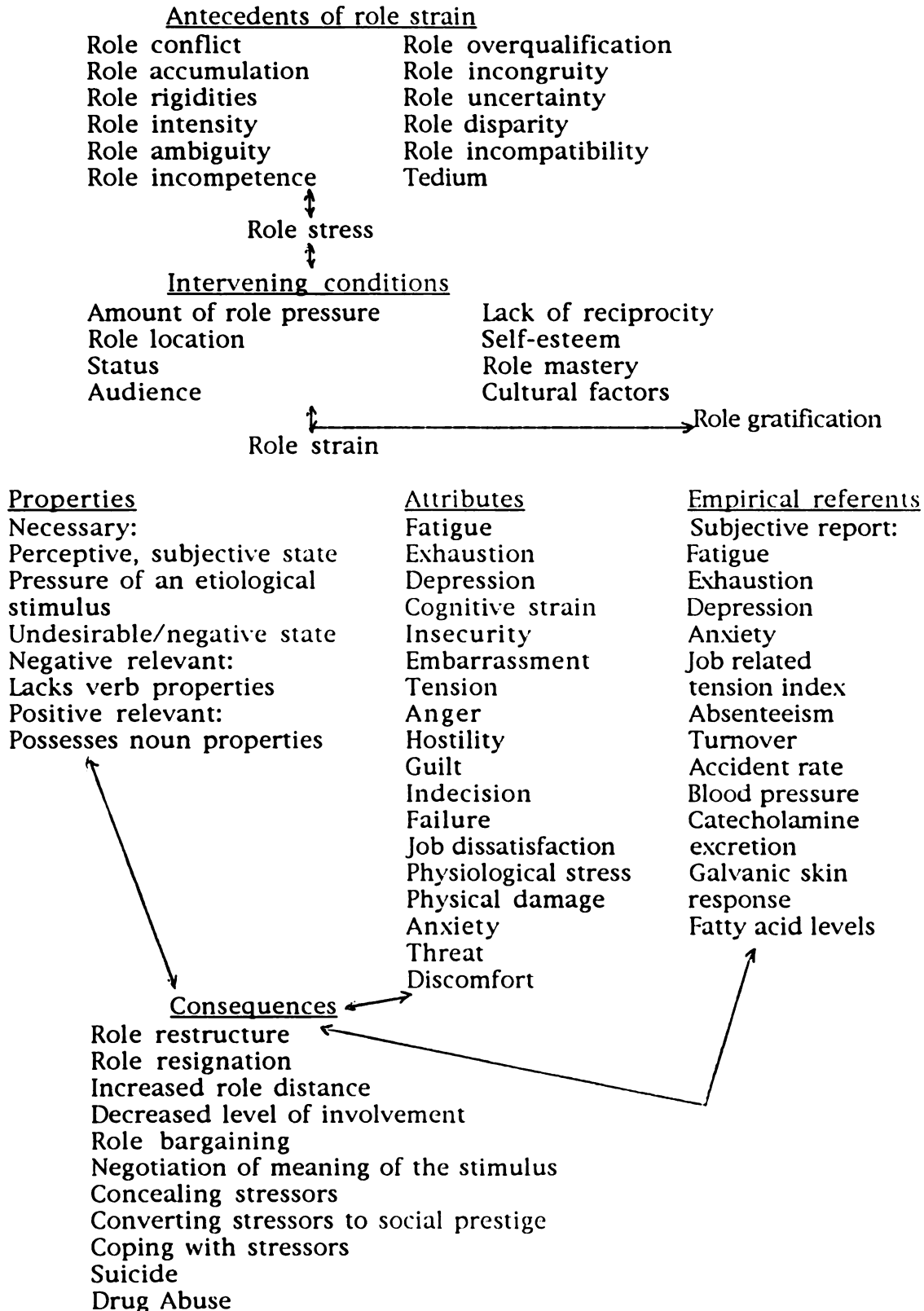
Role theory is the conceptual framework which guided this study. The term role is defined as expected and actual behaviors associated with a position (Hardy & Conway, 1988). As a result of social expectations, individuals may experience role stress and strain. Role stress occurs when persons are subject to conflicting, very difficult, or impossible demands. For example, caregiver daughters who are employed must balance a career with caregiving and domestic duties. Robinson (1983) has identified several caregiving stressors: inconvenience, confinement, family adjustment, changes in personal plans, competing demands on time, emotional adjustments, work adjustments, and feelings of being completely overwhelmed. Thus, role stress may lead to a state of distress, or role strain. Role strain is defined as hardship, challenge, and conflict experienced by

persons as they engage in their normal social roles (Kaplan, 1983). Role strain is more likely to occur when an individual occupies multiple roles.

According to Ward (1986), there are several antecedents to role strain; however, there are two that are particularly relevant to employed caregiver daughters. First, role accumulation creates role strain when an individual participates in many different roles with many different obligations (Ward, 1986). Second, role conflict may occur as a result of multiple roles, especially when a person occupies two positions with completely separate sets of role expectations (Hardy & Conway, 1988). This type of conflict may be experienced by caregiver daughters who are pressured to meet the competing demands of both a mother who requires care and an employer.

In Figure 1, Ward (1986) lists the antecedents of role strain as they lead to role stress. The intervening conditions either lead to role gratification or to role strain. This model includes the properties, attributes, and empirical referents of role strain. Basically, the properties describe the degree of role strain while the attributes of role strain measure the difficulty experienced with multiple roles, and the empirical referents (observable properties) are manifestations of role strain or indicators of role overload. Finally, the consequences of role strain are identified.

An adaptation of Ward's model was the theoretical framework for this study. Figure 2 identifies the multiple roles of women who are caregiver daughters with varying employment status. In this study, impact on schedule and depression are the attributes of



Adapted from Ward, C. R. (1986). The meaning of role strain. Advances in Nursing Science, 8(2), 43.

Figure 1. Potential deleterious effects of role strain.

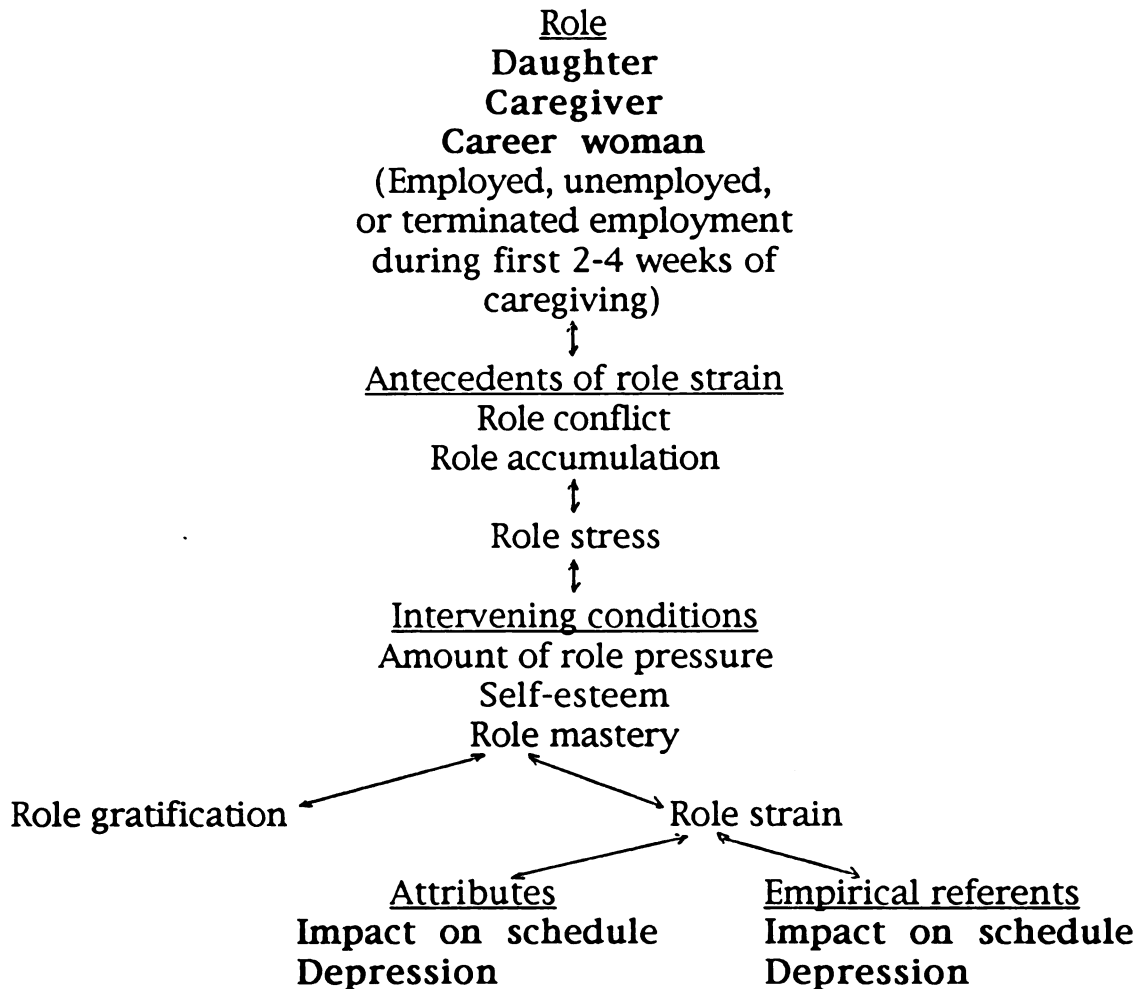


Figure 2. Women with multiple roles may experience impact on schedule and depression.

role strain. This framework emphasizes role conflict and role accumulation as antecedents to caregiver role strain in the daughter, relieved or exacerbated by the intervening conditions (i.e., employment) associated with role pressure, self-esteem, and role as caregiver and career woman. The subsequent role stress may be related to the mastery of the caregiver daughter role. This model does not demonstrate causality, but rather depicts a relationship between role stress/strain, impact on schedule, and depression in caregiver daughters.

Lebowitz (1977) found that most employed women, whatever their occupation, continue to struggle with conflicts between "family obligations, personal desires and ambitions, and the demands and limitations of their work" (p. i). Therefore, the demands of multiple roles may create role strain and present as a negative impact on schedule or depression. Multiple roles including wife, mother, and career woman will likely consume more energy and time than may be available (Hardy & Conway, 1988; Vaughn & Wittig, 1980). By adding parent caregiver to her repertoire of roles, a daughter may find herself compromised and depressed. The prevalence of depression and impact on schedule in the caregiver daughter may vary according to employment status and the associated strain. Caregiver daughters with a balance of roles and subsequent role gratification may not experience role overload and strain.

Some studies have shown that multiple roles are not necessarily detrimental, but may actually reap cumulative rewards (Meneghan, 1989; Moen, Dempster-McClain, & William's, 1991;

Waldron & Jacobs, 1989). Enhanced role performance and role gratification may be welcome recompense provided by a combination of roles. Hardy and Conway (1988) state that role accumulation is associated with a positive sense of self for many women who maintain traditional roles with contemporary roles. Moreover, modern career women may choose alternative methods of care provision (i.e., home care or a retirement home) in order to meet their mother's needs, as well as satisfying their own lifestyle.

The focus of this study was the mother- daughter relationship because it is a unique bond. The role of daughter incorporates a certain closeness toward a mother. For example, daughters outnumber sons as primary caregivers in a ratio of about 4:1 (Brody, Litvin, Hoffman, & Kleban, 1992) and wives are more likely than husbands to be the primary caregiver of their spouses. Women have acquired the nurturing role regardless of their relationship to a significant other. Therefore, this study explored the relationship of caregiver daughters and their mothers.

Methods

This correlational study was a secondary analysis of data from research supported by grant #RO1 AG06584, "Caregivers Response to Managing Elderly Patients at Home", funded by HHS National Institute on Aging. The Principal Investigator was Charles W. Given, Ph.D. from the Department of Family Practice in the College of Human Medicine at Michigan State University, East Lansing, MI. A descriptive survey was used in the original study and data for the current study was analyzed using the SPSS/PC software package.

Sample

First-time family caregivers ($N = 628$) of patients with a broad range of diagnoses were recruited upon the patient's discharge from 27 hospitals in Michigan and surveyed 2 through 4 weeks ($M = 21$ days) after beginning caregiving responsibilities (Given & Given, 1989). Data for the original study were obtained through telephone interviews and self-report questionnaires. From the original sample, a total of 190 daughters were identified. For the current study, a sample of daughters ($N = 120$) was selected based on the following criteria: (a) the daughter was a first time primary caregiver for her mother, (b) the mother was 55 or older, (c) the daughter was assisting with at least one activity of daily living (ADL) or 2 instrumental ADLs or one health care activity (i.e., wound care, catheter care, intravenous feedings, nasogastric feedings, etc.), (d) the mother resided in a home in the community (either her own or a family member's or friend's), (e) the daughter was not a paid caregiver, (f) the daughter was not caring for more than one disabled family member when she entered the study, and (g) the daughter spoke and read English.

Operational definitions

Employment status

Two to 4 weeks after the start of caregiving, daughters were asked to report their previous and current employment status. Current employment status was divided into three categories. The category of "employed" caregiver daughters ($n = 63$) was created by combining full-time ($n = 45$) and part-time ($n = 18$) workers. The

"terminated employment" category ($n = 5$) was made up of caregiver daughters who took a leave of absence ($n = 2$) or quit work to care ($n = 3$) during the first 2 through 4 weeks of caregiving. Lastly, daughters who were retired ($n = 17$) and unemployed or laid off ($n = 35$) composed the third category of those who were "not employed" ($n = 52$). The three employment groups were the independent variables in this study.

Impact on schedule

One dependent variable measured was impact on schedule in the caregiver daughters. Impact on schedule was operationally defined as the score on the Impact on Schedule subscale of the Caregiver Reaction Assessment (Given et al., 1992). A high score reflected a high level of impact on schedule, whereas a low score meant little or no impact on schedule. Scores ranged from 1.0 to 5.0.

Depression

Depression was the second dependent variable operationally defined as the score caregiver daughters obtained on the CES-D (Radloff, 1977). The four subscales within the CES-D were depressed affect (feeling blue, depressed, lonely, tearful, sad), happy subscale (feeling as good as other people, hopeful, happy, enjoying life), somatic/psychomotor retarded activity (feeling bothered, unable to concentrate, unmotivated, lacking appetite, sleeping restlessly) and interpersonal subscale (feeling people are unfriendly, people dislike me). Scores were summed across 20 items, with a potential range of 0-60. Scores 0-16 indicated no depressive symptomatology, whereas scores 16 or greater indicate depressive symptomatology.

Instruments

The tool used to measure impact on schedule is from the Caregiver Reaction Assessment (CRA) (Given, Given, Stommel, Collins, King, & Franklin, 1992). The Impact on Schedule subscale contained five items with each scored using a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree) (see Appendix A). Data on the psychometric properties and construct validity of the instrument are published and show reliability (Given et al., 1992). Given et al. (1992) reported the Cronbach's alpha coefficient was .82 for the Impact on Schedule subscale. The Impact on Schedule subscale has been confirmed as an independent factor in the CRA across caregiver samples (Given et al., 1992). Pohl et al. (1991) reported Cronbach's alpha coefficient was .81 for her sample of caregiver daughters.

Depression was measured using the Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977). This instrument consisted of 20 items measured individually on a Likert scale ranging from 0 (rarely or none of the time) to 3 (most or all of the time) to identify psychological distress by the presence of depressive symptoms in the past month (see Appendix B). Overall reliability and validity was consistent for this instrument across samples (Stommel et al., 1990; Stommel et al., 1993). Stommel et al. (1990) conducted a study of family caregivers ($N = 307$) of elderly, dependent relatives and reported Cronbach's alpha was .89. In the second study, Stommel et al. (1993) studied caregivers of chronically ill elderly ($N = 504$) and reported Cronbach's alpha coefficient was .89.

Hypotheses

Two hypotheses governed this study: (a) There is a greater impact on schedule for employed caregiver daughters than for unemployed caregiver daughters and for those who have terminated employment during the first 2 through 4 weeks of care, and (b) There is a relationship between impact on schedule and level of depression in caregiver daughters by category of employment.

Protection of Human Rights

Consent forms were obtained from caregivers and care recipients during the original study. Human subjects remained anonymous. The original study received approval from the University Committee on Research Involving Human Subjects (UCRIHS). Approval for the original and current studies was obtained from UCRIHS (see Appendices C and D).

Assumptions and Limitations

Assumptions of this study included: (a) The caregiver daughters completed the instruments accurately, and (b) The data were coded accurately. The limitations of this study include: (a) the study used a convenience sample of Caucasian, middle class women; therefore, results may not generalize to the general population, (b) the current study is confined to tools/data of the original study reflecting the limitations of the original study, and (c) concepts other than impact on schedule and depression were not included; therefore, other factors that may affect caregiver daughters were not studied.

Data analysis

Data for the three employment categories were summarized using descriptive statistics appropriate for age, income, living arrangements, education level, and marital status. A one-way analysis of variance (ANOVA) was used to test the first hypothesis: There impact on schedule in caregiver daughters who are unemployed, employed, or have terminated employment during the early part of caregiving. The ANOVA compared scores on the Impact on Schedule subscale of the CRA in the three different employment groups. An ANOVA was selected to test the impact on schedule in the three employment groups by comparing the variability between and within groups.

Pearson Product Moment Correlations were used to test the second hypothesis: There is a relationship between impact on schedule and level of depression in caregiver daughters by category of employment. Correlation coefficients were performed to assess the relationship between impact on schedule and depression. Data were correlated for each employment group.

Results

Selected sociodemographic characteristics of the caregiver daughters by employment status are described in Table 1. Of the total sample, 53% ($n = 63$) was employed either full or part time, 4% (Meneghan, 1989; Moen, Dempster-McClain, & William's, 1991; Waldron & Jacobs, 1989). Enhanced role performance and role ($n = 5$) terminated employment ($n = 3$) or took a leave of absence ($n = 2$) during the first 2 through 4 weeks of caregiving, and 43%

($n = 52$) were not employed as a result of choice, retirement, or layoff. Living arrangements of the caregiver daughters and their mothers were fairly evenly distributed between separate ($n = 54$) and shared ($n = 66$) households. The majority of mothers were widowed ($n = 94$) and ranged in age from 56 to 96 ($M = 76.83$, $SD = 8.2$). Ten percent of mothers were married, but their daughters were still primary caregivers. Ages were similar among mothers of caregiver daughters who were employed ($M = 75.9$, $SD = 8.0$), unemployed ($M = 78.2$, $SD = 8.5$), and those who terminated employment ($M = 74.0$, $SD = 5.7$). Mothers had an annual household income ranging from \$1000 to \$62,500 with an average income of \$26,700 ($SD = \$20,317$) per year. In the 55% of caregiver daughters who lived with their mothers, the daughters' annual salaries were included in their mothers' total annual household incomes.

Most of the caregiver daughters were married ($n = 78$) and ranged in age from 22 to 72 years of age ($M = 48.66$, $SD = 9.92$). The unemployed caregiver daughters were the oldest of the three groups. The unemployed group also accounted for caregiver daughters who were retired ($n = 17$) and may explain why this category was older. Overall, 85% of the caregiver daughters were Caucasian ($n = 102$) and received a current annual household income ranging from \$3000 to \$62,500 ($M = 37,680$, $SD = 18,044$). Employed caregiver daughters earned an annual household income with a mean of approximately \$10,000 more per year than the unemployed and terminated work since 68.3% of the employed daughters were married. Income of the terminated employment group indicated that the reported income

Table 1

Comparison of Caregiver Daughters by Employment Status and
Selected Characteristics (N = 120)

<u>Characteristic</u>	<u>Employment status</u>					
	<u>Employed</u>		<u>Unemployed</u>		<u>Terminated</u>	
	<u>(n= 63)</u>		<u>(n= 52)</u>		<u>(n= 5)</u>	
	<u>number</u>	<u>(%)</u>	<u>number</u>	<u>(%)</u>	<u>number</u>	<u>(%)</u>
Education						
Less than high school	5	(7.9)	17	(32.7)	--	
High school graduate	20	(31.7)	15	(28.8)	2	(40.0)
Some college	26	(41.3)	15	(28.8)	3	(60.0)
College graduate	5	(19.0)	5	(9.6)	--	
Marital status						
Married	43	(68.3)	33	(63.5)	2	(40.0)
Not married	20	(31.7)	19	(36.5)	3	(60.0)
Race						
White	56	(88.9)	42	(80.8)	4	(80.0)
African American	7	(11.1)	10	(19.2)	1	(20.0)
Living arrangements						
With mother	33	(52.4)	30	(57.7)	3	(60.0)
Separate	30	(47.6)	22	(42.3)	2	(40.0)
	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>	<u>M</u>	<u>SD</u>
Age (years)	46.7	8.5	51.3	11.1	46.4	8.4
Income (dollars)	42,681	16,323	31,418	18,682	32,500	16,015

was received before termination of employment or that money may have come from sources other than employment, such as disability or husband's salary.

It was hypothesized that there would be a greater impact on schedule for employed daughters than for unemployed daughters employment categories. Results of the ANOVA indicated no statistically significant differences among the groups for impact on schedule [$F(2,117) = 1.74$, NS]. The terminated employment group received similar scores on the Impact on Schedule subscale with a range of 2.6 to 5.0 ($M = 4.08$, $SD = .98$) as caregiver daughters who were employed with a range of 1.4 to 5.0 ($M = 3.54$, $SD = 1.04$) and unemployed with a range of 1.6 to 5.0 ($M = 3.84$, $SD = .89$). The means indicated that all three groups of caregiver daughters experienced similar impact on schedule during the first 2 through 4 weeks of caregiving.

It was also hypothesized that a relationship between impact on schedule and level of depression existed by category of employment. Overall, the caregiver daughters reported depressive symptomatology. The depression scores on the CES-D were very similar between caregiver daughters who were employed with scores ranging from 0.0 to 48.0 ($M = 16.14$, $SD = 10.13$) and unemployed with scores ranging from 2.0 to 42.0 ($M = 16.76$, $SD = 9.16$). Daughters who terminated employment had the highest mean scores on the CES-D ($M = 19.4$, $SD = 9.23$) with scores ranging from 5.0 to 30.0. As shown in Table 2, a moderately strong and significant relationship between impact on schedule and depression was found

in the employed caregiver daughters group and the not employed group indicating partial support for the second hypothesis.

Table 2

The Correlation of Impact on Schedule and Depression in Caregiver Daughters by Category of Employment

Employed (n = 63)	Unemployed (n= 52)	Terminated employment (n = 5)
.58*	.43**	.56

* $p < .000$. ** $p < .002$.

However, no significant relationship was found between impact on schedule and depression in the caregiver daughters who terminated employment.

Discussion

Interpretation of Findings

Demographic variables

Education levels were of statistical significance ($\chi^2 = .02$). However, no statistical differences were found between the 3 groups of caregiver daughters. According to reports of income, it is not determined whether caregiver daughters received money from disability, retirement, or shared income with their husbands. Furthermore, these incomes reflected the last year prior to

caregiving and not current household income.

The unemployed group included retired caregiver daughters which may have made this group older and more vulnerable to factors associated with aging. Unemployed daughters may have experienced more stress related to aging than to employment or caregiving. This sample did not reflect the findings of previous research that have shown daughters who terminate employment to care for elderly parents tend to be older, have lower education, and lower incomes than employed caregivers (Barnes et al., 1993; Brody, Kleban, Hoffman, & Schoonover, 1987; Pohl et al., 1991).

Dependent variables

In this study, the findings of depression on caregiver daughters who terminated employment did not support findings in the literature, nor did the findings of impact on schedule support findings in the literature. Due to the small sample size ($n = 5$) of the terminated employment group, the results of this study may not apply to the general population. It is difficult to assess whether caregiving contributes to the decision to terminate employment with only 4% of the sample in this employment category, particularly when 2 of 5 caregiver daughters in the terminated employment group were on leave of absence. Although all of the caregivers had depressive symptomatology in this study, it is not known whether impact on schedule or depression vary according to employment status after the 2 through 4 week transition to caregiving. One month may not be enough time to determine whether new caregivers are depressed or experience impact on schedule,

especially if it is not known whether the caregivers are depressed before caregiving. Caregiver daughters may experience the greatest impact on schedule and depression during the transition to care or they may notice a greater impact over time.

Result of Hypothesis Testing

In this section, each hypothesis will be considered separately with a discussion of the interpretation of data.

Hypothesis #1

There is a greater impact on schedule for employed daughters than for unemployed daughters and for those who have terminated employment during the first 2 through 4 weeks of care. This hypothesis was not supported. Mean scores on the Impact on Schedule subscale had little variation between employment groups. Scores of the overall sample indicated moderate impact on schedule, which means that all groups experienced similar impact on schedule. Impact on schedule may have been similar across employment categories because all caregiver daughters may have sacrificed personal time to provide care. Employed caregiver daughters had slightly lower mean scores on the Impact on Schedule subscale than the unemployed and terminated employment groups, while the terminated employment group had the highest mean scores. Despite the variation in scores among employment groups, impact on schedule had the same magnitude and no statistically significant differences were found among groups. Barnes et al. (1995) reported that caregiver daughters who terminated employment reported more impact on schedule than their

unemployed counterpart. Barnes et al. finding was not supported in this study, but her sample was not an inception cohort. In this study, the small size of the terminated employment group was too small to draw conclusions since only a few caregiver daughters quit work during the early transition period. The small size of the terminated employment group may mean that 2 to 4 weeks after starting care is too early in caregiving for the caregiver to quit work.

Other research reports that employed caregiver daughters make substantial adjustments during the first 3 months of caregiving compared to unemployed and terminated employment groups (Franklin et al., 1994). Franklin et al. (1994) looked at daughters during the first 2 through 4 weeks of caregiving and did not find a significant difference in impact on schedule among employment categories. Perhaps, in the second or third months of caring a significant difference occurs among employment categories. After 2 or 3 months, the caregiver daughter may feel either more comfortable with the caregiver role or she might experience increased frustration. A daughter's comfort level with caregiving may depend on her mother's degree of illness and whether her mother's health improves or declines over time. Long term impact on schedule may cause the caregiver daughter to terminate employment after 3 months. It is likely that the caregiver daughter will have less available help as friends and family members who helped initially return to their usual schedules. Financial resources may dwindle as caregiving expenses continue and leaves of absence run out after 2 to 3 months. Most jobs will not allow much time off

work, and even fewer positions provide time off with salary.

Therefore, a caregiver daughter might have to choose between losing her job, taking a family medical leave without pay, or quitting work to care.

Hypothesis #2

There is a relationship between impact on schedule and level of depression in caregiver daughters by level of employment. This hypothesis was accepted in part because there was a statistically significant positive correlation between impact on schedule and depression in employed and unemployed caregiver daughters. There was no statistical significance in the relationship between impact on schedule and depression in the terminated employment group, which may be due to the small number of caregiver daughters who terminated employment.

While all 3 employment categories report depressive symptoms, the prevalence of depression was not reported in the current study. Despite statistical insignificance, it was found that mean scores on the CES-D indicated depressive symptoms in the sample as a whole ($M = 16.55$, $SD = 9.63$), since the mean score is greater than 16. The terminated employment group received the highest mean scores on the CES-D compared to the employed and unemployed caregiver daughters. Daughters who quit work to care may have had higher depression scores because their mothers were sicker and required more skilled care or because they were already depressed.

Few studies were found that look at the relationship between

impact on schedule and depression in caregivers with different employment status. However, the literature does show that a lack of rest time was correlated with depressive symptoms in the family caregiver (Macera et al., 1993). Differences among employment groups may be related to differences in patient diagnoses, amount of care needed, and type of care required.

Implications for Role Theory

In partially supporting the hypothesis based on the relationship between impact on schedule and depression, this study lends partial support for role theory. Nevertheless, it is not known what implications of other possible roles exist for the daughters in this study, beside caregiver and career woman. Caregiver daughters who are not employed may have other roles that employed caregiver daughters do not have (i.e., mother, wife) and vice versa. Also, the magnitude of caregiving is not known because the mother's degree of illness is not clear.

Employed caregiver daughters may experience impact on schedule and depression due to role stress and strain from social expectations that they care for their elderly mothers, as well as earn an income. According to role theory, many different roles with different obligations may lead to role strain. Multiple roles may account for the impact on schedule and depression that employed caregiver daughters experienced in this study. However, role theory does not explain why caregiver daughters who are unemployed and those who terminated employment also experience the same level of impact on schedule. If the number of roles occupied, as well as

the intensity of the roles and tasks of the caregiver daughters was known, this study may have reaped more conclusive data.

Role theory is a model that can be used when looking at caregiver daughters. All of the caregiver daughters in this study experience impact on schedule and depression which may be attributed to multiple roles and the associated role strain. Different types of employment produce various levels of stress and strain. Therefore, the type of job may also influence whether a caregiver daughter experiences impact on schedule and depression, but this is not assessed in this study.

Caregiver daughters who terminated employment had the highest mean scores on the Impact on Schedule subscale and CES-D. According to role theory, they may base the decision to terminate work on excessive role strain and conflict from the completely separate role expectations of caregiving and employment. This study did not explore the reasons for termination of employment. Role theory may be used for future research because it raises further questions for study regarding the implications of role gratification and strain, number of roles occupied, and reasons for terminating employment.

Implications for the Advanced Practice Nurse (APN)

The findings of a significant positive correlation between impact on schedule and depression in employed and unemployed caregiver daughters indicate that assistance and support is required during the transition to caregiving. Although there is no statistically significant relationship between impact on schedule and depression

in caregiver daughters who quit work, it is evident by their scores that they still experience moderate impact even though it was early in caregiving. Since this study shows that caregiver daughters are vulnerable to impact on schedule and depression, APNs are in the ideal position to prepare and educate caregiver daughters regarding the caregiver role. It is important to address caregiver needs early in order to possibly prevent negative impact on schedule and depressive symptomatology from occurring as well as worsening. Caregiver daughters should be involved in their parent's plan of care from the beginning. They should be supported not to neglect their own health and reminded to set aside time for personal needs and respite. APNs should counsel caregivers regarding the typical strains to expect during the transition to care. Although this study shows that all employment groups experience similar depression and impact on schedule, APNs should assess each caregiver daughter and provide an individualized plan of care.

In primary care, APNs are prepared to assess and evaluate caregiver daughters for depressive symptoms and explore psychosocial issues and family dynamics that may be contributing to depression. The APN can assess caregiver needs in numerous ways. For example, the APN can ask the patient during an appointment or a phone call how the caregiver is doing. The caregiver can be encouraged to attend appointments with her parent to primary care and be involved in the ongoing plan of care. The APN can explore living arrangements, hours of employment, number and intensity of roles, and use of formal services during assessment of the caregiver

daughter. After care has been initiated, the APN can monitor the caregiver situation by making periodic phone calls to assess continuing care needs of both the patient and caregiver. The APN in primary care can assist caregiver daughters in locating the necessary resources and support during the transition to caregiving. APNs are ready to implement appropriate interventions, such as counseling, referrals to social work or other disciplines, and/or chemical intervention if severe depression is indicated.

Early respite care and counseling should be instituted before impact on schedule and depression begin. This is of foremost importance when many caregivers fail to seek respite care or assistance until they are under immense stress (Lawton, Brody & Saperstein, 1989). Nursing home placement may not reduce impact on schedule and depression since it is costly and caregivers would still need to fit nursing home visits into their schedules. Therefore, the responsibility of caring for elderly parents is becoming more prominent as patients spend less time in hospitals and nursing homes and more time at home. APNs can ease the transition to caregiving by anticipating both the patient's and caregiver's needs, and by preventing the occurrence of burden. Helpful interventions may include referrals to visiting nurse services, Hospice, support groups, and employment assistance programs. APNs can also increase caregiver access to care by providing support group meetings at job sites before or after working hours.

Nurses in advanced practice are the ideal educators, counselors, and researchers of caregiver daughters. As educators, APNs in

primary care can inform caregivers of the patient's course of illness and disease management strategies. APNs can also counsel caregivers in order to manage feelings of depression, guilt, resentment, and anger. Stommel et al. (1990) found that caregivers may be depressed before they become caregivers of elderly parents. The APN must monitor for signs and symptoms of depression possibly related to family situations in order to provide early intervention to caregiver daughters. Finally, nurse researchers must continue to study caregiver daughters, since this group reports the most deleterious effects on their quality of life from caring for elderly dependents, compared to spouses and other relatives (Jones & Peters, 1992).

With limited options available for caregiving of the elderly, it would be ideal to maintain caregiving at home. By making caregiving more convenient for employed caregivers, the impact on schedule and level of depression may be reduced. APNs in primary care can assess financial capacity and refer caregivers and patients to available resources. The APN can also follow up by assessing continuing needs via a telephone call or office visit at regular intervals after initiating care.

Limitations of the Study

Limitations of the current study reflect the data that have not been examined. In this section, several variables are identified that would have added more meaning if included in this study, such as number of patient dependencies, living arrangement, hours of employment, number of roles, intensity and magnitude of role

responsibilities, and use of formal services.

A very important area to examine is the number and kinds of dependencies of the care recipient and how they might effect impact on schedule and depression. Dellasega (1990) found that the expectations and dependency of the care recipient caused more stress in unemployed caregivers who were generally older and less healthy than employed caregivers. Factors which may effect the amount of time spent caregiving must be considered, such as how sick the mother was and the type of care needed, whether skilled or custodial. The patients' diagnoses would have added insight regarding what kind and how much care was needed. It is necessary to examine the patient's number of dependencies and kinds of needs, because many dependencies may decrease the caregiver's personal time and increase the likelihood of becoming depressed by demanding more time for caregiving tasks. Patients with more dependencies probably require more hours of care. It is not known how many hours were spent providing care in each employment category.

Another variable that was not explored was whether employed and unemployed caregiver daughters who are living with their mothers experienced more impact on schedule and depression than those who lived separately. The sample in this study was almost equally divided in living arrangements, with half of the caregiver daughters living with their mothers and half living separately. Possibly, a difference in impact on schedule and/or depression exists between these groups. Caregiver daughters may experience more

depression and impact on schedule with greater amounts of time spent caregiving as a result of living together.

In addition, this study did not specify if caregiver daughters were employed full or part time and how much time was spent at work and providing care. Daughters who worked full time may have had help providing care from other family members or outside agencies. Whereas, caregiver daughters who spent equal amounts of time between providing care and working may have had less personal time and more impact on schedule and depression.

Another limitation of this study was not knowing how many roles the caregiver daughters had. It is assumed that the caregiver daughters had multiple roles; however, it is not known which employment group had more roles. Furthermore, it is not known if the caregiver with more roles experienced greater impact on schedule and depression.

This study is also limited by not examining whether formal services were used to assist with care or if other caregivers were involved. Caregiver daughters who had respite from caring may have reported less impact on schedule and depression. Caregiver daughters with more financial resources may have used formal caregiving services more often and experienced less impact on schedule and depression than those who had fewer financial resources. Furthermore, the use of informal social support, such as support groups, may have helped prevent or alleviate the deleterious effect of impact on schedule and depression and should be explored. These factors may explain more about why there is a relationship

between impact on schedule and depression in employed and unemployed caregiver daughters.

Recommendations for Future Research

Recommendations for further study include the limitations in the earlier section and the following:

A longitudinal study of caregiver daughters with differing employment status would be beneficial to see if impact on schedule and depression are higher during transition or if they increase over time. This study found that only a small percentage of caregiver daughters terminated employment during the early transition to care. It may be evident in a study of 6 months to a year that more caregiver daughters quit work to care than during the first 2-4 weeks of caregiving. In a longitudinal study, it would be easier to pinpoint when caregivers are most likely to terminate employment. Caregiver daughters who take a leave of absence should also be studied over time and compared to those who quit work.

It would also be beneficial to explore whether caregiver daughters were depressed before initiating care. Depression may exist before caregiving and depression scores obtained after care began would not reflect the caregiver daughter's response to caregiving if she was depressed before initiating care. On the other hand, it may be too early to see depression 2 to 4 weeks after initiating care. It would be helpful to assess depression in caregiver daughters prior to providing care and after a period of caregiving.

Another area that should be investigated is whether daughters terminated employment because of caregiving or for other reasons.

Furthermore, it should be explored if daughters were unemployed because they received financial support elsewhere (i.e., spouse, disability, retirement). The reasons for terminating employment and being unemployed are not known and may be relevant. Daughters who may have quit work for personal reasons, such as declining health rather than to provide care, may be depressed before caregiving.

Finally, financial resources and the use of formal caregiving services should be compared in the different employment groups. It would be beneficial to determine if financial security effects impact on schedule and depression. Also, the involvement of a social worker or home care provider may positively influence the daughter's perception of caring. Caregiver daughters with more resources may experience less impact on schedule and depression.

Summary

The findings of this study have expanded the literature base by comparing impact on schedule and depression in caregiver daughters who are employed, unemployed, and those who terminated employment during the first 2 through 4 weeks of caregiving. A major finding of this study indicates that caregiver daughters may not quit work during the early transition to caregiving. Therefore, continued research is necessary to determine when termination of employment actually occurs.

Appendices

Appendix A

Appendix A

Caregiver Reaction Assessment (CRA)

(1) Strongly disagree (2) Disagree (3) Do not disagree or agree

(4) Agree (5) Strongly agree

In my relationship with my mother:

- | | | | | | |
|---|---|---|---|---|---|
| 1. We're dependent on each other. | 1 | 2 | 3 | 4 | 5 |
| 2. We anticipate each other's moods. | 1 | 2 | 3 | 4 | 5 |
| 3. We nurture each other. | 1 | 2 | 3 | 4 | 5 |
| 4. I feel like I want to support her. | 1 | 2 | 3 | 4 | 5 |
| 5. She is closer to me than others. | 1 | 2 | 3 | 4 | 5 |
| 6. My mother is too involved in my life. | 1 | 2 | 3 | 4 | 5 |
| 7. We're emotionally dependent on each other. | 1 | 2 | 3 | 4 | 5 |
| 8. When we anticipate being apart our
relationship intensifies. | 1 | 2 | 3 | 4 | 5 |
| 9. We anticipate each other's needs. | 1 | 2 | 3 | 4 | 5 |
| 10. My mother and I often argue. | 1 | 2 | 3 | 4 | 5 |
| 11. Our best times are with each other. | 1 | 2 | 3 | 4 | 5 |
| 12. We want to spend time together. | 1 | 2 | 3 | 4 | 5 |
| 13. She shows that she loves me. | 1 | 2 | 3 | 4 | 5 |
| 14. We're honest with each other. | 1 | 2 | 3 | 4 | 5 |
| 15. We can accept each other's criticism
of our faults and mistakes. | 1 | 2 | 3 | 4 | 5 |
| 16. I often feel angry with my mother. | 1 | 2 | 3 | 4 | 5 |
| 17. We like each other. | 1 | 2 | 3 | 4 | 5 |
| 18. We respect each other. | 1 | 2 | 3 | 4 | 5 |

(1) Strongly disagree (2) Disagree (3) Do not disagree or agree
 (4) Agree (5) Strongly agree

In my relationship with my mother:

- | | | | | | |
|---|---|---|---|---|---|
| 19. Our lives are better because of each other. | 1 | 2 | 3 | 4 | 5 |
| 20. We enjoy the relationship. | 1 | 2 | 3 | 4 | 5 |
| 21. She cares about the way I feel. | 1 | 2 | 3 | 4 | 5 |
| 22. We feel like we're a unit. | 1 | 2 | 3 | 4 | 5 |
| 23. There's a great amount of unselfishness
in our relationship. | 1 | 2 | 3 | 4 | 5 |
| 24. I do not like my mother's behavior. | 1 | 2 | 3 | 4 | 5 |
| 25. She always thinks of my best interests. | 1 | 2 | 3 | 4 | 5 |
| 26. I'm lucky to have her in my life. | 1 | 2 | 3 | 4 | 5 |
| 27. She always makes me feel better. | 1 | 2 | 3 | 4 | 5 |
| 28. She is important to me. | 1 | 2 | 3 | 4 | 5 |
| 29. We love each other. | 1 | 2 | 3 | 4 | 5 |
| 30. I'm sure of this relationship. | 1 | 2 | 3 | 4 | 5 |
| 31. My mother sees things from my point
of view. | 1 | 2 | 3 | 4 | 5 |
| 32. I feel that my mother often tries to
change me. | 1 | 2 | 3 | 4 | 5 |
| 33. We are able to share private things
face to face. | 1 | 2 | 3 | 4 | 5 |
| 34. Our relationship is somewhat strained. | 1 | 2 | 3 | 4 | 5 |

Appendix B

Appendix B

Center for Epidemiologic Studies Depression Scale (CES - D)

(0) Rarely or none of the time (1) Some of the time

(2) Most of the time (3) Almost all of the time

During the past month, how much of the time...

- | | | | | |
|--|---|---|---|---|
| 1. were you bothered by things that usually don't bother you? | 0 | 1 | 2 | 3 |
| 2. have you not felt like eating; had a poor appetite? | 0 | 1 | 2 | 3 |
| 3. have you felt that you could not shake off the blues even with the help from family or friends? | 0 | 1 | 2 | 3 |
| 4. have you felt that you were just as good as other people? | 0 | 1 | 2 | 3 |
| 5. have you had trouble keeping your mind on what you were doing? | 0 | 1 | 2 | 3 |
| 6. have you felt depressed? | 0 | 1 | 2 | 3 |
| 7. have you felt that everything you did was an effort? | 0 | 1 | 2 | 3 |
| 8. have you felt hopeful about the future? | 0 | 1 | 2 | 3 |
| 9. have you thought your life has been a failure? | 0 | 1 | 2 | 3 |
| 10. have you felt tearful? | 0 | 1 | 2 | 3 |
| 11. has your sleep been restless? | 0 | 1 | 2 | 3 |
| 12. were you happy? | 0 | 1 | 2 | 3 |

(0) Rarely or none of the time (1) Some of the time

(2) Most of the time (3) Almost all of the time

During the past month, how much of the time...

13. have you talked less than usual?	0	1	2	3
14. have you felt lonely?	0	1	2	3
15. were people unfriendly?	0	1	2	3
16. have you enjoyed life?	0	1	2	3
17. have you had crying spells?	0	1	2	3
18. have you felt sad?	0	1	2	3
19. have you felt that people disliked you?	0	1	2	3
20. could you not get "going"?	0	1	2	3

Appendix C

MICHIGAN STATE UNIVERSITY

Appendix C

October 6, 1995

TO: Charles Given
B108 Clinical Center

Barbara A. Given
A230 Life Sciences

RE: IRB#: 92-280
TITLE: FAMILY HOME CARE FOR CANCER--A COMMUNITY-BASED MODEL
REVISION REQUESTED: 08/10/95
CATEGORY: FULL REVIEW
APPROVAL DATE: 06/05/95

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project including any revision listed above.

CONSENT FORMS FOR THE FOLLOWING SITES HAVE BEEN REVIEWED & APPROVED BY UCRIHS: McLAREN, SAGINAW COOPERATIVE HOSPITALS, ST. JOSEPH MERCY HOSPITAL, WEST MICHIGAN CANCER CENTER, FOOTE HOSPITAL, NORTHERN MICHIGAN HOSPITAL/BURNS CLINIC FOUNDATION, ST. MARY'S HEALTH SERVICES, MERCY MEMORIAL MEDICAL CENTER, MID-MICHIGAN REGIONAL MEDICAL CENTER, ST. LAWRENCE HOSPITAL & HEALTHCARE SERVICES, SPARROW HOSPITAL, MICHIGAN STATE UNIVERSITY & BUTTERWORTH HOSPITAL.

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

PROBLEMS/CHANGES: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)432-1171. testing 123

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Donna Neumark



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MICHIGAN STATE UNIVERSITY

June 6, 1995

TO: Barbara A. Given
A230 Life Sciences

RE: IRB#: 92-280
TITLE: FAMILY HOME CARE FOR CANCER--A COMMUNITY-BASED
MODEL
REVISION REQUESTED: 05/25/95
CATEGORY: FULL REVIEW
APPROVAL DATE: 06/05/95

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project and any revisions listed above.

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

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**PROBLEMS/
CHANGES:**

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If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)432-1171.

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:kaa/lcp



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Appendix D

**MICHIGAN STATE
UNIVERSITY**

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Appendix D

February 22, 1995

**TO: Tricia M. Kemmer
429 College Avenue
Holland, MI 49423**

**RE: IRB#: 95-048
TITLE: THE RELATIONSHIP BETWEEN DEPRESSION AND IMPACT
ON SCHEDULE IN CAREGIVER DAUGHTERS, OF ELDERLY
MOTHERS, WITH DIFFERING EMPLOYMENT STATUS
REVISION REQUESTED: N/A
CATEGORY: 1-E
APPROVAL DATE: 02/22/95**

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project including any revision listed above.

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

**PROBLEMS/
CHANGES:** Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)336-1171.

Sincerely,

David E. Wright
David E. Wright, Ph.D.
UCRIHS Chair

DEW:pjm

cc: Carla L. Barnes



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