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PERCEPTIONS OF SUPPORT IN MALE SPOUSAL DEMENTIA
CAREGIVERS DURING
TRANSITION FROM CAREGIVING TO BEREAVEMENT

By

Cecilia Lee Peasley

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Submitted to
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ABSTRACT

PERCEPTIONS OF SUPPORT IN MALE SPOUSAL DEMENTIA CAREGIVERS DURING TRANSITION FROM CAREGIVING TO BEREAVEMENT

By

Cecilia Lee Peasley

Perceived support among male spousal dementia caregivers was examined at two intervals, prebereavement and postbereavement, over a period of time that averaged six months following the death of a relative with dementia. Comparisons were made between the prebereavement and postbereavement Perceived Support Scale scores of each participant ($n = 12$). Levels of perceived social support among male spousal dementia caregivers did not change significantly over time. Relative consistency of support during bereavement transitions was established. An unanticipated finding was that levels of support for the majority of male caregivers was high during caregiving and stayed high following bereavement. Findings suggest the need for further investigation of male spousal dementia caregiver consistency of support during caregiving transitions.

To Al and Kids

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INTRODUCTION

There are currently over 1 million people in the United States suffering from Alzheimer's Disease (A.D.) and other severe dementing disorders requiring constant care (United States Congress, Office of Technology Assessment, 1987). Chronic strain that is experienced over the course of providing long-term family care may produce changes in social support that may alter mental health (George & Gwyther, 1986; Pearlin, Mullan, Semple & Skaff, 1990).

One frequently identified aspect of social support, often regarded by researchers as the most vital, is that of perceived support (Lyles, King, Given, & Given, 1990). Perceived support measures the quality of support in terms of assessments of relationships (Russell & Cutrona, 1984) and it is the quality of relationships that surfaces as having the greatest impact on caregiver well-being (Jackson & Antonucci, 1991; Lyles et al., 1990).

Levels of depression during dementia caregiving are high for both male and female dementia caregivers. However, there is evidence that bereaved female dementia caregivers experience a pattern of decreasing depression following their relative's death, while male bereaved caregivers

experience an increase in depression (Collins, Stommel, Wang and Given, 1994). This report contrasts with the majority of bereavement literature, where bereaved women are reported to have higher levels of distress as compared to men (Gass, 1987; Osterweis, Solomon & Green, 1984; Thompson, Gallagher, Futterman, Gilewski & Peterson, 1991).

There also seems to be a contrast in the literature in regards to the consistency of social support of caregivers in the transition from dementia caregiving to bereavement. Social support literature predicts consistent support during dementia caregiving to bereavement transitions (Straw, O'Bryant & Meddaugh, 1991; Bass, Bowman & Noelker, 1991), whereas dementia literature predicts that caregivers become isolated and experience decreased levels of support as long as dementia care goes on, but experience improved levels following bereavement (George & Gwyther, 1984; Jones & Martinson, 1992). One frequently cited criticism of the bereavement literature is that researchers tend to focus on social support in dementia caregiving groups after the bereavement experience, but tend to ignore the assessment of the stability of perceived support during the caregiving to bereavement transitions (Bass & Bowman; George & Gwyther, 1984; Norris & Murrell, 1987).

There are substantial numbers of male spousal dementia caregivers, however, there is little research about the characteristics of the bereaved male spousal dementia

caregiver and his special needs and problems (Zarit, Todd & Zarit, 1986; Zarit, Pruchno & Resch, 1980). Dementia caregivers have too often been studied as a homogenous group, whereby men and women have been viewed as having the same characteristics in their transition patterns from caregiving to bereavement.

This proposed study was developed in order to examine dementia caregiving husbands' perceived support during the dementia caregiving to bereavement transition to describe levels of consistency as well as average change over time. It was assumed that examination of perceptions of social support of male spousal dementia caregivers would show that this particular group of caregivers had consistently low perceived support and did not experience an increase in perceptions of support once caregiving ended despite significant reduction of burden.

Social support literature is firm in its contention that perceived support helps to mediate the effects of stress and buffers the impact of significant life events. Greater understanding of the consistency and amount of change in perceptions of support in male dementia caregivers during bereavement transitions may enhance the Family Nurse Practitioner's (FNP) understanding of the male spousal dementia caregiving experience in general. Information about male spousal dementia caregiver perceptions of support can help the FNP in anticipating male spousal dementia

caregivers who may be at greater risk for more serious mental health consequences following bereavement. If individual perceptions of support are low in male spousal bereavement caregivers and we can predict that they will stay low following bereavement then the Nurse Practitioner can initiate early interventions specifically with those male clients most likely to suffer debilitation as a result of the end of prolonged dementia caregiving.

The Experience of Dementia Caregiving

In America alone there are currently over 1 million persons suffering from severe dementia requiring constant care. In addition, estimates indicate that anywhere from 3 to 5 million Americans suffer some form of dementia that can be categorized as mild to moderately disabling (Office of Technology Assessment, 1987). Unless some cure is found, which is unlikely sometime soon, these numbers will increase, largely due to the aging of the enormous "Baby Boom" population (U.S. Census, 1987).

The progression of dementia results in cognitive impairment and memory loss, so that eventually the afflicted person needs supportive care (Hinds & Wade, 1991; Collins, 1993). Approximately 80% of people with dementia are cared for in the community, with family members providing the majority of the care (Baillie, Norbeck & Barnes, 1988; Cantor, 1983; Zarit et al., 1980). This informal support system serves as a major factor in preventing institutionalization of the recipient despite tremendous stress to the caregivers themselves (Cantor, 1983).

Spouses are often the primary source of care for the demented elderly person. Though less than one-fourth of current caregivers who care for people with dementia are male (Zarit et al, 1986), the caregiving gender gap disappears when the focus is on spousal caregivers. In a number of studies involving demented elderly clients, when

spousal caregiving was taken into account, the number of male dementia caregivers ranged from 42% to over 50% (Baillie et al., 1988; Cantor, 1983; Zarit et al., 1990).

In order to understand the problems encountered by dementia caregivers, it is important to understand the vast undertakings that dementia caregiving comprises. Pearlin, Mullan, Semple and Skaff (1990) noted that "demented persons, especially those with A.D., experience such a chronic and progressive impairment, that the nature of the disease constrains the relationship to strictly caregiving demands" (p. 584). Dementia inevitably leads to loss of self-care abilities, creating self-care deficits of varying degrees. Subsequently, the normal process of providing assistance to one another as family members becomes disproportionate. The caregiving relationship evolves into a relationship that is teeming with demands but holds few compensating rewards. Caregiving that may have previously been a fleeting component of a relationship, now becomes a dominant, overriding concern (Goldstein, Pegnery, & Willin, 1981). In dementia caregiving, reciprocal relationships that previously involved an even balance of support dissolve into unbalanced, dependant relationships. The cognitive status of the recipient deteriorates, with resultant memory loss, communication deficits, and recognition failures, leading to varying levels of adversity and behavioral problems (Hinds & Wade, 1991; Pearlin et al., 1990).

Over time, the care of a demented relative becomes increasingly complex, creating a need for the caregiver to invest more of himself into the caregiving situation. Dementia caregiving leaves little time or energy for the caregiver to pursue personal interests. Because of the depth of transformation of the demented individual, the spousal relationship changes dramatically. The degree of complexity of care in conjunction with significant alteration of the caregiver-patient relationship creates a situation in which "caregivers come to feel increasingly separated from the parts of their lives that had been supported or shared by their relative" (Pearlin et al. 1990, p. 385). Spousal dementia caregiving develops into a process whereby the caregiver experiences the gradual loss of family and partnership that may have been provided by the relationship. The dementia process causes the recipient to be physically there but psychologically absent (Bass, Caron & Horbal, 1988). Any mutual affective support that may have been provided by the marital relationship becomes an entity of the past.

Social Support and Caregiving

Social support is one variable that has been studied most frequently in caregiving, primarily because of its stress mediating effects. George and Gwyther (1986) reported that caregivers who indicated inadequate levels of perceived support were significantly lower in dimensions of

well-being than those reporting adequate levels of perceived support. Levels of perceived support provided to caregivers have been noted to significantly relate to caregiver sense of burden (Baille et al., 1988; Dean, Kolody, Wood and Ensel, 1989). High perceptions of support were positively related to coping effectiveness and reduced burden in caregivers of A.D. patients in a study by Fiore, Becker, & Cox (1986).

The supportiveness of the social network, as perceived by the caregiver, consistently impacts caregiver sense of well-being (Given, Stommel, Collins, King & Given, 1988). Caregivers who have been providing care for an extended time, and who believe they get little support, are at a particular high risk for distress (George and Gwyther, 1986; Baille et al., 1988). Conversely, even when the caregiver feels no reduction in their level of burden, when there is a perceived sense that one has a supportive network, caregiver sense of well-being is enhanced (Baille et al., 1988; George & Gwyther, 1986).

Social support in caregiving is regarded as assistance provided to the caregiver from other persons. Social support has two major dimensions, instrumental social support and perceived social support. Instrumental support refers to tangible commodities, such as money, goods, or services provided directly to the caregiver (Cobb, 1979). Perceived support is internalized feelings of being loved

and valued, as well as having the opportunity to reciprocate those feelings onto others (Cobb, 1979).

The two dimensions of instrumental and perceived support have not been found to be highly correlated. There is little evidence that instrumental social support leads to much higher levels of perceived support (Baille et al., 1988). One study (Dean, Kolody, & Wood, 1989) assessed the quality of relationships in the elderly. It was proposed that the two different dimensions of social support can show an almost opposite relationship. In examining emotional well being of elderly subjects it was established that there was a positive correlation between instrumental support and depression and a negative correlation between perceived support and depression. For the purposes of this study, social support is defined as perceived support. Perceived support is the individual's assessment of support that does not necessarily reflect the quantity of support but rather reflects the degree of closeness and quality of relationships that the individual perceives to be available (Weiss, 1974). Support theory suggests that relationships must possess a degree of intimacy that reflects closeness as a requirement for the development of perceived support (Russell & Cutrona, 1984). Since no one single relationship can provide all the dimensions of intimacy required by individuals, multiple relationships are developed. Different types of relationships help individuals satisfy

various dimensions.

Perceived support consists of six dimensions of relating, frequently referred to as provisions. These provisions are identified as; feelings of attachment; degree of social integration; participation in activity that enhances feelings of self worth; kin relationships; nurturance concerns; and matters of guidance that the individual perceives is available to them if needed (Russell & Cutrona, 1984).

The concept of perceived support decrees that all six of these provisions are necessary to some degree within our various relationships in order for adequate perceptions or feelings of support to occur, however, individuals vary with respect to their needs. As a result, relationships become specialized in their provisions. Subsequently, individuals must maintain a number of different interpersonal relationships in varying degrees in order to establish conditions necessary for well being (Weiss, 1974).

The roots of interpersonal relationships need to be established in early socialization and attachment processes. Continued development of rudimentary social relationships is also dependant upon reinforcement in adolescence, maturity in mid adulthood and adjustment and reorientation with the diminishment of personal resources in late life (Jackson & Antonucci, 1991; Weiss, 1974). Individuals tend to bank resources gained from interaction with others in early

courses of life and call on these resources in later life in times of stress. "The banking and withdrawal of resources has the critical function of supplying affective or perceptual based dimensions of social support" (Weiss, 1974, p.84). An individual's banking behaviors consist of deposits and withdrawals of support, which may be distributed in various ways, but is in any event a constant activity dependent upon the individual's perceptions of available support (Weiss, 1974). Difficulty may be encountered by the individual if social isolation occurs and they are subsequently unable to spend their deposits or if opportunity for expenditure from the fund is met with opposition (Jackson & Antonucci, 1991).

Studies involving male dementia caregivers and their perceptions of support report that during dementia caregiving, male caregivers have difficulty maintaining social support in that they focus minimally on relationships or affective expression and tend to avoid interpersonal connectiveness (Miller, 1987; Pruncho & Resch, 1989). Dementia caregiving males tend to sacrifice relationship development during caregiving and instead focus upon task accomplishment and environment control. When given respite time, male dementia caregivers are less likely to make relationship contacts, such as group involvement, but instead are inclined to concentrate on interests unrelated to their family situation (Miller, 1987). Even when mutual

support groups are offered, men do not readily avail themselves, preferring to deal with their problems alone (Gregory, Peters, Cameron, 1990).

Gender issues involving social support in dementia caregiving are probably related to how men and women are socialized (Collins, et al., 1994; Miller, 1990; Miller, Mcfall & Montgomery, 1991). The traditional stereotype of men consists of a cluster of traits that are instrumental in nature, that is, interested in things, emphasizing achievement and accomplishment, not affective expression (Lin, Woelfel & Dumin, 1986). Yet affective expression helps to sustain the quality of relationships. This may be especially important during the difficult task of dementia caregiving. Perhaps the extent to which affective supports are acknowledged earlier in caregiving allows the male spousal caregiver access to the support of others during bereavement, whereas failure to engage affectively during caregiving may lead to impoverished perceptions of support during bereavement.

Social support literature predicts consistent perceived support during dementia caregiving to bereavement transitions (Straw et al., 1991; Bass et al., 1991). Consistency of support would be reflected by high correlations between caregiving and bereavement. A positive correlation would mean that male dementia caregivers would experience either consistently high relative levels of

perceived support during caregiving to bereavement transitions or consistently low relative levels of support during caregiving to bereavement transitions. A negative correlation would mean that male dementia caregivers' levels of support would be inversely related during bereavement transitions, that is, those who have relatively high levels of perceived support prior to bereavement would experience relatively low levels following bereavement and those with low levels of perceived support during caregiving would experience high levels following bereavement.

Bereavement and Social Support In Dementia Caregiving

Bereavement is recognized as a major life event that requires more readjustment than any other life event (Blazer, 1990; Osterweis, Solomon & Green, 1984).

Bereavement is often thought of as a type of psychological work that is a normal process of coming to terms with the meaning of an event (Norris & Murrell, 1987). Bereavement elicits feelings of being alone or unattached, memories of earlier losses, guilt over unresolved conflicts or imagined wrongs, and questions concerning one's purpose in life.

Bereavement of a relative's death is most acute during the first 2-4 months. Following those first months, symptoms gradually subside in varying degrees for about a year (Blazer, 1990). Increased symptoms are often noted at the first year anniversary but following the anniversary reaction, resolution begins to occur. Resolution of grief

is characterized by acceptance, reconstructing identity and social reintegration. Recurrence of symptoms may ensue but they are usually brief and resolve easily. Most research points to one year as the time required for function to return to normal (Blazer, 1990).

The bereavement experience associated with the dementias has unique characteristics because of the nature of the disease as well as the caregiver's experiences during the time of providing caregiving (Bass, Caron & Horbal, 1988; Collins, Liken, King & Kokinas, 1993; Jones and Martinson, 1992). One unique feature of dementia caregiving that affects social support is the issue of pre-death grieving. In dementia care, the bereavement process begins well before the death event. During pre-death, a specific social process seems to develop (Liken and Collins, 1993). During this process the caregiver experiences separation, termination and loss that accompany bereavement, but unlike normal bereavement, in pre-death dementia grieving, caregivers generally suffer alone and in silence (Collins et al., 1993; Jones & Martinson, 1992; Liken & Collins, 1993). Supportive persons who may be in the caregiver's network may not recognize the dynamics of what is happening, and are therefore unable to offer their support. In addition, dementia caregivers may be so involved in the stress of caregiving that they may be unable to conceptualize the source of their feelings of loss to others (Liken & Collins,

1993). Subsequently, the impact of the predeath process may be a factor enhancing low perceptions of support.

It seems reasonable to assume that the family caregiver of a dementia patient would feel some relief at the cessation of the burden of caring for the patient and a willingness to resume a more normal life (Collins et al., 1993). However, the dominance of the caregiver's relationship with their demented relative as well as the length of the dementing illness puts caregivers at risk of becoming socially isolated from sources of potential support during caregiving (Malone, Haley & Fleece, 1983). This isolation and limited social support may extend into the bereavement transition as well.

Bereaved caregivers often cite an intense need to discuss their caregiving experiences, more so than their need to discuss the actual death of their demented spouse (Collins, Liken & King, 1993). If the bereaved caregiver feels that there is no one to talk with who truly understands the difficulties that they have experienced then they may be ill-equipped to cope with bereavement transitions (Collins et al., 1993). It might be that lengthy dementia caregiving leaves male spousal caregivers with a type of social isolation following bereavement that they find difficult to overcome. This may be due to the nature of their socialization process as well as their approach to dementia caregiving. Subsequently, these

individuals may have difficulty moving onto the next stage of their life. If the dementia caregiving individual has opportunity to discuss and synthesize the total experience of their relative's death this opportunity for discussion may lead to a sense of peace and aid the bereavement transition (Collins et al., 1993) and in turn serve to reinforce perceptions of support. Based on this idea, it is logical to assume that inadequate perceptions of social support may leave the male caregiver distressed, subsequently experiencing a more difficult bereavement transition.

In the study that is the source for this secondary analysis (Impact of Alzheimer's Disease on Family Caregivers, NIMH #1-RO1 Mh41766) perceived support measures were taken, on average six months following the bereavement event. This allowed for support measures to be taken during routine daily living following a reasonable amount of time for adjustment and not during the crisis period that immediately follows bereavement. An increase in perceptions of support would reflect increased feelings of having more emotional support in terms of guidance and assistance as well as improved opportunity for intimate interactions. Decreased postbereavement perceptions of support would reflect that the bereaved male dementia caregiver would feel less support in terms guidance, assistance, aid, or intimacy as compared to earlier perceptions of support

during caregiving.

Summary

The dementia caregiving situation is different from other caregiving situations. Consequently, caregivers, including male caregivers, respond differently. Despite the fact that the dementia literature predicts a sense of relief after caregiving and a subsequent increase in social support, when male caregivers were examined independently, greater levels of distress were noted following dementia bereavement (Collins et al., 1994).

Studies fail to recognize that dementia caregiving and dementia caregiving bereavement may appear to be separate events, but in fact are part of a single ongoing response. Perceived support plays an important role in moderating the stressors associated with ongoing life events such as dementia caregiving transitions. Understanding the consistency of the male spousal dementia caregivers perceptions of support may enhance understanding of male spousal dementia caregiver response in bereavement period transitions.

Greater understanding of the consistency of perceptions of support in bereaved male spousal dementia caregiver transitions may be useful to the FNP in the primary care setting. The FNPs understanding of the relationship of prebereavement support to postbereavement support in the dementia caregiving situation may prompt preventative measures in the early stages of the caregiver process.

These measures might include bereavement counseling before the actual death, education regarding the dementia process to caregivers, and development of a counseling approach that addresses the caregivers need to evaluate their caregiving experiences retrospectively (Collins et al., 1993).

Study Purpose

This study examined male spousal dementia caregiver perceptions of support over time. This study was an attempt to describe the relative consistency as well as the average change in level of perceived support during caregiving and following bereavement among male spousal dementia caregivers. The assumption was that if perceptions of support are high during caregiving then high levels of perceived support would be maintained following bereavement and if levels of perceived support are low during caregiving then low levels of perceived support would be maintained following bereavement, indicating relative consistency.

It is well documented that in the period immediately following bereavement social support measures usually increase, primarily due to the presence of support persons rallying around the bereaved (Blazer, 1990; Lund, 1989). Measures of perceived support for this study, however, were not taken immediately after bereavement but, on average, about six months following the bereavement event. Examining perceptions of support long after the initial bereavement event may help us to understand what becomes of social support for male spousal dementia caregivers in the months following bereavement. Do those who have high levels of support during caregiving continue to have high levels of support in the months following bereavement? Do those who have low levels of support during caregiving continue to

have low levels of support in the months following bereavement? Do support levels change significantly over time?

The hypothesis of this study is: Male spousal dementia caregivers who experience low levels of perceived social support during caregiving will continue to experience low levels of perceived social support during bereavement transitions and; male spousal dementia caregivers who experience high levels of perceived social support during caregiving will continue to experience high levels of perceived social support during bereavement.

Conceptual Framework

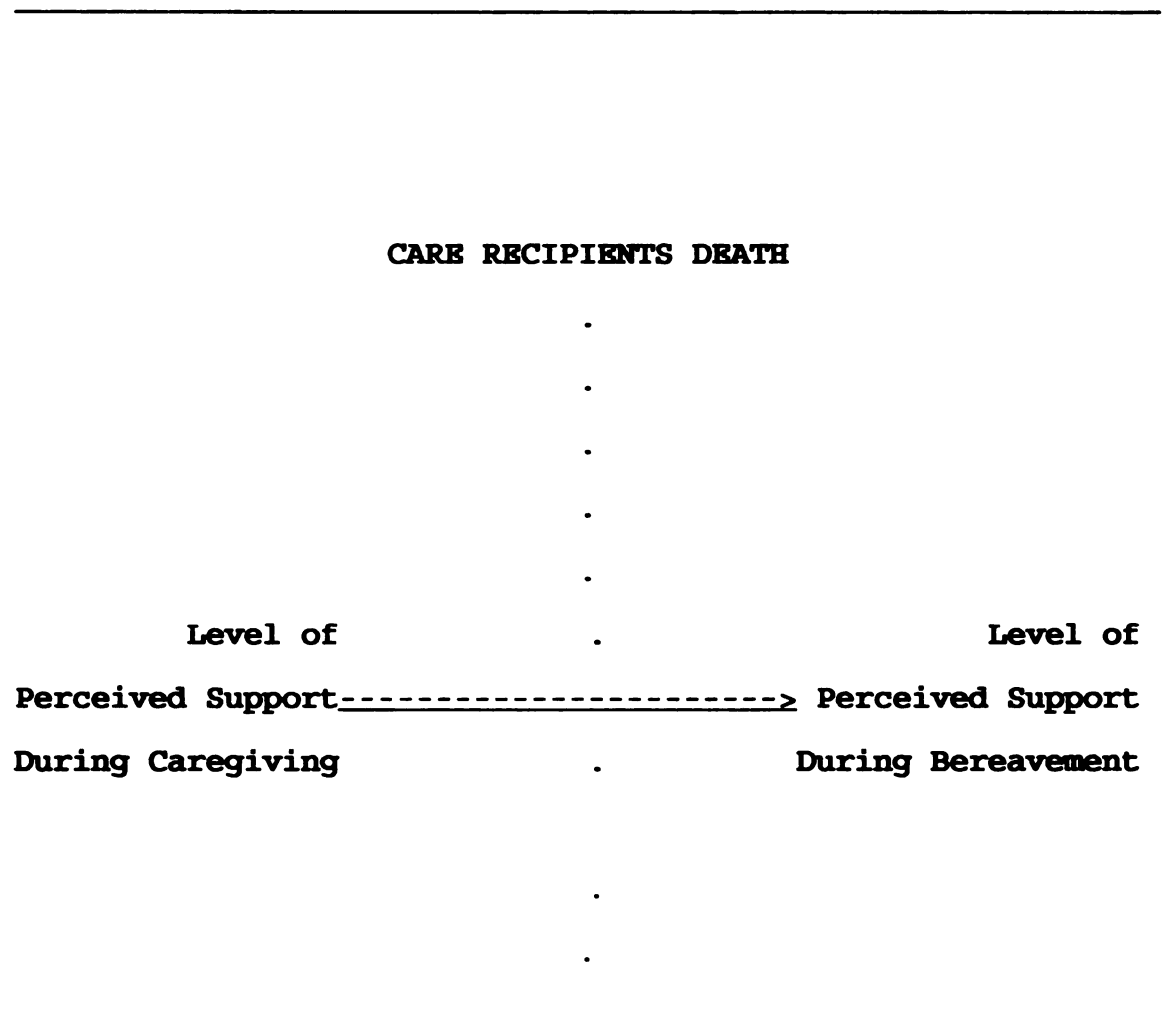
There have been numerous assumptions regarding the influence of social support upon life events. Researchers often address what happens to social support after an event or will retrospectively examine social support following an event, but few researchers have taken the time to examine the link between social support and life events (Lin et al., 1986). It has yet to be determined if there is consistency or inconsistency of social support following a stressful life event and there are few models available that attempt to provide explanation.

Lin et al., (1986) identified a lack of research documenting the complexity of the link between social support and life events and sought explanation. A series of models were developed that depicted the intricacies of social support, life events and depression. Lin's (1986) Life Events model was a part of that series. Lin's (1986) model (Life Events) envisioned perceived support as an independant factor between life events. Lin's (1986) model postulates that perceived support levels will remain consistent during life event transitions regardless of the life event. Lin argues that life events will influence the direction of perceived support but that the direction will not be a dramatic change but rather a consistent increase or decrease dependant upon levels of support prior to the event. According to Lin (1986), if an individual has high

perceptions of support prior to a stressful life event then the occurrence of the stressful life event may stimulate an increase in social support and; if the individual has low perceptions of support prior to a stressful life event then the occurrence of the stressful life event may stimulate a decrease in social support. Lin (1986) contends that individuals will not regress from high perceptions to low perceptions or advance from low perceptions to high perceptions as a result of life events.

Since this study does not include depression, Lin's (1986) model is modified as represented by the Stability of Social Support during Dementia Caregiving Transition Model (Figure 1). Modification of the Lin (1986) model allows for support of the concept that perceived social support in caregiving is consistent with perceived social support in bereavement transitions for male spousal dementia caregivers. This author contends that male dementia caregivers will not experience significant changes in perceived social support during bereavement transitions despite cessation of the burden of caregiving. This author contends that those caregivers who already enjoyed adequate levels of support will sustain those levels and that those caregivers who experienced already low levels of support during caregiving will continue to experience low levels of support following bereavement.

Figure 1: Level of Social Support during Dementia Caregiving Transitions Model



METHODS

Research Design

Permission has been provided to perform this secondary analysis on data from the following grant supported studies. "The Impact of Alzheimer's Disease on Family Caregivers" (NIMH #1-R01 MH41766) funded by the National Institute of Mental Health, Charles W. Given and Barbara Givens, Principal Investigators; "The Impact of Alzheimer's Disease on Family Caregivers" (NIMH #2-R01 MH41766) funded by the National Institute of Mental Health, Clare Collins, Principal Investigator.

A single dimension of perceived social support was derived from the twenty-six items on the Social Provisions Scale by researchers (NIMH #1-R01 MH41766, "The Impact of Alzheimer's Disease on Family Caregivers") during Phase 1 of the Caregiver study. Phase 1 was a separate grant in which the primary aim was to develop valid test measures that could be used in an elderly population (NIMH #1-R01 MH41766, Executive Summary, "The Impact of Alzheimer's Disease on Family Caregivers" Charles W. Given Ph.D., & Barbara A. Given Ph.D., Co-principle Investigators). Following the initial grant, a second grant was obtained which allowed for

multidimensional measurement of family caregivers response to caregiving and caregiving bereavement over time (NIMH #2-6R01 MH41766, Clare Collins Ph.D., Principal Investigator). It is from these two studies that scale scores were derived for analysis in this study.

Sample Procedures

The criteria for entry into the study by caregiver/patient dyad included the following: 1) the patient was at least 55 years old; 2) the patient was dependent in at least one instrumental activity of daily living (IADL) and one activity of daily living (ADL); 3) the patient had received a diagnosis of A.D. or other progressive dementia; 4) the caregiver was self-identified as the family member providing the most care to the relative with dementia; and 5) the patient with dementia was residing in the community at the initial onset of data collection (Impact of Alzheimer's Disease on Family Caregivers, Grant R01 MH41766).

Initial contact for this convenience sample was made with the Michigan chapters of the Alzheimer's Disease and Related Disorders Association to recruit family members caring for a patient with Alzheimer's Disease in their home. Eight local chapters then sent a letter describing the study, along with a postcard that the family caregiver was to return to the research team. A cover letter explaining the study and a return postcard were sent to adult day care

centers, home health care agencies and geriatric clinics. Clinicians were asked to distribute information to the families in their agencies. Families interested in participating in the study were asked to return the postcard indicating their name, address and the best time to be contacted. A direct mailing was done by the Michigan Chapter of the Alzheimer's Association to individuals on their mailing list using the same card back system. Use of local radio and television advertisement as well as posting in local libraries and church bulletins were utilized to enhance recruitment. Potential participants were screened by data collectors to determine that eligibility criteria of the study were met.

The sample used for this secondary data analysis were male spousal dementia caregivers who were providing the majority of residential care to their relative at the first measure of the study, and completed at least one post bereavement measure. It is these scale scores that will be analyzed. Of the data available, 12 male spousal caregivers met this criteria.

Data Collection Procedures

Participants in the study were informed that they were participating in a longitudinal study that would involve several encounters both by telephone and by mail. Participation was entirely voluntary and this fact was made public at the initial onset. Withdrawal from the study

could occur at any time. Issues of confidentiality with an explanation as to how the study would be utilized was provided. Informed consent was obtained and the study was approved by the U.C.R.I.H.S.

Each caregiver study participant completed a self-administered booklet containing the modified Social Provisions Scale which had been mailed to them (See Appendix A). The University Committee on Research Involving Human Subjects at Michigan State University approved the procedures used in this secondary analysis (Appendix B).

Operational Definition of Variables

In this study, perceived support is operationalized as scores on a shortened version of the Social Provisions Scale (SPS) that was designed to measure facets of closeness among populations (Russell & Cutrona, 1984). The initial scale contained 26 items, with six different scales, each representing one of the six provisions. The six scales could not be confirmed by factor analysis on the shortened version but a single dimension of affective support was derived from the twenty-six items (Given and Given, 1989). The shortened version of the SPS contains seven items relevant to perceived support available to elderly persons caring for a family member in their home.

During administration of the modified SPS the caregiver was asked to respond to seven items. The following seven items of the SPS are (Russell, Altmaier, and Van Velzen, 1984):

1. There are people I can depend on to help me if I really need it.
2. There is no one I can turn to for guidance (for help) in times of stress.
3. If something went wrong, no one would come to my assistance.
4. I have close relationships that provide me with a sense of emotional security and well-being.
5. There is someone I could talk to about important decisions in my life.
6. There is no one I can depend on for aid if I really need it.
7. There is no one with whom I feel comfortable talking about problems.

Answers to the individual items were recorded on a four-point Likert scale and ranged from strongly disagree to strongly agree. Scores for each provision ranged from (1), indicating unavailability of the provision to (4), indicating its availability. Items 2, 3, 6, and 7 were reverse scored.

Male spousal caregivers are spouses who are self-described as providing the majority of care for their

relative who has been diagnosed with A.D. or a related dementia. Bereavement is operationalized as that period of time following the death of a recipient of care who had been diagnosed with either A.D. or some other dementing disorder.

Instrumentation

The shortened scale, reported in Table 1, contains 7 items that dementia caregiving researchers felt were relevant to perceived support that was available to elderly persons caring for a family member in their home. During Phase 1 this shortened version of the original scale was administered to two independent samples of caregivers. Stability of the scale was confirmed by administering the same instrument again to one sample of caregivers one month later. High reliability and strong internal consistency was demonstrated (alpha .87). Tests for reliability were again performed during Phase 2 (alpha .87) and again at one month follow up (alpha .85) (RO1-MH 41766, Executive Summary). Test of validity of the Social Provisions Scale had not been clearly identified in the Alzhiemers' Caregiver study (Givens et al., 1993).

RESULTS

The findings described in this section were based on data obtained from completed self-reported SPS questionnaires, consisting of 12 male subjects that were eligible for this study. Tables showing the results of the correlations and total scale scores are incorporated.

Sociodemographic Characteristics

The sample for this study was 12 male spousal dementia caregivers who experienced bereavement. The average age for the total sample drawn was 72.6 years with a range of 61 to 84 years. All of the participants were Caucasian. The average income among all of the subjects was \$32,818.18 annually, ranging from a low income of \$12,000 to a high of \$65,000. One person had less than a high school education, five participants had a high school education, four had some college, and two persons had a bachelor's degree or more. Two persons were employed part-time, two full-time and eight were retired. Of those employed one worked as a professional, one was a farmer, one was merchant and one was a laborer.

Scale Stability

This study employs Chronbach's alpha to confirm stability of the scale. Prebereavement and postbereavement measures were analyzed. The prebereavement wave produced a coefficient of .90 on the SPS (7 items) (n=12). The postbereavement wave produced a coefficient of .93 on the SPS (7 items) (n=12). The high values reflect a high degree of internal consistency of the self-report questionnaire for this analysis.

Differences of Perceived Social Support in Bereavement Transitions

A comparison of scale scores from the SPS were obtained during the prebereavement and postbereavement waves of the Alzheimer's Caregiver Study (Table 1).

Table 1, SPS Scale scores of male caregivers (n = 12)

<u>Wave</u>	<u>Mean</u>	<u>Std Dev</u>	<u>Range</u>
Preber	2.86	.61	1.86 - 4.00
Postber	3.08	.79	1.71 - 4.00

T- Test for paired sample was employed to test for a significant difference between perceived levels of social support during caregiving transitions (Table 2). No difference was found between perceived levels of social support during caregiving and following bereavement (p=.165) Evidence of no significant difference in levels of

postbereavement support as compared to prebereavement support strengthens the assumption that male spousal dementia caregivers do not experience a significant change in their amount of perceived social support during their transition from caregiving to bereavement.

Table 2, T-test for Bereavement Transitions (n=12)

Paired Differences				
Mean	SD	t-value	df	2-tail Sig
.2250	.525	1.49	11	.165
95% CI (-.108, .558)				

Relative consistency was investigated by the Pearson correlation (r). The hypotheses subjected to the statistical test is that there will be a positive correlation between prebereavement and postbereavement scale scores. In fact, this occurred in that the correlation matrix display of prebereavement with postbereavement scale scores indicated a moderately strong positive relationship ($r=.747$) with a significance level of $p .005$ (Table 2).

Table 3, Pearson Correlation Coefficients (n=12)

	Postber
Preber	.747
	$p .005$

This researcher assumed that the majority of the participants perceived support scores from the caregiving to bereavement transitions would be consistently low due to the nature of the dementia caregiving situation. This was not the case. When establishing a cut-off rule that mean scores above 2.5 would be considered 'high' and mean scores below 2.5 would be 'low', the majority of subjects scored in the 'high' range during caregiving as well as bereavement. Though changes in scale scores were not significant, instead of scale scores decreasing following bereavement as was assumed by the author, scale scores increased in the majority of the cases. Only one score was noted to be negatively correlated. Three prebereavement scores were 'low'. Two of the three 'low' scores stayed in the low category and the third score went from 'low' to high (Table 4).

Rank order of the scale scores show that prebereavement scores had a total of eleven different ranks while postbereavement had a total of eight different ranks. The median for prebereavement scores was 2.93. Postbereavement scores had a median of 3.07. The lowest prebereavement score was 1.86. The lowest postbereavement score was 1.71. The first, or higher ranked, and the ninth and tenth, or lower ranked, prebereavement scores decreased postbereavement, the balance of the scores increased. The tenth ranked, or lowest, prebereavement score was the only

score to be negatively correlated. All other scores were positively correlated (Table 4).

Five of the top six prebereavement scores continued to maintain or improve their ranking postbereavement. Of the lower six postbereavement scores, all but one score increased, but only the eighth ranked prebereavement score managed to enter the postbereavement ranks primarily occupied by higher prebereavement scores (Table 4).

Table 4, Mean Scale Scores for SPS

Caregiving			Bereavement		
Id	Mean	Cut-	Mean	Cut-	Corr
		off		off	
1	2.86	above	3.00	above	+
2	2.14	below	1.71	below	+
3	3.57	above	3.71	above	+
4	3.14	above	4.00	above	+
5	3.00	above	3.14	above	+
6	3.43	above	4.00	above	+
7	4.00	above	3.71	above	+
8	2.57	above	3.57	above	+
9	1.86	below	2.57	above	-
10	2.57	above	3.00	above	+
11	2.43	below	1.71	below	+
12	2.71	above	2.86	above	+

Interpreting Hypothesized Results

The hypothesis of this study was that male spousal dementia caregivers who experience low levels of perceived social support during caregiving will continue to experience low levels of support during bereavement and; male spousal dementia caregivers who experience high levels of perceived social support during caregiving will continue to experience high levels of perceived social support during bereavement. The tests of statistical significance support the original research hypotheses. The Pearson correlation $r=0.747$ occurred at the .005 level of significance, revealing that there is a strong consistent relationship between levels of perceived support during bereavement transitions for male spousal dementia caregivers. The majority of scores, both high and low, tended to increase following bereavement, but the amount of change in scores was not significant, as indicated by t-test statistic 1.49, $p=0.165$.

Discussion

Levels of perceived support during bereavement transitions among male spousal dementia caregivers for this study do not change significantly and perceived support scores are relatively consistent. This strengthens the social support literature that contends that there is consistency of perceived support in the transition from dementia caregiving to bereavement (Straw et al., 1991; Bass et al., 1991). This does not support the dementia

literature which predicts that caregivers experience low levels of perceived support during caregiving but have significantly increased levels of support following bereavement (George & Gwyther, 1984; Jones & Martinson, 1992).

It is important to consider the amount of time elapsed between bereavement and social support measures when comparing the results of this study to current social support literature that examines the consistency of perceived support during the caregiving to bereavement transition (Bass et al., 1991; George & Gwyther, 1984; Jones and Martinson, 1992; Straw et al., 1991). Current social support literature does not examine consistency of social support in dementia bereavement transitions for such an extended time after the initial bereavement crisis. Comparing the results of this study with current social support and bereavement literature that examines consistency of support needs to proceed with caution. This author predicted consistency of support for male spousal dementia caregivers during bereavement transitions. Lin's (1986) theoretical model contends that social support is interactive with but not dependant upon life events. The Stability of Social Support during Bereavement Transitions Model, developed for the purpose of this study, supports that bereaved male spousal dementia caregiver social support levels, whether high or low, ought not to change

significantly despite bereavement. The results of this study strengthens support for the current model.

The majority of prebereavement SPS scores were "high" and tended to stay in the "high" range postbereavement. This is inconsistent with the theory that perceived support and depression are inversely correlated. One explanation might be that the SPS was not administered in its entirety and the six subscales representing the six provisions were not confirmed on the shortened version (Given and Given, 1989). Items 1, 3 and 6 address issues of depending on help from others; having someone to rely on in an emergency. These appear to represent the provision of 'relationships'. Items 4 and 7 seem to represent the provision of 'emotional attachment' while item 5 resembles the provision of 'guidance'. The provisions of social integration, self worth and nurturance do not seem to surface. The concept of perceived support decrees that all six provisions are necessary to some degree within our relationships for adequate perceptions of support to occur (Weiss, 1974). Consideration needs to be given to the fact that the shortened version of the SPS may not have been an adequate measure of the concept of perceived support among the male spousal dementia caregivers involved in this study.

Given the average age of the participants in the study it was surprising to see the number of subjects with levels of education beyond high school. Average income was above

the national average (U.S. Bureau of the Census, 1987). Level of education and level of income, both above the national average for that particular generation of males (U.S. Bureau of the Census, 1987), may have played a role in influencing results.

Factors that prompted the 1st ranked subject with the highest prebereavement and the 9th and 10th ranked subjects with some of the lowest prebereavement scores to feel less perceived support following bereavement bear investigation. Problems such as loss of self esteem associated with caregiving, illness, financial concerns or increased social isolation following caregiving may all be components to consider. Discovering the similarity or dissimilarity of issues affecting both upper and lower ranked subjects who experienced decreased perceptions of support following bereavement might help us to understand those elements in a male dementia caregivers life that create lower support levels after death of their spouse. The lowest prebereavement score was the only score that was inversely correlated. It would be interesting to qualitatively evaluate the influence of the bereavement experience upon this caregiver and determine what variables may have prompted this change.

This study is a secondary analysis, which is a rather weak design. The data already existed, making it impossible for this researcher to play a role in gathering information.

Any questions or ideas that the researcher may have had regarding the data had to be relegated to wishful thinking. Any errors that may have occurred during data collection are unknown (Polit and Hungler, 1991).

The small nonrandom sample size of male caregivers limits power of the statistical analysis of perceived support during bereavement transitions. The group for this study was preexisting, was not acquired by random selection, and was formed by a self-selecting process. Members of this particular group may have agreed to be a part of the study due to their individual characteristics. Subjects may have appreciated opportunities to express themselves and may have found the interest of the researchers a source of support. The opportunity to connect in some way to others who were experiencing similar issues may have enhanced feelings of attachment. Other potential subjects may have felt too burdened, isolated, or depressed to participate in a study of this nature.

The shortage of supportive literature; the nonrandom, self selecting, small sample size; and questions regarding adequate measure of perceived support on the shortened version of the SPS scale make interpretation of the results of this study tentative.

Suggestions for Future Research

There is a need to have more longitudinal studies investigating change over time of perceived support in male dementia caregiving. Relationships are easier to identify when it is clear that one variable changes prior to changes in another (Polit and Hungler, 1991). Shorter, more frequent intervals between measurements may be helpful so that subtle changes could be more easily explained.

Research samples consisting of considerably greater amounts of male spousal dementia caregivers are needed in order to provide more power to statistical analyses. In addition, a more heterogeneous sample would lend greater credibility to predictions.

It is interesting to note that while other bereaved males have lower levels of depression as compared to females following loss of a spouse (Gass, 1987; Osterweis et al., 1984; Thompson et al., 1991), male dementia caregiver levels of depression increase while female dementia caregiver levels of depression decrease following bereavement (Collins et al., 1994). It is often assumed that there is an inverse correlation between depression and perceived support (Baille et al., 1988) but this study raises questions as to the role of perceived support in alleviating depression in male spousal caregivers. Repeat studies need to be performed to determine the validity of these questions. If consistency in perceived support is validated and depression scores are

sustained then other variables may need to be considered other than perceived support as a factor affecting depression in male dementia caregivers who experience bereavement.

It would be interesting to note the levels of perceived support for the bereaved female caregivers in this study. Since depression scores for dementia caregiving women improved as compared to men despite the stress of lengthy caregiving, it may be helpful to examine the perceived support variable of female bereaved spousal caregivers and compare their levels of consistency to the levels of consistency in the male bereaved spousal caregiver.

Implications for Advanced Nursing Practice

While the majority of social support literature advocates the significance of social support and its buffering effect on life events (Cobb, 1988; Lin, 1986; Weiss, 1974), a few studies indicate that social support may not be a primary buffer for bereaved spousal dementia caregivers. In some studies, social support is only moderately helpful to the adjustment process of many older bereaved spouses. Faletti, Gibbs, Clare, Prunchno & Bermen, (1989) indicate that perceived support was influential in affecting bereavement outcomes, but even then, the measure of variability explained by social support was only between 4% and 14%. Gass (1989) reported that social support was only associated with lower psychosocial dysfunction for widows but not widowers. This suggests the need for the FNP to recognize that the impact of perceived support upon the bereaved male spousal dementia caregiver may differ from the impact of perceived support upon the bereaved female spousal dementia caregiver. Though male spousal dementia caregivers may have adequate levels of perceived support during caregiving, it can serve as no reassurance that high levels of perceived support during dementia caregiving will serve as a buffer against detrimental effects experienced by male spousal dementia caregivers following bereavement.

The data results in this research report suggests that there is a need for the FNP to assess the male caregivers

levels of perceived support. An important concern would be those male spousal dementia caregiver who had low levels of support during caregiving, as it can be assumed that their low levels of support will remain consistent throughout the bereavement transition. Male caregivers with low levels of perceived support bear close observation in the primary care setting as they are prime candidates for depression and its sequelae.

The male caregiver needs to be aware that the cessation of caregiving burden may not bring changes in social support. Education needs to be provided that stimulates insight into use and activation of support networks. It is important for the FNP to stress the essential nature of interactions with others so that when caregiving ends, social integration is preserved. Helping the male caregiver preserve his social identity may aid in enhancing his self esteem, which may become depleted once the role of primary caregiver is lost.

The findings from this research suggest that even those males with high levels of perceived support require intervention. High levels of perceived support indicate strong interpersonal ties but strong ties over long periods of time may limit the individual's social networks (Lin, 1986). Without a variety of social resources, it is less likely that the bereaved male caregiver will diversify his social mobility following bereavement (Lin, 1986). As a

result even those male caregivers with high levels of perceived support may need help broadening his support system.

FNP's can be instrumental in public policy development around issues that affect family caregivers. FNP's can work within their own communities to develop programs that assist caregivers. One area that has received more attention recently is how volunteers can be utilized to serve long-term care providers. FNP's could also be involved in designing and implementing educational and support groups for male spousal dementia caregivers. Advocating for funding sources of caregiver services including public and private monies could be a role FNP's might play. Male caregivers who have experienced the demands of spousal caregiving could be mobilized to express their views. FNP's know intimately the trials family caregivers experience and the toll that caregivers pay. This knowledge needs to be conveyed to those who formulate policies that affect families.

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APPENDIX A

APPENDIX A

Social Provisions Scale

1. There are people I can depend on to help me if I really need it.
- * 2. There is no one I can turn to for guidance (for help) in times of stress.
- * 3. If something went wrong, no one would come to my assistance.
4. I have close relationships that provide me with a sense of emotional security and well-being.
5. There is someone I could talk to about important decisions in my life.
- * 6. There is no one I can depend on for aid if I really need it.
- * 7. There is no one with whom I feel comfortable talking about problems.

* Negatively scored items

Note. From "The impact of Alzheimer's disease on family caregivers" by B. Given and C. Given, 1989, Executive Summary.

APPENDIX B

MICHIGAN STATE UNIVERSITY

November 28, 1995

TO: Cecilia L. Peasley
8544 Zbytowski Rd.
Alpena, MI 49707

RE: IRB#: 95-610
TITLE: PERCEPTIONS OF SUPPORT IN MALE SPOUSAL DEMENTIA
CAREGIVERS DURING TRANSITIONS FROM CAREGIVERS TO
BEREAVEMENT
REVISION REQUESTED: N/A
CATEGORY: 1-E
APPROVAL DATE: 11/27/95

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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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.

University Committee on
Research Involving
Human Subjects
(UCRIHS)

Michigan State University
232 Administration Building
East Lansing, Michigan
48824-1046

517/355-2180
FAX: 517/432-1171

Sincerely,

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

DEW:bed

cc: Clare Collins

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

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