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OF RELATIVES WITH ALZHEIMER'S DISEASE**

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**Anne Marie McKune**

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PERCEIVED COMPETENCE AND POSITIVE WELL-BEING IN  
FAMILY CAREGIVERS OF RELATIVES WITH ALZHEIMER'S DISEASE

By

Anne Marie McKune

A THESIS

Submitted to  
Michigan State University  
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for the degree of

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## ABSTRACT

### PERCEIVED COMPETENCE AND POSITIVE WELL-BEING IN FAMILY CAREGIVERS OF RELATIVES WITH ALZHEIMER'S DISEASE

By

Anne Marie McKune

This study examined the relationship between caregiver perceived competence and caregiver positive well-being in caregivers of a relative with dementia in a community setting. This research was a secondary analysis of a 4-year longitudinal study of family caregivers of dementia patients funded by the National Institute of Mental Health (2R01-MH41766). A cross-sectional design was used to examine Wave 3 data from self-administered questionnaires with sample size of 109. Using multiple regression analysis, caregiver perceived competence was shown to be significantly related to caregiver positive well-being. Implications for nursing practice and future caregiving research are presented.

To Angela and John with all my love

## ACKNOWLEDGMENTS

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## INTRODUCTION

Senile Dementia of the Alzheimer's Type (SDAT) is a progressive and irreversible dementia that afflicts 4 million American adults. If one considers the family members who care for the individuals with SDAT, the number of affected Americans would more than double. SDAT is the 5th leading cause of total disability in the United States and the 4th leading cause of death for adult Americans (Kuhlman, Wilson, Hutchinson, and Wallhagen, 1991).

In response to current health care delivery trends, the majority of SDAT individuals reside in the community rather than in nursing homes. The person responsible for the care of an individual with SDAT often needs to help the demented patient with bathing, feeding, dressing, transportation, and management of incontinence. This type of responsibility for another adult has the potential to cause high levels of stress. Dementia caregivers vary in their levels of distress to the caregiving challenges in SDAT (Schulz, O'Brien, Bookwala and Fleissner, 1995). The SDAT caregiver may be faced with a multitude of problematic situations. The caregiver may have to deal

with the relative with SDAT being actively resistant to care offered, becoming agitated or violent, and in need of constant supervision. When the care recipient's functioning becomes impaired and chronic, the act of caregiving may be conceptualized as a stressor. Cognitive incapacity and increase in limitations of activities of daily living (ADLs) are the most frequently cited hassles and objective burden caregivers encounter (Kinney and Stephens, 1989; Poulshcock and Deimling, 1984). The caregiver may also face a lack of financial resources and insurance coverage, inadequate formal assistance programs in the community, competing family obligations and outside employment and the lack of knowledge and skills required to provide care for an individual with SDAT. The caregiver's energy becomes depleted due to the chronic, progressive deterioration of the SDAT individual over time (Wilson, 1989).

Health care professionals (HCPs) need to understand how family SDAT caregivers can be helped with the caregiving role. The responsible person to provide the care in the home is most often spouses or significant others (Kuhlman et al., 1991). The caregiver role may have been assumed voluntarily out of a sense of dedication and commitment to the loved one with SDAT or resulting from a family decision-making process in which the role was imposed on another resulting in an unwanted set of

role obligations (Given, Collins, and Given, 1988). Caregivers as a group are selected for their roles within their families largely by virtue of their psychological strength (Haley, Levine, Brown, Berry, and Hughes, 1987), or from situational and family pressures without consideration of personality traits (Gold, Reis, Markiewicz, and Andres, 1995). The level of perceived competence of the primary caregiver to perform the tasks of caregiving for the relative with SDAT is not a factor in the decision-making process. HCPs may need to help the family caregiver by increasing the caregiver's knowledge and skills in the performance of daily caregiving tasks and fostering the perception of competence of their skills both in a quantitative and qualitative manner.

The process of SDAT caregiving is frequently conceptualized in the research literature using a stress model. Caregiving stressors may translate into significant and detrimental outcomes for the SDAT caregiver. One of the outcomes of the caregiving process is the effect on the caregiver's mental health (Pearlin, Mullan, Semple and Skaff, 1990). The adverse effects have been researched more than the positive effects and this is reflected in the SDAT caregiving research. The documented adverse effects range from anxiety, hostility, anger, and depression to sleep disturbance, somatization and lower life satisfaction (Given and Given, 1991; Kuhlman et al.,

1991; Schulz et al., 1995). The risk of adverse impact to both physical health and mental health has been associated with SDAT caregiving (Pruchno and Potashnik, 1989; Schulz et al., 1995; Zarit, Todd and Zarit, 1986). Research comparing the mental health of SDAT caregivers to the general population (matched for age and gender) show that SDAT caregivers display a higher level of negative affect, have more signs of psychological distress, and use more psychotropic drugs (Pruchno and Potashnik, 1989).

While some SDAT caregivers are adversely affected by caregiving, others seem to minimize damage to themselves. These caregivers may reappraise caregiving as a challenge and view the process as a personal growth experience (Stephens, Norris, Kinney, Ritchie and Grotz, 1988). These caregivers embrace the gains which experience yields. The SDAT literature documents caregivers who have strong communication with social networks that provide needed reinforcement and feedback (Ellis, Miller, and Given, 1989), who are gratified with their caregiving tasks (Motenko, 1989), and who cultivate beliefs that something has been gained by their hardships of caregiving (Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch, 1995) experience a greater sense of positive well-being. The research literature has also shown that caregivers who are involved in ADL care (Given, King, Collins and Given,

1988) and who provide more care to the dementia patient (Lawton, Rajagopal, Brody and Kleban, 1992) find positive rewards from the caregiving experience. HCPs can help family SDAT caregivers by assisting the caregiver in promoting a positive self-concept that will augment to greater positive well-being. While the positive aspects of caregiving have been explored, the relationship between caregiver's perceived competence and caregiver's positive well-being has not been investigated.

#### Purpose of the Study

This study will focus on the relationship between the caregiver's self-perception of caregiving competence to perform the needed tasks of caregiving for a relative with SDAT at home and the caregiver's positive well-being. This study will answer the question: Is there a relationship between caregiver perceived competence and caregiver positive well-being when cognitive functioning and ADL assistance requirements of the relative with SDAT are controlled?

### THEORETICAL FRAMEWORK

#### Introduction

This secondary analysis will be guided by the model of caregiving stress formulated by the research of Pearlin, Lieberman, Menaghan and Mullan (1981) and refined by the work of Pearlin et al. (1990). In Pearlin's et al. (1990) conceptual model of Alzheimer's caregiving stress (Figure



1), there are 4 main domains: (1) background, family and network composition, sociodemographic characteristics of the patient and caregiver and program availability in the community; (2) stressors distinguished as primary and secondary; (3) moderators or mediators; and (4) outcomes.

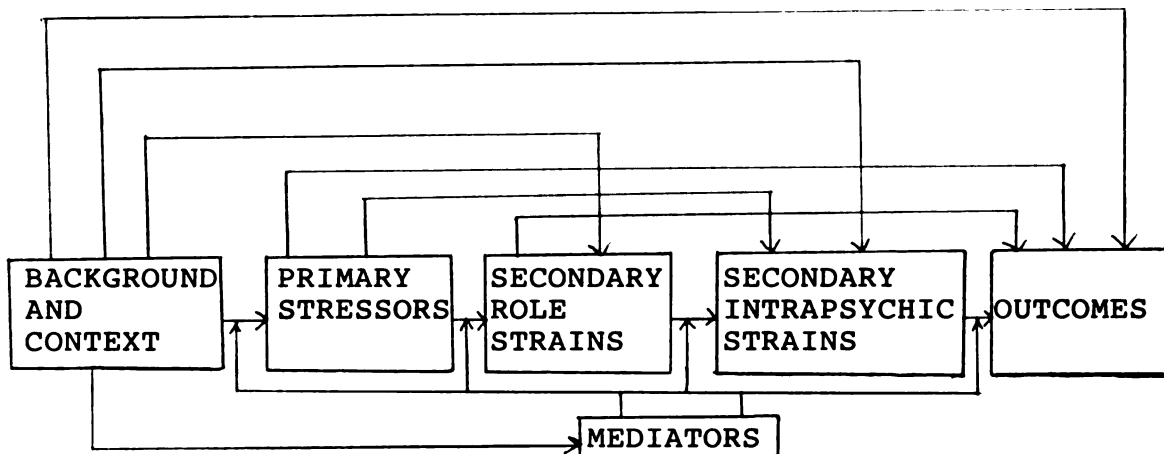


Figure 1. Caregivers' stress model (Pearlin et al., 1990).

This caregiving stress model displays dynamic characteristics that treat stress not from a unitary phenomenon or a single perceived stressful situation but from caregivers' lives becoming organized and changing over time and the effects of this mix of circumstances, experiences, responses and resources on their self judgments (Aneshensel et al., 1995; Pearlin et al., 1981). Caregiving stress is a complex process with numerous potential variables that may impact caregiver well-being. Any aspect of the first three domains have the potential

and capability of effecting the outcome to the process of SDAT caregiving. This theory shows how multiple situations such as change in patient status or experience and skills in caregiving may effect the emotional well-being of the caregiver in the caregiving process. The primary interest of this study is to examine the relationship between caregiver perceived competence and positive well-being while taking into account the possibility of aspects from other domains in the model influencing the relationship.

#### Background/Sociodemographics

This domain contains three elements:

(1) characteristics of the caregiver such as age, gender, education, employment status, marital status, years of caregiving and living arrangement with the SDAT patient; (2) social support network that represents the totality of one's relationships and not actual assistance which the caregiver may use; and (3) availability and accessibility to community-based formal programs. Any aspect of this domain may influence the relationship of stressors in SDAT caregiving and the outcome.

#### Stressors

The act of caregiving in and of itself is not the sole source of stress in SDAT. The variation in consequences of stressors among caregivers is influenced by caregiver's positive self-concept, health and behavior

(Pearlin et al., 1990). Stress arises when demands exceed resources. Stressors as defined by Pearlin et al. (1990) are "the problematic conditions, experiences, difficult circumstances and activities for people that threaten them, thwart their efforts, fatigue them and defeat their dreams" (p. 586). In SDAT, the patient's status of waning cognitive abilities exerts pressure on the caregiver's own sense of self and eventually on the caregiver's emotional well-being (Aneshensel et al., 1995). As the provision of care to assist with ADLs becomes more extensive and more frequent, the caregiver may become overwhelmed and the emotional well-being of the caregiver becomes affected (Aneshensel et al., 1995). Patient status variables such as cognitive incapacities and ADL requirements are considered to be primary objective stressors in Pearlin's et al. (1990) theory. The original set of hardships in the caregiving stress process are subjective and objective primary stressors. Primary stressors may lessen or intensify over time. Primary objective stressors generate primary subjective stressors like the loss of balance, loss of intimacy, and the loss of reciprocity in the SDAT caregiver/patient relationship and the overload of the caregiving role.

According to Pearlin's et al. (1990) theory, primary stressors proliferate into secondary stressors of role strains and intrapsychic strains. Secondary stressors

function as the channel through which primary stressors come to damage emotional well-being (Aneshensel et al., 1995). Secondary role strains are the roles and activities outside the caregiving situation like conflict in the family, economic strains, work conflict and constriction of social and recreational life.

The demanding nature of objective primary stressors leads to intrapsychic strains. Intrapsychic strains are internal dimensions of self-concept (Pearlin et al., 1990). Under the relentless and progressive nature of SDAT, the caregiver's self-concept may be diminished or damaged leaving the caregiver vulnerable to alterations in well-being (Pearlin et al., 1990). According to Pearlin's et al. (1990) theory, three intrapsychic strains may occur: loss of self, lack of caregiver competence and absence of caregiving gains. The primary interest in this study is the self-perception of caregiver competence. Competence deals with the caregiver developing a self-evaluation of how well he/she performs the role of caregiver (Aneshensel et al., 1995). The absence of competence causes an alteration in the positive elements of self-concept and feelings of not being competent as a caregiver. Thus, doubt in one's own competence in the caregiving role leaves the caregiver vulnerable to an alteration in emotional well-being. Both primary and secondary stressors have the potential to produce

deleterious effects and the terminology is not intended to denote the degree of importance. The variances in the severity of secondary stressors might help explain the differences in outcomes (Aneshensel et al., 1995).

### Mediators

Mediators modify or regulate the causal relationship between stressors and outcomes. Mediators are: coping, social support, financial endowment and mastery (or self-efficacy). The mediators limit the proliferation of secondary stressors by buffering or cushioning the effect of the severity of the stressor. Mediators may have the capacity to limit the proliferation of secondary stressors. Mediators may explain outcome variability for the effects of buffering can be judged by looking directly at the outcome (Pearlin et al., 1990).

### Outcomes

Outcomes are the effects or consequences of stressors. Care-related stress outcomes are usually observed as involving the individual's physical health and emotional well-being (either positive or negative); the ability to sustain themselves in their social roles, including family relations; and the yielding of caregiver activities. The element of emotional distress is likely to become apparent first; and then, if the stress persists, physical well-being falters (Pearlin et al., 1990).

For the purpose of this study, the primary focus

of the caregiver stress model of Pearlin et al. (1990) has been displayed to examine the relationship between caregiver perceived competence and caregiver positive well-being (Figure 2). This segment of the caregiving stress model depicts the caregiver's perception of whether or not the level of patient demands are stressful. The caregiver must evaluate his/her perceived competence level and deal with the level of demands. If the caregiver perceives a satisfactory level of competence, then the outcome may not alter the caregiver's positive well-being. If the level of perceived competence is not satisfactory to the caregiver, then a deleterious outcome may develop.

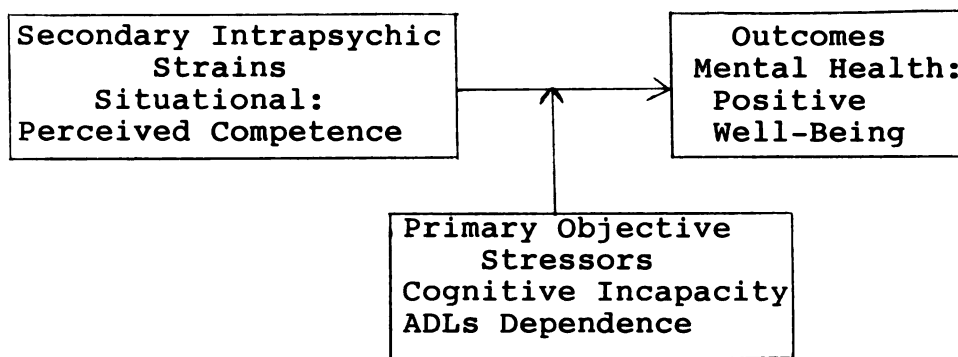


Figure 2. Primary focus model of present study.

## REVIEW OF THE LITERATURE

### Perceived Competence

The daily caregiving tasks for a SDAT relative may range from assisting with dressing, bathing and feeding;

to possibly dealing with new and unfamiliar chores like balancing a checkbook and preparing meals; to supervising and managing unpredictable and/or violent behavior. Care demands shift over time as the care recipient progresses in the level of dementia but the demands do not necessarily increase in intensity or occurrence (Zarit et al., 1986). A person with moderate dementia may exhibit wandering but low assistance requirements with activities of daily living (ADLs) and a person with severe dementia may have no desire to wander but requires total physical care. These shifts in care demands may dictate the caregiver to gain new skills or increase their degree of competence in the different areas of caregiving.

There is limited research on the topic of perceived competence of a caregiver giving care to a relative with SDAT. Wilken, Altergott and Sandberg (1996) examined the influence of feminine and masculine sex-role orientation of spousal caregivers on the self-perception of competence while caring for confused partners. They concluded that as cognitive incapacity increases, the self-perception of competence decreases. They suggest that greater caregiver competence can be predicted by masculine sex-role traits like assertiveness, competitiveness and control.

The concept of control is discussed in the SDAT literature as mastery. Mastery has been defined by Pearlin

et al. (1990) as "the control individuals feel they are able to exercise over forces importantly affecting their lives" (p. 589). In Pearlin's et al. (1990) theory, mastery is a personal psychosocial resource equated with self-efficacy and internal locus of control where as caregiver competence is the self-evaluation of how well one performs the role of caregiver and is denoted as an intrapsychic strain. Caregiver competence is an element of self-concept and involves skill enhancement. Mastery is an issue of control over environment and situations has been shown in the literature to exert positive effects on emotional well-being and offsets the effects of care-related stressors (Aneshensel et al., 1995). Pagel, Becker and Coppel (1985) have linked the loss of mastery or the perceived loss of control with depression in family caregivers of SDAT patients. Lawton, Kleban, Moss, Rovine and Glicksman (1989) defined caregiving mastery as the general feeling of competence in the caregiving role and most closely corresponds with Pearlin's et al. (1990) concept of caregiver competence. For the purpose of this study, Lawton's et al. (1989) concept of caregiving mastery will be equated with caregiver perceived competence.

Not all caregivers have the same degree of skills to manage tasks. The caregiver's perception of whether or not the task at hand is burdensome or stressful is referred to as caregiving appraisal. Lawton et al. (1989)



defined the term as "the cognitive and affective appraisals and reappraisals of the potential stressor and the efficacy of one's coping efforts" (p. P61). One's perception of competence in performing caregiving tasks is important in managing the caregiver role. Management involves the use of problem-solving skills, adaptability, the use of informal and formal support networks and minimizing disruptive patient behavior, family conflict and personal stress (Pallett, 1990).

In longitudinal analysis, Zarit et al. (1986) suggest that caregivers may tolerate problem behaviors over time. Caregivers learn to manage problems more effectively or they simply adapt and do not let the problems bother them anymore. Therefore, perhaps this growing tolerance may induce underestimation of the caregiver's perception of competence.

Collins, King, Given and Given (1994) researched factors that influence community service use among family caregivers of SDAT patients. They proposed that two important internal cues to seek services are the caregiver's appraisal of competency and psychological distress. Actual competency to manage the changing and challenging situation (i.e., patient is unable to ask for assistance to use the bathroom) may not be as high as the caregiver perceives it is or the caregiver may accurately perceive competency levels and does not need

any assistance from informal and/or formal services. An accurate perception of the limitations of one's competence is a strong incentive to seek help from others in the caregiving situation.

Caregiver's perception of competence is enhanced by the feedback that others provide. The more sources of possible positive feedback the caregiver has, the less impact a negative evaluation of caregiving skills will have (Skaff and Pearlin, 1992).

#### Conceptual Definition of Perceived Competence

For the purpose of this study, the concept of perceived competence is defined as the self-appraisal by the caregiver of the extent to which they perceive their caregiving efforts to be adequate in performing needed tasks.

#### Positive Well-Being

The majority of the literature in caregiving research focuses on the negative outcomes in the domain of mental health. Negative affect as the outcome of the SDAT caregiving process is usually conceptualized in the literature as depression, the decrease of life satisfaction, psychological distress or negative affect (George and Gwyther, 1986; Haley et al., 1987; Pagel et al., 1985; Pruchno and Potashnik, 1989).

There is an increasing amount of literature on the positive aspects of SDAT caregiving. Positive outcomes

to the SDAT caregiving process have been conceptualized in the research literature as caregiving satisfaction, caregiving uplifts and perceived positive rewards (Kinney and Stephens, 1989; Lawton et al., 1989; Montenko, 1989). Caregiving satisfaction encompasses enjoying being with the care-recipient or helping makes the caregiver feel closer to the care-recipient (Lawton et al., 1989). Caregiving uplifts are seeing the care-recipient calm or the care-recipient showing affection (Kinney and Stephens, 1989). Perceived positive rewards are an opportunity to repay a previous debt to the care-recipient (Montenko, 1989). This study will focus on the positive aspect in the global mental health domain.

In the global mental health domain, negative emotional states and positive well-being are subjectively determined by the caregiver's perception of the stress of SDAT caregiving. The subjective measure of well-being has more conceptual overlap with mental burden than objective measures of well-being. Positive well-being shows more mental subjective well-being and depression shows less mental subjective well-being (Stuckey, Neundorfer and Smyth, 1996). Therefore, positive well-being and depression are related mental health outcomes but not identical and should not be viewed as a positive-negative continuum. Rather, different aspects of mental health differ in the degree of caregiver perception of stress

or burden (Lawton et al., 1992; Stuckey et al., 1996).

Caregivers show great individual variability in their reactions to the stress of SDAT caregiving (Haley et al., 1987). In longitudinal SDAT caregiving research, some dementia caregivers experienced burnout while others improved their emotional well-being (Zarit et al., 1986). The longer a caregiver gives care, the better the caregiver's mental health may be either due to the "survival" effect (Gilhooly, 1984); the caregiver has had greater time to learn to cope and adjust (Zarit et al., 1986; Collins, Stommel, Wang and Given, 1994); or the caregiver has accepted the situation and chose to make the best of the situation (Williamson and Schulz, 1993).

A sense of well-being can be positively influenced by social networks of the SDAT caregiver. Ellis, Miller and Given (1989) studied the relationship between communication and positive well-being in care providers for patients with SDAT. They identified a casual relationship between family abandonment and involvement in ADLs which could lead to the prediction of social burden and isolation for the SDAT caregiver. They concluded that the perception of increased social support through communication of the social networks that the caregiver uses leads to greater positive well-being. Thus, positive well-being can be achieved for SDAT caregivers if

communication is effective with the social support network.

Motenko (1989) defined caregiving as "an expression of the bonds that tie people to their loved ones. This expression is necessary to maintain continuity in values, self-respect, and identity" (p. 166). Not all SDAT caregivers have feelings of moral responsibility or feel an emotional bond to the SDAT relative. Motenko (1989) concluded that wife caregivers who feel more gratified with their caregiving tasks, such as time for self, ADLs assistance to the relative and emotional support, had experienced an increase in positive well-being. Therefore, a feeling of gratification can be achieved from SDAT caregiving and positively influence well-being.

Caregivers who engage in the self-appraisal and reappraisal process can experience a greater positive affect. By cultivating beliefs that something has and can be gained by the hardships of SDAT caregiving (Aneshensel et al., 1995), and by redefining an event to derive mental stimulation or personal growth (Stephens, et al., 1988), the caregiver is able to experience a greater positive affect and is able to identify beneficial aspects of their caregiving experience.

The involvement in ADLs for the relative with SDAT has shown to influence caregiver positive well-being. Caregivers who provide more care and who are more heavily involved with the care may achieve positive well-being

by the increase chance for interaction with the individual with SDAT (Given et al., 1988; Lawton et al., 1992).

Conversely, high care recipient needs can also lead to stress and adversely effect emotional well-being.

To safeguard against the potential detrimental toll caregiving may take on SDAT caregivers, it is important to search for ways that will nurture the caregiver's positive well-being. HCPs must assist the caregiver in fostering a sense of accomplishing something positive even if the perception of stress can not be altered.

#### Conceptual Definition of Positive Well-Being

For the purpose of this study, the concept of positive well-being is taken from the 2-factor higher order model designed by Veit and Ware (1983). The 2-factor model was designed to measure general psychological distress and psychological well-being. Positive well-being will be defined as the combination of general positive affect and emotional ties; it is the feeling of cheerfulness and having interest in and enjoyment of life. Positive well-being is having more subjective well-being than less (ie, depression).

#### Relationship Between Perceived Competence and Positive Well-Being

The relationship between caregiver perceived competence and caregiver positive well-being is a critical component in the caregiving process but has received little

recognition in the SDAT caregiving research. Haley, Levine, Brown and Bartolucci (1987) studied 44 primary caregivers of senile dementia relatives and 44 matched control caregivers who were not caregivers of impaired relatives. The study concluded that caregivers who had increased levels of perceived competence in managing care activities and behavioral problems also displayed decreased levels of depression and physical health problems. The Haley et al. (1987) study should have been the stepping stone for further research on the relationship between perceived competence and well-being, but very limited research has been done up to this point in time on this particular relationship.

In order for a caregiver to successfully cope and manage with the chronically stressful situation of caregiving for a relative with SDAT, they must be able to identify those aspects of care which they perceive they are competent to handle and those tasks which they can not perform to their satisfaction. Pearlin's (1990) theory illustrates that stressors that evolve directly from providing care may give rise to stressors outside the boundaries of caregiving and disrupt the self-concept of the caregiver. The perceived competence a caregiver possesses is the reaction to the caregiving process; an individual, specific process variable that flows from caregiving. The caregiver may never have had to face

such tasks or situations as those associated with SDAT caregiving before in the caregiver's lifetime. A person is never fully cognizant of her/his capabilities or skill level until she/he encounters an unfamiliar situation; ie, SDAT caregiving.

A major outcome to the caregiving process, as predicted by Pearlin's (1990) theory of caregiving, is the alteration in the mental health of the SDAT caregiver. Positive well-being is a global mental health outcome that is not caregiving specific like the process variable of caregiver perceived competence. Positive well-being may be modified during everyday life stresses and burdens and therefore is not caregiving specific.

The caregiver's needs are based on a balance of gains and losses in caregiving, both of which the caregiver may experience at the same time. Lawton, Brody and Saperstein (1991) believe the caregiving themes of ego challenge and continuity influence perceived competence. Some caregivers may perceive caregiving for a relative with SDAT as a challenge and a test of personal competence to perform the required caregiving tasks well and view caregiving as an important stage in adult development. In a social context, the caregiver role provides continuity for the caregiver, strengthens the sense of competence as a caregiver and is an important source of security. Both of these caregiving themes serve to increase



self-feelings of caregiving satisfaction and positive affect.

This secondary analysis on the relationship between caregiver perceived competence and caregiver positive well-being is in much need with the limited research available on this relationship. This study will advance our knowledge in SDAT caregiving research by determining if a relationship exists between caregiver perceived competence and caregiver positive well-being when controlling for cognitive incapacity and ADL assistance requirements.

#### Extraneous Variables

As the cognitive abilities of the SDAT patient decline and the level of caregiving involvement to assist the SDAT patient in ADLs rises, a threat to the well-being of the caregiver in respect to emotional and physical well-being and perception of self-concept becomes likely. The SDAT caregiving literature has well documented that the variables of cognitive incapacity and ADL assistance requirements are the most likely variables to influence the relationship between well-being and self-concept of the SDAT caregiver (Aneshensel et al., 1995; Deimling and Bass, 1986; Kinney and Stephens, 1989; Poulshock and Deimling, 1984; Skaiff and Pearlin, 1992).

Pearlin's et al. (1990) caregiving stress theory denotes cognitive incapacity and ADL assistance as primary stressors which can proliferate into secondary stressors

and influence the outcome of SDAT caregiving. The other two major domains of the theory, background and sociodemographic characteristics and mediators, can also effect the caregiving process and alter the outcome to SDAT caregiving. Even though the domains of background and sociodemographics and mediators are a part of the stress model of Pearlin et al. (1990), they are not the primary focus of this study.

The degree to which an individual with SDAT is unable to perform a minimal set of intellectual tasks and the degree to which that same individual is unable to perform ADLs for self increases the potential for the creation of compounded stress on the caregiver. This objective stress leads to the likelihood of producing a lack of competence as a caregiver and developing a deleterious outcome from the caregiving experience (Pearlin et al., 1990). Therefore, since cognitive incapacity and ADL assistance requirements are the extraneous variables that are most likely to influence the relationship between caregiver perceived competence and caregiver positive well-being when SDAT is involved, this secondary analysis will control for these two extraneous variables.

#### Significance of Proposed Study to SDAT Caregiving Research and Advanced Practice Nurses

The significance of this study to the advancement of our knowledge regarding the relationship between caregiver perceived competence and caregiver positive

well-being is described in four main areas.

First, in present SDAT caregiving research there is a tremendous amount of confusion in the conceptualization and operationalization of variables used in caregiving literature. The differences among researchers in this respect makes for inconsistent and discontinuous knowledge. Positive well-being has been conceptualized in other research studies by positive affect, life satisfaction or morale. This study dealt with the issue by using measurement scales that were designed to operationalize the specific concepts examined in this study.

Second, some caregiving research studies that pertain to SDAT used caregivers that provided care to persons with mental impairment or physical disability and generalized the results of their study to the SDAT caregiver population. The SDAT caregiver population is a very qualitatively unique population. This study furthers SDAT caregiving research by using SDAT caregivers only and generalizing the results to the population studied.

Third, other SDAT caregiving research studies have used relatively small sample sizes; mainly a sample size less than 50. This secondary analysis will use a sample size of greater than 100 which will enhance the power of the study.

Fourth, caregiving research pertaining to SDAT has given little, if any, attention to the relationship between

caregiver perceived competence and caregiver positive well-being. SDAT caregiver research has examined the concept of caregiving mastery and emotional well-being but not individual caregiver competence. This study will constitute the first, to my knowledge, where caregiver perceived competence and caregiver positive well-being will be directly correlated in an SDAT caregiver population.

Advanced practice nurses (APNs) with their diverse capabilities as educators, change agents and clinicians will be able to use this study as a research base to aim intervention programs at easing secondary stressors that might relieve the caregivers of some of the deleterious outcomes and preserve positive well-being. APNs are able to influence the caregiving situation by assisting the caregiver to focus on aspects that can be modified and manage aspects of care that may alter a positive experience. APNs are able to assist the caregiver in developing an awareness of declining competency to manage the caregiver role and can educate the caregiver on how to build on the perceived competency of the caregiver to enhance the caregiver's skills and to detect the appropriate time to discuss problems so the caregiver can avoid the "too little, too late" syndrome. These then represent the significant features of this research.

## METHODOLOGY

Research Design

A cross-sectional correlational design will be used to determine if a relationship exists between the two primary study variables: caregiver perceived competence and caregiver positive well-being in caregivers who care for a relative with Alzheimer's disease at home. The data for this secondary analysis was taken from the 4-year longitudinal study "The Impact of Alzheimer's Disease on Family Caregivers" (grant #2R01-MH41766 funded by NIMH) whose principal investigator was Dr. Clare Collins at Michigan State University. One of the specific aims of the original study was to compare the longitudinal course of depression among residential caregivers, bereaved caregivers, and caregivers who institutionalized their relative.

Data Collection

Telephone interviews of 1.0 to 1.5 hours in length and mailed self-administered questionnaires were used to collect the information from the caregivers in the original study. For this secondary analysis, data will be used from the self-administered booklets (SABs) of wave 3. Wave 3 designates the third time in the 4 year study that the caregivers were asked to give information via the telephone interview and by filling out the SAB. Wave 3 was approximately 36 months from the initial data collection. Wave 3 was selected because it was the only

wave in the original study in which the Perceived Competence scale was administered. These SABs were mailed questionnaires that were independently filled out by the participants.

#### Limitations of this Study

This particular study design was chosen because the study will hope to explain and determine if a relationship exists between the variables. One of the limitations of the study design is the nonprobability sampling plan used; the use of probability sampling would have increased the external validity of the study and increase the generalizability of the results. Another aspect of the study that might possibly be viewed as a limitation is the addition of 101 participants at the end of wave 2 data collection in the original study. This addition of participants may be an issue of measurement bias. Since the new 101 participants had not gone through the interview process at the prior wave, they may view the interview process differently. The participants at the prior wave had already been exposed to a previous telephone interview and self-administered questionnaire.

A major limitation in this secondary analysis is that as the person doing the secondary analysis, this researcher had no control over the measures used or how the data was collected. A secondary analysis of data limits the researcher to information obtained by the principal investigator. Finally, the use of cross-sectional analysis

makes it difficult to show causal order of the variables in the relationship.

#### Sampling Procedure and Criteria

The sample for this quantitative study was a volunteer, nonrandom sample of caregivers who were recruited for a 4-year longitudinal study of the experience of providing care to a family member with Alzheimer's disease. A letter describing the study was distributed to potential subjects identified from mailing lists of the Alzheimer's Association, the Michigan Association of Adult Day Care Centers, and health agencies in southwest Michigan. The letter was accompanied by a postage paid card to be returned to the research staff by individuals interested in participation.

Potential caregiver/relative dyads who made contact with the research staff were telephoned and screened for the following criteria: (1) the relative was at least 55 years old or above; (2) the relative was dependent in at least one instrumental activity of daily living (IADL) and one activity of daily living (ADL); (3) the caregiver reported that the relative had a medical diagnosis of Alzheimer's disease or related dementia; (4) the caregiver was self-identified as the family member who assumed primary responsibility for the relative with dementia; and (5) the relative resided in the community setting at the time of entry into the study.

For this secondary analysis, the sampling criteria

was: (a) caregivers must have completed wave 3 by returning the completed SAB and (b) the caregiver must have taken care of the relative in the home setting at the time wave 3 was administered.

### Measures and Instruments

For the purpose of this study, caregiver positive well-being was operationalized by the Positive Well-Being instrument as developed for the Rand Corporation (Veit and Ware, 1983). The Positive Well-Being is a 10 item questionnaire that is measured on a 4-point Likert scale. The higher score one obtains, the more positive well-being one has. The total possible score range was 0-40. The self-administered questionnaire asked participants to indicate how often in the past month they had experienced feelings of calm and peacefulness, felt free from tension, been a happy person, satisfied with personal life, felt fresh and rested, expected to have an interesting day, enjoyed the things that she/he did and felt hopeful about the future. The participants were to chose the answer closest to the way she/he had been feeling as: (1) rarely or none of the time; (2) some of the time; (3) most of the time; and (4) almost all of the time.

Veit and Ware (1983) showed a very strong internal consistency for this scale. The Mental Health Inventory designed by Veit and Ware (1983) was field tested at six different sites with a combined N of 5,089 which was a noncaregiving sample of all adults. The Cronbach's alpha



for the psychological well-being factor was .92. For the 1-year stability analysis of the scale, an identical version of the MHI was field tested to a subsample at each site with an  $N = 3,525$ . For this 1-year interval, the stability coefficient was .63 for the psychological well-being factor (Veit and Ware, 1983).

For the purpose of this study, caregiver perceived competence was operationalized using a revised 5-item scale from the Caregiving Mastery (ie, perceived competence) 6-item scale designed by Lawton et al. (1989). Since Lawton's et al. (1989) caregiving mastery scale has not been extensively used, this researcher was faced with the dilemma as to whether or not to use all or portions of his original scale. The evidence needed to support this researcher's decision to use the competence scale came from Dr. M. P. Lawton (personal communication, July 1, 1996) and information on the reliability score he sent this researcher on an unpublished sample of  $N = 580$  using his original scale. The Cronbach alpha for his unpublished sample was .71. For this secondary analysis, the Lawton et al. (1989) competence scale was reanalyzed using the sample of  $N = 96$  from the original study. The Cronbach alpha was .73 for the 6-item scale; and after the deletion of item 3 ("I should be doing more for \_\_\_\_."), the reliability improved to .76. It was decided by this researcher that the revised 5-item perceived competence scale showed good internal

consistency.

The issue of face validity was analyzed. A major advantage of using the Lawton et al. (1989) competence scale is the strong theoretical fit between my conceptual definition of caregiver perceived competence and Lawton et al. (1989). Paraphrased from an earlier definition, caregiver perceived competence is a self-perception to judge one's own ability to perform needed tasks during the caregiving process (Lawton et al., 1989).

The 5-item competence scale chosen taps the concepts of uncertainty to help the patient, knowing that the patient is getting proper care when the caregiver is taking care of the patient, ability to handle most of the problems in the care of the patient, pretty good at figuring out what the patient needs; and feeling that she/he as caregiver could be doing a better job in caring for the patient. The self-perceived ability of the caregiver to perform certain duties/tasks for their relative with SDAT was scored on a 5-point Likert scale as: (1) strongly disagree; (2) disagree; (3) neither agree nor disagree; (4) agree; and (5) strongly agree. The perceived competence scale was only used in the SABs of wave 3. The higher the positive score, the higher the perceived competence is for the caregiver who cares for a relative with SDAT. The total possible score range was 0-25.

For the purpose of this study, patient ADL requirements were measured by using the subscale of ADLs

from the Caregiver Involvement Inventory which was designed in the original study (Final Report, 1987). The caregiver involvement inventory consists of 34-items that measures 3 sets of tasks the caregiver may be involved in to assist the SDAT patient. The tasks include: (1) activities of daily living (ADLs); (2) instrumental activities of daily living (IADLs) and; (3) health care activities which are specific medical treatments. The ADL subscale included: eating, dressing, bathing, grooming, toileting and walking. Caregivers were asked if the care recipient required assistance with the activity in a yes/no format producing a nominal measure, a simple counting of activities. The greater number of yes responses, the greater the number of ADLs in which the relative required assistance.

For the purpose of this study, patient cognitive status was measured by using the subscale of Cognitive Behaviors that was taken from the Behavioral Symptoms of Alzheimer's Patients scale designed in the original study (Final Report, 1987). The scale was developed after the review of the SDAT literature failed to show an existing measure that incorporated the full range of behavioral problems common among persons with dementia. The Cognitive Behaviors subscale used a 4-point Likert response measure with (0) not at all; (1) sometimes; (2) most of the time; and (3) always. The caregiver was asked 7 items on how frequently the relative with SDAT displayed the following behaviors: unable to recognize familiar

people, seem confused, forgot what day it is, get the present mixed up with the past, forget where she/he is, forget important or recent events, and repeat herself/himself or ask the same question over and over again. The higher the score, the greater the cognitive impairment the relative with SDAT had. In the original study, the Cronbach's alpha with an  $N = 307$  was .91; at Phase 1 with an  $N = 120$ , the Cronbach's alpha was .82; and at Phase 2 with an  $N = 93$ , the Cronbach's alpha was .79 for this subscale.

#### Protection of Human Subjects

The caregivers involved in the original study were informed of the purpose of the study; and if they chose to participate, signed an Institutional Review Board approved consent form. Verbal consent was obtained from each caregiver at each subsequent data collection point. The original study was reviewed and approved by the University Committee on Research Involving Human Subjects (UCRIHS) at Michigan State University. There were no identified risks to the caregivers in the original study. Confidentiality was provided by the use of case numbers versus names on all questionnaires.

For the purpose of this secondary analysis, this author obtained approval from UCRIHS at Michigan State University before analyzing the data (Appendix C). This researcher had access to data only via case numbers on a disk that was obtained after receiving approval from

UCRIHS. The disk contained no identifying information which safeguarded confidentiality and prevented this investigator from identifying any individual who participated in the original study.

## RESULTS

Data were analyzed using the SPSS statistical program. The alpha level for all used significance tests was  $p=.05$  unless otherwise indicated.

### Sociodemographics of Sample

Univariate statistics of mean, standard deviation, and range were used to organize the sociodemographic information of the SDAT caregivers and the SDAT relatives as shown in Table 1. Several characteristics were dichotomous and are also shown as percentages. The characteristic of race in the original study showed 93% Caucasian with only 7% as minority patient/caregiver dyads so that characteristic is not included. The caregiver sample ( $N=109$ ) resembles other research SDAT caregiver samples as being mostly female (77%), over the age of 60 (mean 62.5,  $SD=10.7$ ), living with the SDAT relative (87%) and related to the SDAT relative as a spouse (72.5%). The SDAT caregivers were not employed (74.7%) at the time of data collection of Wave 3. The educational status of the caregivers shows 84% are high school graduates or greater with 24% being college graduates and/or professionals. The duration of care ranged from 6 months to 20 years which depicts SDAT as a chronic disease.

Table 1. Sociodemographic Characteristics of Caregiver and Relative with SDAT

	Relative N=109	Caregiver N=109
Age (Mean, Std. Dev.)	72.1 (8.3)	62.6 (10.7)
Range	56-91	32-82
Gender		
Male	59 (54%)	25 (23%)
Female	50 (46%)	84 (77%)
Marital Status		
Married	84 (77%)	98 (90%)
Single	2 ( 2%)	6 (5.5%)
Widowed	20 (18%)	-
Separated	1 ( 1%)	-
Divorced	2 ( 2%)	5 (4.5%)
Duration of Care (in months)		60.3 (42.4) Range 6-240
Living Arrangements*		
with relative		95 (87%)
without relative		12 (13%)
Caregiver Educational Level		
less than High School		17 (15.6%)
HS graduate		30 (27.5%)
some college		36 (33.1%)
college grad/professional		26 (23.8%)
Caregiver Employment Status		
employed		28 (25.6%)
not employed		81 (74.4%)
Caregiver Relationship		
spouse		79 (72.5%)
child		20 (18.3%)
other		10 ( 9.2%)

\*Missing 2 from sample total of N=109

The average duration of care was 5 years (SD=3.5 years) and 47.7% caring for the SDAT relative for 5 years or greater. One could define this group of SDAT caregivers are seasoned and not novices. Only 24.7% have cared for the SDAT relative for less than 2 years and over 58% have cared for the SDAT relative for 3 years and over.

#### Extraneous Variables

Pearson r correlation coefficients were performed on the interval data of sociodemographic characteristics of patient age, caregiver age and length of caregiving to determine if a significant relationship existed among these background variables and the primary study variables. The correlation coefficients are shown in Table 2. Neither patient age, caregiver age or duration of care were found to be significantly related to the two primary study variables.

One-way ANOVAs were performed on the categorical data of caregiver sociodemographic characteristics of marital status, educational level, employment status, relationship to SDAT relative, gender and living arrangements in relationship to the SDAT relative to determine if a significant relationship existed among any of these background variables and the two primary study variables. The one-way ANOVAs (Table 3.) for the categorical sociodemographic characteristics showed a significant relationship between perceived caregiver competence and caregiver employment status ( $F(1, 99)=6.5$ ,

Table 2. Correlation Coefficients of Sociodemographic Characteristics and Perceived Competence and Positive Well-Being (N = 109).

	BCAGE	BDURCARE	BPAGE	COMPMEAN	PWELL
BCAGE		.24 p=.01	.16 p=.10	-.07 p=.50	-.05 p=.63
BDURCARE	.24 p=.01		.07 p=.50	.03 p=.73	.15 p=.13
BPAGE	.16 p=.10	.07 p=.50		-.04 p=.67	.02 p=.88
COMPMEAN	-.07 p=.50	.03 p=.73	-.04 p=.67		.33 p=.00
PWELL	-.05 p=.63	.15 p=.13	.02 p=.88	.33 p=.00	

Table 3. ANOVAs of Sociodemographic Characteristics to Perceived Competence and Positive Well-Being (N = 109).

	Caregiver Perceived Competence	Caregiver Positive Well-Being
Living Arrangements	F = .32 p = .56	F = 2.65 p = .10
Caregiver Marital Status	F = .63 p = .53	F = .19 p = .82
Caregiver Educational Status	F = .54 p = .66	F = 1.76 p = .16
Caregiver Employment Status	F = 6.58 p = .01	F = .23 p = .63
Caregiver Relationship To Relative	F = .79 p = .45	F = 1.40 p = .25
Caregiver Gender	F = .96 p = .33	F = .24 p = .62



$p=.01$ ). Employed caregivers had less perceived competence whereas unemployed caregivers displayed a greater level of perceived competence. Caregiver gender, caregiver marital status, caregiver educational level and caregiver living arrangements to the SDAT relative were not found to be significantly related to either of the two primary study variables. Thus, caregiver employment status was added as an extraneous variable to the multiple regression model.

Univariate statistics were performed to calculate the means, standard deviations and range for the 6 ADL tasks. A Cronbach alpha was not obtained due to the nominal nature of the score. The ADL assistance requirements shown in Table 4. for the SDAT relative in wave 3 indicated a high need for assistance with the 6 ADL tasks with a mean of .78 (SD=.28) out of a possible range of 0-1. The caregivers (N=107) assisted the SDAT relative most in dressing, grooming and bathing (N=97 or 90.6%), followed by need to assist with toileting (N=87 or 74.7%) and eating (N=76 or 71.6%). Walking was the least ADL task that required assistance from the caregiver (N=54 or 50.5%).

Univariate statistics were performed to calculate the mean, standard deviation and range of the 7 items on the cognitive incapacity scale. A Cronbach alpha was performed to determine the internal consistency of the scale for the sample in this study. The level of cognitive

incapacity shown in Table 4. was moderately high for the SDAT relative in wave 3 with a mean of 1.89 (SD=.61) out of a possible range of 0-3. The SDAT relative was almost always forgetful (mean=2.27, SD=.91) and confused (mean=2.02, SD=.79). In this study, the cognitive incapacity scale maintained internal consistency with a Cronbach alpha of .74 compared to a Cronbach alpha of .79 (N=93) in the original study.

Overall, the SDAT relatives in this study showed a high degree of need for assistance with ADLs and a moderately high level of cognitive incapacity.

Table 4. Means, Standard Deviations, Ranges and Cronbach Alphas for the Scales Used in the Study

Scale	Mean	SD	Ranges		Cronbach Alpha	
			Possible	Actual	Original Study	This Study
ADLs*	.78	.28	0-1	0-1	--	--
Cognitive Incapacity	1.89	.61	0-3	.4-3	.79	.74
Perceived Competence	3.67	.59	1-5	1.6-5	.76	.72
Positive Well-Being	2.34	.63	1-4	1-3.8	.92	.92

\*No determined alpha due to nominal measurement

#### Primary Study Variables

Univariate statistics of mean, standard deviation and range and Cronbach alphas were performed on the two primary study scales (Table 4.). The 5-item Perceived Competence scale used in this study showed acceptable

internal consistency with Cronbach alpha of .72. The caregivers felt moderately competent (mean=3.67, SD=.59) to care for the SDAT relative. With the actual range minimum being 1.6, the caregivers did not strongly disagree on any of the items on the scale. The Positive Well-Being scale (Table 4.) showed strong internal consistency with Cronbach alpha of .92. The caregiver's overall mean of 2.34 (SD=.63) indicates that some to most of the time the caregivers had feelings of positive well-being over the past month.

The SDAT caregivers in this study displayed a perception of feeling competent as a caregiver with associated positive feelings of mental health some to most of the time.

#### Answer to Study Question

A step-wise multiple regression analysis with forward entry of variables was performed to quantify the relationship between caregiver perceived competence and caregiver positive well-being. This statistical procedure is a method used for understanding the effect of two or more independent variables on a dependent variable (Polit and Hungler, 1995). Block style entry of variables was used to extract the effect of the extraneous variables. The patient characteristics of ADLs and cognitive incapacity were entered first so caregiver employment status could be examined in relation to positive well-being without these two patient characteristics influencing the

relationship. Then, caregiver employment status was entered so the combined simultaneous influence of the two patient characteristics and caregiver employment status could be extracted from the relationship between caregiver perceived competence and caregiver positive well-being. The patient characteristics of ADLs and cognitive incapacity (Table 5.) explained 1% of the total variance in caregiver positive well-being. Neither of these patient characteristics were statistical significant to positive well-being in this regression model.

Table 5. Multiple Regression Predicting Positive Well-Being in SDAT Caregivers (N = 109).

Step	Beta	Mult R	Total R <sup>2</sup>	Adj R <sup>2</sup>	F-value	F-signf
Block 1 Patient ADLs Cognitive Incapacity	.05 -.08	.12	.01	.01	.63	.53
Block 2 Caregiver Employment	-.01	.14	.02	.01	.61	.61
Block 3 Primary Variable Competence	.38*	.39	.15	.13	4.04	.0046*

\*p < .005

When the caregiver variable of employment status was added to the multiple regression model, the explained variance was 2% of the total variance in caregiver positive well-being. The percent of explained difference was only 1%. Caregiver employment status was not found to be

statistically significant to positive well-being in this regression model.

After the combined effects of ADLs, cognitive incapacity and caregiver employment status were removed and the primary study variable caregiver perceived competence was added to the multiple regression model, the explained variance increased to 15% of the total variance in caregiver positive well-being. The adjusted R-squared changed by .13 for caregiver perceived competence. The predictor variable of caregiver perceived competence was significant ( $F=4.04$ ,  $p=.0046$ ) in relationship to caregiver positive well-being by this multiple regression model.

## DISCUSSION

### Interpretation Relative to Framework and Literature

It is important to acknowledge the complexity of the SDAT caregiving process. Pearlin's et al. (1990) stress model of SDAT caregiving illustrates this complexity and one must be aware that there are numerous potential variables that can effect the ultimate outcome of the SDAT caregiving process that were not evaluated in this study that could have effected the examined relationship. This secondary analysis looked at only a compact segment of the Alzheimer's caregiving stress model of Pearlin et al. (1990) which focused on an intrapsychic secondary strain in relation to a positive mental health outcome to the caregiving process. This was a preliminary study of the

examination of the relationship between caregiver perceived competence and caregiver positive well-being. This study was able to determine that caregiver perceived competence is a strong predictor variable of caregiver positive well-being. The value of this study should not be diminished but more variables need to be added to the multiple regression model designed in this study. Pearlin's et al. (1990) stress model will lend theoretical guidance as to what variables should be potential variables.

In accordance with Pearlin's et al. (1990) conceptualization of the caregiving stress process and the literature review based on this topic, one would predict that the primary stressors of ADL dependence and cognitive incapacity would effect the relationship between caregiver perceived competence and positive well-being. In this analysis, that did not happen. Using the SDAT caregiver sample in this study, this researcher was unable to find support to include ADLs and cognitive incapacity as significant predictors of caregiver positive well-being. This researcher was able to find support to state that caregiver perceived competence is a significant predictor of caregiver positive well-being bearing in mind that caregiver perceived competence is not the only predictor.

The SDAT caregivers in this study were seasoned caregivers who were able to express feelings of positive well-being from the caregiving experience with maintenance of a comfortable level of perceived competence. These

findings are supported by Aneshensel et al. (1995) who concluded that as patient condition worsens over time, the caregiver's appraisal in relation to caregiving decreases the doubt about skills in performing caregiving tasks and the caregiver feels positive about the job they are doing.

Of the caregiver variables examined in relation to caregiver perceived competence and caregiver positive well-being, only one was significant to either of the primary study variables and that was caregiver employment status. Although the mean differences were significant as calculated by ANOVA, the variable of caregiver employment status was not a significant predictor in the regression model. Caregiver employment status was unable to account for more than 1% of the total variance found in caregiver positive well-being.

There is much research that shows that SDAT caregivers experience depression and other adverse effects as the outcome to the caregiving process (Given and Given, 1991; Kuhlman et al., 1991; Pruchno and Potashnik, 1989; Schulz et al., 1995). Research also shows that caregivers can vary in their response to the caregiving process (Collins et al., 1994; Williamson and Schulz, 1993; Zarit et al., 1986) which shows that adverse outcomes to the caregiving process do not need to be the norm. The findings in this study aid the growing body of much needed research literature that is documenting that feelings of positive

well-being can be achieved as an outcome to the caregiving process. The possession of a self-perception of competence in the caregiving role is only one factor that has the potential to influence caregiver positive well-being.

#### Limitations and Methodological Problems

One of the most serious limitations of this study was the voluntary convenience sample. The sample only used caregiver/patient dyads who used adult day care centers, health agencies or where on the Alzheimer's Association mailing list. The sample did not encompass caregivers who are "doing it alone", who do not seek outside assistance or perceive that no assistance is necessary. The sampling procedure is similar to other SDAT caregiving research sample. This sampling procedure limits the generalizability of the study's findings.

The diagnosis of SDAT or related dementia was self-reported by the caregiver and not a medical diagnosis. Diagnostic uncertainty must be viewed as a limitation in the study for the results may not be applicable for caregivers with relatives that have been medically diagnosed with SDAT or a related dementia.

Due to the cross-sectional design of this secondary analysis, the reader must be cautious in the findings since directionality of the relationship of the primary study variables can not be determined. The use of cross-sectional design in SDAT caregiving has been the major design used in the research literature up to this point in time.



SDAT caregiving is a complex process that encompasses the family and not just a single individual. A limitation of this study is that it attempted to simplify the caregiving process by looking at only the primary caregiver and not the family dynamics and functioning.

The operationalization of the concept of caregiver perceived competence in this study was used by a 5-item scale. The concept of perceived competence may not have been represented to its fullest capacity with only 5 items. A more broad, encompassing scale of the self-perception of competence may have been justified.

#### Recommendations for Future Research

Now that caregiver perceived competence has been shown to be a factor that can strongly predict caregiver positive well-being, further research on the topic needs to be done. Longitudinal research studies need to be undertaken to examine perceived competence level of the SDAT caregiver over time and at different stages of the relative's course of dementia. Caregiver positive well-being needs to be examined in relationship to caregiver perceived competence over time. Does the relationship between these two variables remain stable?; do they change?; how do they change?; and what influences the change?

An experimental study that would examine the relationship between caregiver perceived competence and caregiver positive well-being would be interesting. An experimental study to see if an intervention to improve

perceived competence would result in an improvement in positive well-being.

This study evaluated the relationship between caregiver perceived competence and caregiver positive well-being examining the effects of ADL assistance requirements of the SDAT relative, the level of cognitive incapacity of the SDAT relative and caregiver employment status on this relationship. Future research on this topic needs to encompass variables that have the potential to alter the relationship between caregiver perceived competence and positive well-being. Patient behavior variables of night time wandering, incontinence and agitation need to be examined. A step further in research would include the examination of caregiver's perceived competence to positive well-being when the SDAT patient moves into the nursing home setting.

The relationship between caregiver perceived competence and caregiver positive well-being needs to be evaluated by taking into consideration the perception of the caregiver's physical health before and after caregiving; financial/economic constraints; the use of social support network and prior caregiver experience. The consideration of family dynamics and functioning as well as the quality of the prior relationship and role status of caregiver to patient should be evaluated. The difference between caregiver's perception of competence and level of competence perceived by the external system is important to examine.

Research needs to be undertaken in the future to attempt to persuade more male caregivers, nonspousal caregivers and minority caregivers to participant in research studies. Research studies also have to find a way to include the elusive caregivers who have isolated themselves and the care-recipient from formal caregiving programs or who have chosen not to use services or seek assistance in their caregiving role.

#### Implications for Nursing Practice

After the APN evaluates this study for strengths and weaknesses, she/he will determine that the limitations do not invalidate the findings and conclusions. This study is theoretically based which only further strengthens the knowledge of APNs. The APN needs to consider not only characteristics of this study that may fit her own nursing practice, but also whether or not her/his present nursing behaviors are effective or does she/he need to change present practice behaviors (Stetler and Marram, 1976). APNs must decide for themselves whether or not to apply these research findings into direct action.

According to Stetler and Marram (1976), the APN has 3 choices in the decision-making process of what to do with this study's findings: (1) nonapplication; (2) cognitive application; or (3) direct application. This researcher advocates the use of this study to APNs in the area of cognitive application. Clinically, it is important to assess caregiver perceived competence and safeguard

against the caregiver underestimating her/his caregiving skills. In collaboration with the caregiver, the APN can determine areas of strength and weaknesses in the caregiving role. The APN then can teach the necessary skills in the areas of weakness of the caregiver's perceived competence level. APNs will need to determine if the caregiver has redefined their meaning of satisfactory completion of caregiving tasks through the course of the disease. A major role the APN will have is to validate the caregiver's ability to perform the caregiving tasks. The APN must review with the caregiver those aspects of care that can not be controlled and reassure the caregiver that it does not translate into meaning the care is being performed incorrectly. The APN may use her assessor role and educator role to boost caregiver's self-perception of competence in the SDAT caregiving role.

The findings of this study would require minimal cost to incorporate into practice but would require the APN to use her/his case management role to provide the necessary holistic care of both the SDAT patient and the SDAT caregiver. The APN may use the researcher role to replicate this study to determine the significance of caregiver perceived competence and caregiver positive well-being first hand.

The cost-effectiveness in incorporating the findings of this study into practice lie in the interventions necessary to decrease and/or prevent the incidence of

depression in SDAT caregivers and foster positive well-being. APNs need to direct efforts to aid the caregiver in avoiding the proliferation of secondary stressors that can be prevented or minimized and promote the aspects of mental health. The APN should assist the caregiver in evaluating what aspects of the current caregiving situation can be modified and managed. Assessment of caregiver positive well-being is important. The APN must remember to examine the mental health of the SDAT caregiver. Unfortunately, health care professionals (HCPs) often fall one question short when dealing with the SDAT patient/caregiver dyad. HCPs will address the patient problem forgetting that the patient problem has the potential to proliferate into a caregiver stressor. The use of Pearlin's et al. (1990) model will guide APNs to ask that question in order to provide holistic care and see the "whole" picture. The APN determination of the caregiver's inability to meet caregiving demands is crucial for the positive well-being of the caregiver.

The APN must use her counselor role to evaluate the mental health status of the SDAT caregiver and provide assistance when the caregiver is in need of emotional support. The APN must instill hope into the SDAT caregiver and provide the nurturance to enhance positive mental health. The APN can assess the need for respite care for the caregiver, explore what activities the caregiver enjoys doing and determine the pattern of social support the

caregiver utilizes.

The final implication to APNs this study suggests addresses the current legislation proposed in California. Legislation to determine competency of skills of family members or designated caregivers to care for an individual being discharged from a hospital with a chronic disease is being proposed. The APN must be aware of the societal concerns this proposed legislation entails. APNs will need to be cognizant of a potential conflict between the self-perception of competence of a caregiver and the health care system's "gold standard of care". APNs must rationalize should HCPs even judge competency of caregivers or is caregiving a personal and family matter not open to outside scrutiny? HCPs ask, even sometimes demand, that a family member take home an individual from the hospital when that caregiver does not perceive she/he are competent to do so. Will judgment of competence from an outsider deleterious effect the positive well-being of the caregiver? APNs are in the prime position to deliver holistic care and examine all aspects of the caregiving process.

This study examined the relationship between caregiver perceived competence and caregiver positive well-being in family caregivers of a SDAT relative in the home setting. Caregiver perceived competence was found to be one factor that is able to account for the variance in caregiver positive well-being. Health care delivery trends will demand

the continuation and maintenance of home care for SDAT individuals. The SDAT caregiver will undoubtedly be faced with the stress of SDAT caregiving. Family SDAT caregivers must not be left to face this stress alone and must be supported in their caregiving efforts so they will not abandon this role. APNs are at an unique position to foster the caregiver's perception of competence and provide holistic care to promote positive well-being in this vital and important group of informal caregivers.

## **APPENDICES**



## APPENDIX A

## APPENDIX A

## POSITIVE WELL-BEING

For each question, read the statement then circle the one answer that comes closest to the way you have been feeling during the past month. There are no right or wrong answers.

DURING THE PAST MONTH, HOW MUCH OF THE TIME...

1. have you felt that the future looks hopeful and promising?

ALMOST ALL THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME
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2. has your daily life been full of things that were interesting?

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME
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3. did you feel relaxed and free of tension?

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME
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4. have you generally enjoyed the things you do?

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME
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5. have you felt calm and peaceful?

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME
---------------------------	---------------------	---------------------	----------------------------------

6. have you felt cheerful, lighthearted?

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME
---------------------------	---------------------	---------------------	----------------------------------

7. were you a happy person?

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME
---------------------------	---------------------	---------------------	----------------------------------

8. have you been satisfied or pleased with your personal life?

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME
---------------------------	---------------------	---------------------	----------------------------------

9. have you expected to have an interesting day?

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME
---------------------------	---------------------	---------------------	----------------------------------

10. have you been waking up feeling fresh and rested?

ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME
---------------------------	---------------------	---------------------	----------------------------------

## APPENDIX B

## APPENDIX B

CAREGIVING INVENTORY  
Perceived Competence

In the questions that follow, please circle the response that most represents how you feel about each statement. The blank line in the statements represents the name of the person for whom you provide care for. Answer all the questions in response to caring for your relative. Circle one response for each statement.

1. I am uncertain what to do to help \_\_\_\_\_ .  

STRONGLY	AGREE	NEITHER AGREE	DISAGREE	STRONGLY
AGREE		NOR DISAGREE		DISAGREE
  
2. I know that \_\_\_\_\_ is getting proper care when I take care of him/her.  

STRONGLY	AGREE	NEITHER AGREE	DISAGREE	STRONGLY
AGREE		NOR DISAGREE		DISAGREE
  
3. I could be doing a better job caring for \_\_\_\_\_.  

STRONGLY	AGREE	NEITHER AGREE	DISAGREE	STRONGLY
AGREE		NOR DISAGREE		DISAGREE
  
4. I feel able to handle most of the problems in the care of \_\_\_\_\_.  

STRONGLY	AGREE	NEITHER AGREE	DISAGREE	STRONGLY
AGREE		NOR DISAGREE		DISAGREE
  
5. I am pretty good at figuring out what \_\_\_\_\_ needs.  

STRONGLY	AGREE	NEITHER AGREE	DISAGREE	STRONGLY
AGREE		NOR DISAGREE		DISAGREE

## APPENDIX C

## APPENDIX C

# MICHIGAN STATE UNIVERSITY

January 22, 1997

TO: Clare Collins  
A-129 Life Sciences

RE: IRB#: 97-012  
TITLE: THE RELATIONSHIP BETWEEN PERCEIVED COMPETENCE  
AND POSITIVE WELL-BEING IN CAREGIVERS OF  
RELATIVES WITH ALZHEIMERS DISEASE IN THE  
COMMUNITY SETTING

REVISION REQUESTED: N/A  
CATEGORY: 1-E  
APPROVAL DATE: 01/17/97

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.

**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.



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University Committee on  
Research Involving  
Human Subjects  
(UCRIHS)

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

517/355-2180  
FAX 517/432-1171

**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.

Sincerely,

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

DEW:bed

cc: Anne McKune

## LIST OF REFERENCES

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Aneshensel, C.S., Pearlin, L.I., Mullan, J.T., Zarit, S.H., & Whitlatch, C.J. (1995). Profiles in caregiving: The unexpected career. San Diego, CA: Academic Press, Inc.

Collins, C.E. (1987). The Impact of Alzheimer's Disease on Family Caregivers. Final Report of Grant No. 2R01-MH41766, National Institutes of Mental Health.

Collins, C., King, S., Given, C.W., & Given, B. (1994). When is a service a service: Understanding community service use among family caregivers of Alzheimer's patients. In E. Light, G. Neiderhe, & B. Lebowitz (Eds.), Stress effects on family caregivers of Alzheimer's patients (pp. 316-329). New York: Springer.

Collins, C., Stommel, M., Wang, S., & Given C.W. (1994). Caregiving transitions: Changes in depression among family caregivers of relatives with dementia. Nursing Research, 43 (4), 220-225.

Deimling, G.T., & Bass, D.M. (1986). Symptoms of mental impairment among elderly adults and their effects on family caregivers. Journal of Gerontology, 41 (6), 778-784.

Ellis, B.H., Miller, K.I., & Given, C.W. (1989). Caregivers in home health care situations: Measurement and relations among critical concepts. Health Communications, 1 (4), 207-226.

George, L.K., & Gwyther, L.P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. The Gerontologist, 26 (3), 253-259.

Gilhooly, M.L.M. (1984). The impact of care-giving on care-givers: Factors associated with the psychological well-being of people supporting a dementing relative in the community. British Journal of Medical Psychology, 57, 35-44.

Given, C.W., Collins, C.E., & Given, B.A. (1988). Sources of stress among families caring for relatives with Alzheimer's disease. Nursing Clinics of North



America, 23 (1), 69-81.

Given, B., & Given, C.W. (1991). Family caregiving for the elderly. In J. Fitzpatrick, R. Taunton & A. Jacox (Eds.), Annual review of nursing research: Vol. 9 (pp. 77-101). New York: Springer.

Given, B., King, S., Collins, C., & Given, C. (1988). Family caregivers of the elderly: Improvement and reactions to care. Archives of Psychiatric Nursing, 11 (5), 281-288.

Gold, D.P., Reis, M.F., Markiewicz, D., & Andres, D. (1995). When home caregiving ends: A longitudinal study of outcomes for caregivers of relatives with dementia. Journal of the American Geriatrics Society, 43 (1), 10-16.

Haley, W.E., Levine, E.G., Brown, S.L., & Bartolucci, A.A. (1987). Stress, appraisal, coping and social support as predictors of adaptational outcome among dementia caregivers. Psychology and Aging, 2 (4), 323-330.

Haley, W.E., Levine, E.G., Brown, S.L., Berry, J.W., & Hughes, G.H. (1987). Psychological, social, and health consequences of caring for a relative with senile dementia. Journal of the American Geriatrics Society, 35 (5), 405-411.

Kinney, J.M., & Stephens, M.A.P. (1989). Hassles and uplifts of giving care to a family member with dementia. Psychology and Aging, 4 (4), 402-408.

Kuhlman, G., Wilson, H., Hutchinson, S., & Wallhagen, M. (1991). Alzheimer's disease and family caregiving: Critical synthesis of the literature and research agenda. Nursing Research, 40, 331-337.

Lawton, M.P., Brody, E.M., & Saperstein, A.R. (1991). Respite for caregivers of Alzheimer patients: Research and practice. New York, NY: Springer Publishing Company.

Lawton, M.P., Kleban, M.H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiver appraisal. Journal of Gerontology: Psychological Sciences, 44 (3), 61-71.

Lawton, M.P., Rajagopal, D., Brody, E., & Kleban, M.H. (1992). The dynamics of caregiving for a demented elder among Black Americans and White families. Journal of Gerontology: Psychological Sciences, 47 (4), S156-S164.

Motenko, A.K. (1989). The frustrations,

gratifications, and well-being on dementia caregivers. The Gerontologist, 29 (2), 166-172.

Pagel, M.D., Becker, J., & Coppel, D.B. (1985). Loss of control, self-blame and depression: An investigation of spouse caregivers of Alzheimer's disease patient. Journal of Abnormal Psychology, 94 (2), 169-182.

Pallett, P.J. (1990). A conceptual framework for studying family caregiver burden in Alzheimer's-type dementia. IMAGE: Journal of Nursing Scholarship, 22 (1), 52-58.

Pearlin, L.I., Lieberman, M.A., Menaghan, E.G., & Mullan, J.T. (1981). The stress process. Journal of Health and Social Behavior, 22, 337-356.

Pearlin, L.I., Mullan, J.T., Semple, S.J., & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 30 (5), 583-591.

Polit, D.F., & Hungler, B.P. (1995). Nursing research: Principles and method (pp. 431-440). Philadelphia, PA: J.B. Lippincott Company.

Poulshock, S.W., & Deimling, G.T. (1984). Families caring for elders in residence: Issues in the measurement of burden. Journal of Gerontology, 39 (2), 230-239.

Pruchno, R.A., & Potashnik, S.L. (1989). Caregiving spouses physical and mental health in perspective. Journal of the American Geriatrics Society, 37 (8), 697-705.

Schulz, R., O'Brien, B.S., Bookwala, M.S., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. The Gerontologist, 35 (6), 771-791.

Skaff, M.M., & Pearlin, L.I. (1992). Caregiving: role engulfment and the loss of self. The Gerontologist, 32, (5), 656-664.

Stephens, M.A.P., Norris, V.K., & Kinney, J.M., Ritchie, S.W., & Grotz, R.C. (1988). Stressful situations in caregiving: Relations between caregiver coping and well-being. Psychology and Aging, 3 (2), 208-209.

Stuckey, J.C., Neundorfer, M.M., & Smyth, K.A. (1996). Burden and well-being: The same coin or related currency? The Gerontologist, 36 (5), 686-693.

Veit, C.T., & Ware, J.E. (1983). The structure of

psychological distress and well-being in general populations. Journal of Consulting and Clinical Psychology, 51 (5), 730-742.

Wilken, C.S., Altergott, K., & Sandberg, J. (1996). Spouses' self-perceptions as caregivers: The influences of feminine and masculine sex role orientation on caring for confused and non-confused partners. American Journal of Alzheimer's Disease, 11 (6), 37-42.

Williamson, G.M., & Schulz, R. (1993). Coping with specific stressors in Alzheimer's disease caregiving. The Gerontologist, 33 (6), 747-755.

Wilson, H. (1989). Family caregiving for a relative with Alzheimer's dementia: Coping with negative choices. Nursing Research, 38 (2), 94-98.

Zarit, S.H., Todd, P.A., & Zarit, J.M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. The Gerontologist, 26, 260-266.

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