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The Relationship Between Grandparent Caregiver Reactions and Support Group Participation

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THE RELATIONSHIP BETWEEN GRANDPARENT CAREGIVER REACTIONS AND SUPPORT GROUP PARTICIPATION

By

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A THESIS

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ABSTRACT

THE RELATIONSHIP BETWEEN GRANDPARENT CAREGIVER REACTIONS AND SUPPORT GROUP PARTICIPATION

By

Karen F. Rishel, R.N., B.S.N.

The purpose of this study was to determine if there was a relationship between support group participation by grandparent caregivers and reactions to their caregiving situation. There were 25 grandparents primarily caucasian, and from rural areas or small towns. All were high school graduates and nearly half attended college. A descriptive correlational design was used, and the conceptual framework was Dowdell's adaptation of Given's model on caregiver strain.

No correlations were found that were statistically significant between the number of groups attended and the subscales of Given's Caregiver Reaction Assessment. This may have been related to the sample size. Although the subjects differed from several studies with regard to race, community, and educational levels, some findings were similar such as reasons for assumption of care and reasons grandparents sought out support.

More research is needed to determine the helpfulness of groups to be able to utilize them beneficially for referral.

Acknowledgements

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I also want to thank my committee members Dr. Linda Nicholson Grinstead and Dr. Colleen Smitherman for their valuable comments and input. Thanks go also to Dr. Linda Scott who was instrumental in running the statistical program.

My deepest respect and thanks to the grandparent participants of the Relatives as Parents Program and the support group coordinators Dan and Glenda Levandusky. My respect and admiration also to grandparents everywhere who are taking on the challenging role as caregiver out of love and concern for their grandchildren.

A special acknowledgement to my husband David, my sons Derek and Erik, other family and friends who have encouraged me by their support and patience, and to my Lord who has sustained me.

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CHAPTER 1

CONCEPTUALIZATION OF STUDY

Statement of Problem

In the last decade an increasing amount of attention has been focused on the phenomenon of grandparents who have become primary caregivers for their grandchildren. The United States Bureau of the Census (1991) report reveals that approximately 1.5 million children live with their grandparents without parents in the home and an additional 2.5 million children live in the home of their grandparents either with one or both parents present. This reflects a 50% increase over the last 15 years.

Historically, grandparents became caregivers for their grandchildren primarily because of parents' unemployment, young age of parents, or unmarried status of parents (Burton, 1992). More recent studies show that grandparents are assuming the caregiving role for additional, more troublesome and complex reasons such as substance abuse by parents, child abuse or neglect, incarceration, divorce, mental or physical illness, and death (Dowdell, 1995; Dressel & Barnhill, 1994; Ehrle & Day, 1994; Jendrek, 1994; Kelley, 1993; Minkler, Roe, & Price, 1992; O'Reilly & Morrison, 1993; Seamon, 1992; Woodworth, 1996). Woodworth (1996) reports that substance abuse was the most frequent primary cause (44%) followed by child abuse or neglect (28%), teenage pregnancy or parent failure to handle children (11%), death of parent (5%), unemployment of parent (4%), divorce (4%), and other reasons such as incarceration and mental or physical illness (4%). Although these percentages reflect the primary causes, the percentages may be somewhat misleading as these causes are not mutually exclusive but greatly overlap and intertwine. It is due to the increasing number of such occurrences that grandchildren are being left with their grandparents for all or a significant part of their rearing (Shore & Hayslip, 1994).

Grandparents have accepted this role out of their love and concern for the well-being of their grandchildren. However, the grandparents often find themselves experiencing very complex emotional, financial, and legal problems. They are challenged to integrate their conflicting emotions of love and concern with emotions of anger and frustration for the situations that necessitated their assumption of this role. Grief is also an emotional response - grief over the situation and grief over the loss of freedom to realize their own dreams (Pinson-Milburn, Fabian, Schlossberg, & Pyle, 1996).

Grandparents find themselves facing not only their own declining health and the incapacity of their children, but the possibility that their grandchildren may themselves need an exceptional amount of attention because of the emotional impact of the events that precipitated the change in caregivers (Pinson-Milburn et al., 1996). Indeed, Dubowitz, Zuravin, Starr, Feigelman, and Harrington (1993) note that children in out of home placement do have frequent behavior problems of a clinical nature.

There is no specific age that represents grandparents. Grandparents less than 40 or over 80 may become caregivers of grandchildren. There is no single pattern in caregiving arrangements. Some are very informal and some involve legal custody or adoption. Some grandparents are caregivers for a relatively short period while others make a lifelong commitment. Many grandparents lack adequate resources but others do have adequate resources (Pinson-Milburn et al., 1996).

Grandparents have concerns over legal issues as grandparent rights in the legal system are restricted and very ambiguous. At a support group meeting grandparents made statements of feeling "invisible in the courtroom" and "afraid of the court system." Custodial grandparents have rarely won battles for permanent custody contested by parents (Derdeyn, 1985; Herman, 1990). Many grandparents have only informal arrangements for the care of the grandchildren. Although they have primary caregiving responsibility, they experience difficulty enrolling children in school and face bureaucratic nightmares as they try to gain the most basic entitlements for their grandchildren such as health insurance or medicaid, social security benefits, food stamps, or Aid to Families with Dependent Children (Ehrle & Day, 1994; Minkler & Roe, 1993; Pinson-Milburn et al., 1996).

Financial resources are frequently strained by assuming the care of a grandchild or grandchildren. In Kelley's (1993) study, 56% reported financial difficulties in rearing their grandchildren. Some grandparents needed to stop working in order to care for the grandchildren. Other grandparents reported financial strain as a result of having to move out of lower cost senior housing into housing that allowed children. The financial burden is compounded by the inability to obtain financial relief from those sources often available to parents and foster parents. In Dowdell's (1995) study nearly half of the participants did not receive any additional funds when they assumed caregiving.

All of these issues place incredible stress on grandparent caregivers. Yet despite the demands and problems of accepting parental roles, grandparents accept this responsibility rather than allow grandchildren to live in unsafe conditions or give them up to foster care. Although many negatives are reported in the literature, studies have also reported positive outcomes. Grandparents stated they felt useful, needed, noticed, and depended upon as they assumed the vitally important caregiver role (Pinson-Milburn et al., 1996).

Related to the identification and increasing awareness of this new caregiver group over the last decade is the proliferation of support groups in communities across the nation. These support groups can be important sources of emotional support, guidance, and information for those going through this life crisis and transition. What group members gain from involvement in a group can be explained by Reissman's (1995) "help paradox" that giving help is more beneficial than receiving it. Group members not only receive support, they also give support to others, which increases their sense of control and their feelings of being valued and capable. There are many different kinds of support groups from self-help groups to professionally led treatment programs. Determining what the needs are and what interventions are most effective will be helpful in making referrals and developing future programs.

Purpose

The purpose of this study is to determine if there is a relationship between support group participation and caregiver's subjective perceptions and reactions to their caregiving situation.

Significance of Study

Nurses as health care providers need to be aware that their client population may include grandparent caregivers whose physical and emotional health will be impacted by the assumption of this caregiving role. Grandparent caregiving is, in addition, an intergenerational phenomenon involving persons at various ages and developmental levels. Knowledge of available support systems and their effectiveness would increase nurses' ability to respond in the most effective way for their clients.

In comparing different caregiver groups, Strawbridge, Wallhagen, Shema, & Kaplan (1997) identified that the burden is greater for grandparent caregivers than for other caregiver groups and recommended further research to address the unique service needs of this vulnerable population. A type of support group that has been growing in response to these needs is the self-help group. The continuous growth of self-help groups and the personal testimony of those who have benefited from them offer some evidence that self-help is effective and expanding. However, research indicates that little has been done to evaluate the effectiveness of support groups.

This study adds to the growing body of research on the grandparent caregiver by looking for a relationship between support group participation and reactions to the caregiver role.

Research Questions

The research questions are based on the five subscales of the instrument used for the measurement of caregiver burden. The measures of caregiver burden are conceptualized as caregivers' perceived impacts and/or reactions to the process and situations of caregiving (Stommel, Given, & Given, 1990). The following research questions were asked.

1. Is there a relationship between number of support group sessions attended and caregiver perceived impact on self esteem?

2. Is there a relationship between number of support group support group sessions attended and caregiver perceived impact on family support?

3. Is there a relationship between number of support group sessions attended and caregiver perceived impact on finances?

4. Is there a relationship between number of support group sessions attended and caregiver perceived impact on daily activities?

5. Is there a relationship between number of support group sessions attended and caregiver perceived impact on health?

Definition of terms

For the purpose of this study, the investigator used the following definitions of relevant terms:

1. Grandparent caregivers were individuals who had assumed the role of primary caregiver for a period not less than 6 months for a grandchild under the age of 18.

2. A support group was operationally defined as a self-help small group structure for mutual aid and the accomplishment of a special purpose (Katz & Bender, as cited in Minkler & Roe, 1993). It provided for mutual assistance for members in dealing with their common needs or life disrupting problems, and it endeavored to bring about desired social and or personal change.

3. Caregiver reactions were the positive and negative responses to caregiving roles (Given, King, Colllins, & Given, 1988).

Conceptual Framework

This study used a modified version of Given's model on caregiver strain. Given's model was developed in the late 1980's for the purpose of examining how families respond to the challenge of caring for their elderly (Given et al., 1988). The model provides a framework for explaining how the characteristics of the care receiver (patient), the caregiver, and the process of caring (involvement in care) influence caregiver reactions (see Figure 1). Given et al. (1988) explain the term caregiver reaction in the following manner: "We prefer to conceptualize family members' responses to their caregiving roles as reactions rather than burdens, thereby recognizing that these feelings may be both positive and negative and may vacillate over time" (p. 283).

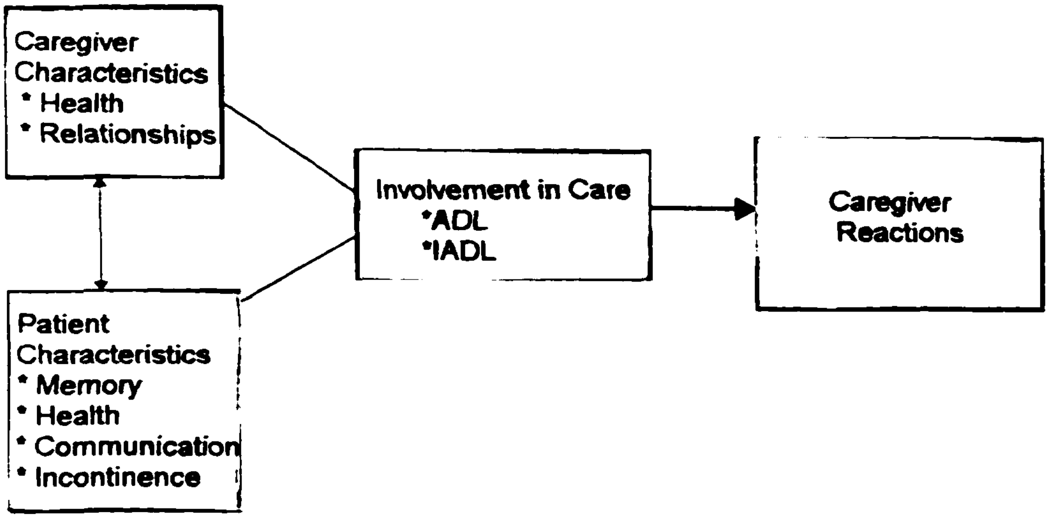


Figure 1. Given's Caregiver Strain Model.

Dowdell (1995) adapted Given's model to study the reactions of grandmother caregivers to the burdens of caregiving of high risk grandchildren. Dowdell acknowledged that the adapted model needs testing but believes that the interaction among grandmother caregivers and grandchildren and the process of caring will affect grandmother outcomes. Dowdell stated that the characteristics of the grandchild have direct influence on the grandmother caregiver. The grandchild characteristics also have direct influence on the need for caregiver social supports and the level of caregiver involvement needed in the caregiving environment. Dowdell added social and financial supports to the model as these were not specifically addressed in Given's model. Dowdell states that social support and formal assistance are not only important factors in understanding the relationships between stress and caregiving but will have an effect on the caregiving environment. All of these factors together influence the grandmother caregiver outcomes of physical health, esteem, and perceived level of family support (see Figure 2).

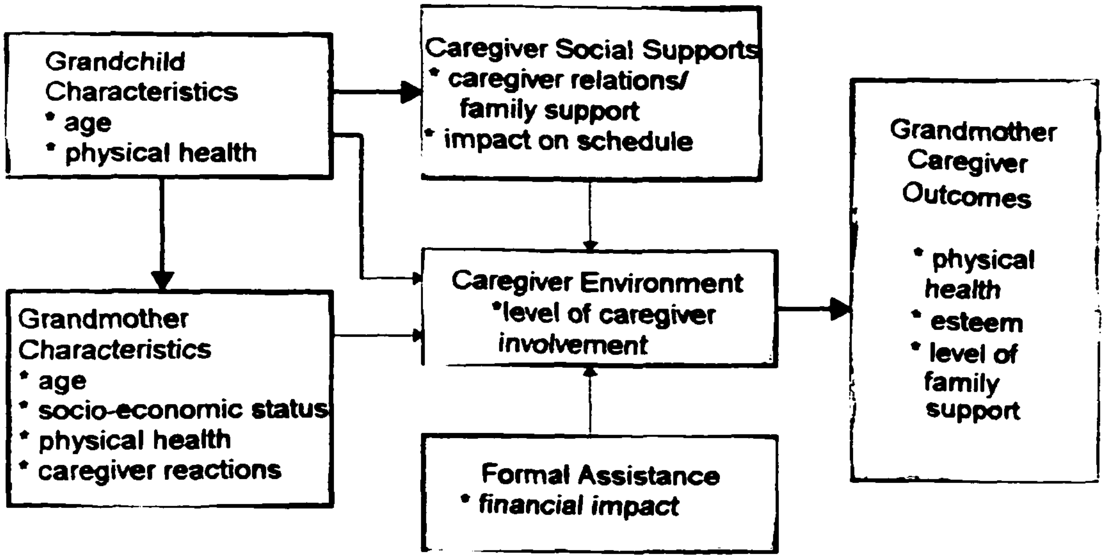


Figure 2. Given's Caregiver Strain Model as adapted by Dowdell.

The current research study examined the relationship between grandparent participation in a caregiver support group as a form of social support and caregiver outcomes. Support groups can be conceptualized as a continuum of supportive group interventions, with self-help groups at one end and treatment groups at the other (Schopler & Galinsky, 1995). Some support groups are associated with national organizations while others are created by local practitioners or non-professionals. Goals include emotional release, validation of concerns, reduction of social isolation, information, improved coping, decreased stress, problem-solving, and at times, advocacy (Schopler & Galinsky). Groups are sponsored by churches, social service agencies, senior citizen advocacy organizations, or other concerned groups. There is so much diversity it is difficult to categorize them.

CHAPTER 2

REVIEW OF RESEARCH LITERATURE

Caregiver Research

The first researchers to acknowledge the burden felt by family caregivers were Grad and Sainsury in 1963 (as cited in Vitaliano, Young, & Russo, 1991). They identified burdens felt by family caregivers of mentally ill persons. In 1979, Fengler and Goodrich identified caregivers as the "hidden patient" in a study of wives of elderly disabled men. In 1980, burden as a research construct was developed by Zarit, Reever, and Bach-Peterson, who did research with family caregivers of individuals with dementia. Since that time, burden of caregivers has been a topic of intensive research. Much of the research was descriptive in nature attempting to define and conceptualize burden and determine its components. Burden has been divided into objective burden, as defined by the circumstances of caregiving and the characteristics of the caregiver and the care recipient, and subjective burden as defined by the emotional responses and feelings of the caregiver in response to the caregiving situation (Thompson & Doll, 1982). Researchers found caregivers having increased physical and mental health problems and decreased well-being (Anthony-Bergstone, Zarit, & Gatz, 1988; Cantor, 1983; Cohen & Eisdorfer, 1988; Deiming & Bass, 1986; George & Gwyther, 1986; Haley, Levine, Brown, Berry, & Hughes, 1987; Kinney & Stephens, 1989; Poulshock & Deimling, 1984; Strawbridge, Wallhagen, Shema, & Kaplan, 1997; Zarit et al., 1980). In the Strawbridge et al. (1997) study the scores of three distinct caregiver groups were compared to those of non-caregivers. All of the caregiver groups showed higher levels of depressive symptoms and unhappiness as compared to the noncaregiver group.

Caserta, Lund, and Wright (1996) found that emotional burden was particularly high among those who did not derive much satisfaction from their caregiving experiences. Caregivers feeling deprived of doing things they wanted and expected to do were more likely to be depressed and less likely to derive positive or satisfying aspects from caregiving. Segal and Schall (1996) also found that caregiver life satisfaction correlated negatively with caregiver burden for caregivers of individuals with stroke. Although most of the literature indicates that caregiving burden is highly correlated with depression, it has not been able to show a cause and effect relationship. Some researchers question if having an underlying depression would increase the caregivers perception of the severity of burden.

Although the focus has been on negative aspects of caregiving, not all aspects of caregiving are negative. Given, King, Collins, and Given (1988) remarked that it is unclear why families persist in caregiving activities for years (if caregiving is such a strain or burden). A few studies report measures of well being as a response to caregiving including feelings of usefulness, improved relationships with person being cared for, and increased pride in ability to deal with crises (Brody, 1985; George & Gwyther, 1986; Hoyert & Seltzer, 1992; Motenko, 1989). Noonan and Tennstedt (1997) explored the question of why some caregivers do well and others in similar circumstances do not. Depression scales, self esteem scales, and a meaning in caregiving scale were used. Results showed that finding meaning in caregiving was negatively associated with the experience of depressive symptoms and positively associated with the ability to hold positive beliefs about caregiving and about the self as caregiver.

Grandparent Caregiver Research

Near the end of the decade of the 1980's and especially in the decade of the nineties, there has been increasing focus on another group of caregivers previously not recognized and this is the grandparent caregiver group. Research as described below indicates that stress and burden for this caregiver group may be even greater than for other groups of caregivers. The special circumstances of this relationship can bring about additional adverse psychological and health reactions. Strawbridge et al. (1997) compared grandparent caregivers, spouse caregivers, and adult-child caregivers to non-caregivers. They found that grandparent caregivers had poorer results on mental and physical health measures than other caregivers. In another grandparent caregiver group compared with a normative sample, increased psychological distress was found (Kelley, 1993; Kelley & Damato, 1995). In Burton's (1992) study, 86% of the grandparents felt anxious or depressed most of the time. Minkler, Roe and Price (1992) found approximately 34% of the participants reported feeling depressed some of the time during the week and exhausted early in the day and 33% reported a worsening of emotional health. Reports of anxiety, exhaustion, and depression were frequently found (Dressel & Barnhill, 1994; Hayslip, Shore, Henderson, & Lambert, 1998).

Grandparent caregivers are at higher risk for health problems than other caregiver groups (Minkler & Roe, 1993; Strawbridge et al. 1997). Kelly & Damato (1995) reported that 42% of their sample experienced increased physical and emotional problems. Almost half of the grandmothers in Dowdell's (1995) study reported a serious physical problem or illness. Minkler, Roe, and Price (1992) found that just under half of the participants in their study were in pain and were concerned about their health, with nearly a third reporting a worsening of both physical and emotional health. These grandparents also reported missing doctor appointments because of caregiving responsibilities. Three caregiver groups studied by Strawbridge et al. (1997) experienced more burden than non-caregivers, but the grandparent caregivers group experienced poorer physical health and more stressful life events than the other caregiver groups. In Burton's (1992) study when grandparents identified stressful outcomes of their caregiving situations, 61% reported smoking more, 36% reported drinking heavily, and 35% complained of increased medical problems with diabetes and arthritis. Other grandparents reported increased smoking and drinking as well to cope with the additional stress of increased responsibilities (Minkler, Roe, & Price, 1992).

Many stressors have been found that contribute to the amount of emotional and physical problems. Ehrle and Day (1994) found that the participants in their grandparent study reported the most prominant problem was "the exhausting chronic family conflict focused on the irresponsible behavior of their children" (p. 75). The situation was further complicated when grandparents were not yet finished rearing their own children or found themselves caring for disabled elders as well (Minkler, Roe, Robertson-Beckley, 1994). Kornhaber (1985) noted that such situations obscure roles and responsibilities in the family structure. Wilson (1986) noted that when noncustodial parents reside with or near the child, both the children and adults may suffer from role confusion. Spouses and children who are not the parents of the grandchild are also affected by the redistribution in the family relationships (Kelley & Damato, 1995).

The assumption of caregiving places additional stress on marriage. In Minkler and Roe's (1993) study none of the married caregivers reported improvement in their marriage, and 33% of them reported a negative change. Dressel and Barnhill (1994) reported the grandmothers in their study generally had no one with whom they could reliably share or divide tasks over any meaningful period of time, and frequently they were also caring for some of their unemployed adult children or an elder parent.

Some of the grandparent's emotional stress is related to their worries and concerns for their grandchildren. Soloman and Marx (1995) reported that the grandparents perceived difficulties for their grandchildren in the lack of appropriate role models, the children's inability to understand the living situation, the grandchild's future emotional problems when they realize they were abandonded by their parents, the age disparity, the parental visits, and the grandchild becoming overly attached to the grandparents. Jendrek (1994) found grandparents were concerned that the parent would be unable to care for the grandchild, that the parent might take the grandchild and fail again, and that the grandparents might become so attached to the child that they may not want to give the child up to the parent. Kelley (1993) also recorded concerns identified by the grandparents: 22.5% expressed concern about psychological harm to the child due to abuse and abandonment, 17.5% were afraid that the grandchildren would be returned to unfit parents, 12.5% were afraid that the children would inherit the substance abuse behaviors of the parents, and 10% were concerned about the child receiving adequate education.

In addition to familial concerns, many grandparents face personal conflicts. In Kelley and Damato's (1995) study 32% responded that social isolation caused by the caregiving situation was the most difficult for them, and 17% felt that the loss of the traditional role of grandparenting was most difficult. Feelings of obligation to care were complicated by feelings of anger, fear, and guilt. Grandparents reported feeling guilty about the lack of closeness they have with those grandchildren for whom they are not the caregivers (Minkler et al., 1994). Personal loss was experienced due to the assumptions of cargiving when their peers were free to pursue other activities (Ehrle & Day, 1994).

A number of studies have found that the care of the grandchildren results in a strain on the family's resources. Strawbridge et al. (1997) reported that a higher proportion of grandparent caregivers reported financial problems than the other caregiver groups. This burden is further intensified in families who are also providing care for an elderly parent, a disabled family member, or additional grandchildren (Burton, 1992; Dowdell, 1995; Kelley, 1993; Kelley & Damato, 1995; Seamon, 1992).

Financial burden for this group is compounded by difficulty in obtaining financial relief from those sources often available to parents and foster parents. Almost half of the participants in Dowdell's (1995) study did not receive social service reimbursement. Insensitivity to the needs of caregiving grandparents by social agencies and the legal system compounded the strain of the caregiver role. Many families established informal arrangements for the care of the grandchildren instead of working through the court system and legally adopting the children. Grandparents often had difficulty enrolling children in school and obtaining health insurance and social security benefits for the grandchildren without legal documentation (Ehrle & Day, 1994; Minkler & Roe, 1993). Sometimes it is the behavior of the adult child that interferes with the grandparents' ability to get financial support. Some grandparents reported that the adult child took the money given to them for their children by the welfare system but would not give any of the money to the grandparents providing for their children's care. They further reported that the grandparents did not try to get the money for fear that their child would take the grandchildren from them (Roe, Minkler, & Barnwell, 1994). Providing primary caregiving for a grandchild has also been identified as disrupting the caregivers' ability to continue employment (Dressel & Barnhill, 1994; Minkler et al., 1994; O'Reilly & Morrison, 1993).

Within the grandparent caregiver group there are sub-groups that endure even greater burdens. These are the grandparents that care for children of drug addicted parents. Parental drug abuse was the greatest risk factor for many disabilities and behavioral problems in the grandchildren (Pinson-Milburn, Fabian, Schlossberg, & Pyle, 1996). Grandparents raising a child with emotional or behavioral problems had lower self esteem and more strained relationships than those grandparents raising normal grandchildren, and the former saw their roles as grandparents more negatively (Hayslip, Shore, Henderson, & Lambert, 1998). Roe, Minkler, Saunders, and Thomson (1996) found that when grandparents in this situation were asked globally how they were doing emotionally since assuming caregiving, 34% reported no change, 30% reported that they were worse, and 36% reported they were doing better. However, when they responded to another set of questions on how they had felt within the last week, 78% reported being totally exhausted, 72% reported being depressed, 70% felt they could not get going, 58% reported they needed a break or they would go crazy, and 47% reported they were lonely.

Minkler, Roe, and Price (1992) had some similar findings and suggested global self-ratings of health may be overly optimistic. Information from qualitative research indicated grandparents minimized health problems saying they, "Can't let it (health) get in the way." Some grandparents who reported decline in health attributed it not to caregiving but to watching the deterioration of their adult child. In Burton's (1992) study of African American grandparents caring for grandchildren of drug addicted parents, 86% of the group reported feeling depressed or anxious most of the time.

Ehrle and Day (1994) reported as well that the chronic family conflict between the grandparents and their adult children who exhibited irresponsible behavior such as drug abuse and illegal activities was especially stressful. Ehrle and Day (1994) found difficulty with grandparents trying to obtain legal custody. Frequently this was very expensive and the courts generally placed the burden of proof on those challenging the rights of the natural parents. The grandparent found it difficult to go into a legal battle to show their own children to be unfit parents. However, without legal sanction, the grandparents often had much difficulty obtaining medical care, insurance benefits, and other community services without the parent's authorization.

Despite the large amount of negative impact found in research, there are some studies that highlight the rewards as well as the challenges. Many grandparents took on this role enthusiastically and provided stable, loving, and structured environments (Solomon & Marx, 1995). For some grandparents, even in the face of severe family disruption, the stresses of raising grandchildren were offset by discovering personal strengths, by being able to help someone else, by feeling appreciated and valued, and by being able to enjoy the love and companionship of their grandchildren (Burton, 1992; Burton & deVries, 1993; Dressel & Barnhill, 1994; Ehrle & Day, 1994; Kelley & Damato, 1995; Minkler & Roe, 1993). Roe, Minkler, Saunders, and Thomson (1996) reported that 20% of the participants in their study reported a change for the better in their health and 84% reported feeling appreciated. Burton's (1992) study of African American grandparents whose children were drug addicted described their role as gratifying, feeling it gave them a reason for living, and that the grandchildren were "the Lord's blessing." In a study on caregivers to frail elders, Noonan and Tennstedt (1997) may have explained how some caregivers can see positive benefits better than others. They found that those people who had greater ability to find meaning in caregiving had less depressive symptoms and more self esteem.

Support Group Research

There is research that gives credibility to the helpfulness of support. However, due to the ambiguous definition of support as a concept, it is difficult to accurately measure and compare results.

There are also many design limitations to which researchers readily admit. Shern and Fireman (1985) studied two groups under controlled conditions. The group that participated in a psychologist-mediated mutual support group for patients with arthritis had greater improvement in joint tenderness than patients in the control group who did not participate. Jensen (1983) reported on patients with chronic respiratory problems who participated in self-help group activities over a 6 month period. These patients were less likely to be hospitalized than other patients of same chronicity. Hinrichsen, Revenson, and Shinn (1985) reported that those individuals in treatment for scoloisis that participated in a peer support group had less psychosomatic symptoms and higher self esteem than those in a non-participating group. Spiegel (1993) found that women suffering from metastasized breast cancer who participated in a weekly support group on average survived 12 to 18 months longer than women who were assigned to control groups.

Caregiver Support Group Research

In the study by Benson, Fisher, Diana, Simon, Gamache, Tessler, & McDermeit (1996), which evaluated a multisite network of funded family support programs for the mentally ill, the results indicated program participation was associated with favorable family outcomes including reduced levels of family stress and burden. Another study of family psychoeducational programs in New York indicated the programs were a very useful component of community based psychiatric care (McFarlene, Dunne, Lukens, Newmark, McLaughlin-Toran, Dearkins, & Horen 1993). A study by Toseland, Rossiter, and Labrecque (1989) examined differences among three types of groups; one was professionally led, one was peer led, and one group had no intervention. Both groups with intervention reported improvements in caregiving skills and increased knowledge of community resources. The control group made few or no gains in these areas. There were no differences between the two groups in terms of emotional fulfillment or reduction of caregiver related stress.

Some studies challenge the assumption that support seeking behavior is positive. Monahan, Green, and Coleman (1992) evaluated caregiver characteristics that indicated a vulnerability for which a support group provided a supportive, palliative, or restorative intervention. They found that the caregivers who experienced greater emotional distress directly attributed to caregiving attended significantly more sessions than did others. Baseline caregiver subjective burden was associated with significantly greater attendance. Attendance at support groups seemed to be positively related to individual variations in perceived need.

In a study on perceived control and adaptation in elder caregivers, Wallhagen (1993) found that higher levels of perceived control were associated with higher levels of life satisfaction and lower levels of depression and subjective symptoms of stress. Caregivers with higher levels of perceived control and greater perceived resources had lower levels of depression. Support-seeking behavior was associated with more reported symptoms of stress. These findings challenge the assumption that support-seeking or information seeking behaviors are inherently positive or problem-focused (Billings & Moos, 1984).

Grandparent Caregiver Support Group Research

Minkler, Driver, Roe, and Bedeian (1993) surveyed support programs for grandparent caregivers and found the most common problem facing such programs was a lack of financial support with 80% having no support whatsoever. They found that those attending the group meetings saw them as extremely valuable despite the fact that child care and transportation presented a problem. The programs were limited in their ability to provide child care which was the most frequently cited reason for program discontinuance. The lack of program funds also made it difficult for such programs to be able to evaluate their effectiveness.

Summary of Research Review

Although caregiving studies demonstrate the relationship of stress and burden of care to the emotional and physical wellbeing of caregivers, stress/burden antecedents are multidimensional, and determining the relationships among them is very complex (Zarit & Toseland, 1989). Also, studies are often limited both in their validity and their generalizability because of their design. Powell (1993) identified factors that complicate research such as loosely defined samples, differences in operation and intent in group meetings, flawed research designs, and differences in the interpretation of study results. There is no available listing of all grandparent caregivers. Often subjects are recruited from caregiver programs and so may more likely be stressed to the point of seeking help. There are no conclusive results on the most effective interventions (Whitlatch, Zarit, & von Eye, 1991). This is likely because of the high degree of variability in persons' adaptability to the caregiving situation. Also, both stressed and non-stressed individuals seek support which confounds results when looking for improved outcomes.

However, researchers continue to look to research to help define and provide answers to this national problem. Dowdell (1995) calls for further research to examine grandmothers' income levels in addition to their perception of financial status as it affects caregiver burden and physical health. Research is needed to further describe variations by ethnic group, social class, and urban verses rural communities (Burton, 1992; Minkler, Roe, & Price,1992; Seamon, 1992). Dubowitz, Zuravin, Starr, Feigelman, and Harrington (1993) believe there is a need for additional research in kinship care to guide public policy and clinical practice. Future research is needed to identify effective informal and formal supports for grandparents who assume this challenging role (Kelley, 1993; Minkler, Roe, & Price, 1992; Strawbridge et al., 1997). Lack of support program funds limits the programs in being able to evaluate their effectiveness (Minkler, Driver, Roe, & Bedian, 1993).

This study addressed some of the areas above. Income levels and perception of financial burden were addressed. This sample was primarily caucasian, middle class, and small town or rural as compared to several grandparent studies where the sample was primarily African American grandmothers from urban areas. It also attempted to identify any relationships between support group participation and grandparent reactions to their situation.

CHAPTER 3

METHODS

Design

A descriptive correlational design was used to determine if there was a relationship between support group attendance and scores on the Caregiver Reaction Assessment subscales. The Pearson product-moment correlation analysis was used to assess the degree of linear relationship between these variables.

Sample and Setting

The population of concern was grandparent primary caregivers. A convenience sample was recruited from those individuals attending a particular support group. A description of the sample was obtained through demographic and other descriptive data.

The support group was called Relatives as Parents Program, and it meets monthly in a church basement. The group has been meeting for nearly 2 years. It was started by a married couple who are raising their grandson and who saw a need for more help and support in their community. The group started with 5 people in attendance at the first meeting, and at the time of the study, 25 to 30 people were coming on a monthly basis. Grandparents could bring their grandchildren with them and child care was provided. A meal was provided by everyone bringing a prepared food of their choice. There was an agenda of items of interest, but the meetings were not rigidly structured. Exchange of information and support among those in attendance was encouraged. The group has sought out avenues for material assistance as well as emotional support. The group accented empowerment by encouraging involvement in activities such as: promoting and facilitating events for relative caregivers, and meeting with social service representatives, members of the judicial system, and legislators as ways to learn about and take action on areas of concern.

Measures

The Caregiver Reaction Assessment (CRA) was used in this study. The instrument was originally developed with a population of caregivers providing care to homebound elderly patients. The CRA has five subscales that measure impact on caregiver esteem, family support, finances, schedule, and caregiver health (Given et al., 1992; Given et al., 1988). It has been rigorously tested psychometrically by the developers. They began with 40 items that were reduced to 24 items following exploratory factor analysis. The internal consistency of the subscales was calculated using Cronbach's alpha. The alpha coefficients of the 5 subscales ranged between .80 and .90 displaying a high degree of reliability (Given et al., 1992).

The developers also did a factor analysis to confirm factorial invariance across different care-receiver groups and caregiver groups. In the study sample of 377, there were 101 caregivers of Alzheimer's patients and 276 caregivers of cancer patients. Of those caregivers, 287 were spouse caregivers and 90 were non-spouse caregivers. The comparative fit indices ranged between .980 and .996 on all measures, indicating stability of the instrument's subscale structure across different groups of caregivers (Given et al., 1992). Dr. Charles Given was contacted and he gave feedback regarding some minor changes to make in the CRA for a grandparent caregiver (Appendix A).

A survey to collect demographic data was also used. The demographic data collected were: age of grandparents and grandchildren, sex of grandparent, race of grandparent, financial situation, education, the number of grandchildren being cared for, other minors in the household, duration of caregiving, circumstances of caregiving assumption, and presence or absence of legal custody. In addition, survey questions asked caregivers how they came to be involved in a support group and how many of the monthly support group meetings they have attended (Appendix B).

Procedures for Data Collection

Prior to data collection, permission to conduct research with human subjects was obtained from Grand Valley State University's Human Research Review Committee (Appendix C). Permission was also obtained in writing from the support group founders (Appendix D).

The researcher attended the monthly meetings of the Relatives as Parents Program, and the group was aware that the researcher's purpose was to do research with their support group. At the meeting just prior to the questionnaires being sent out, the group was informed that one set of two questionnaires would be sent to each household and that a letter (Appendix E) would accompany the questionnaires explaining the research in more detail. This letter also served as their consent to participate. In the consent letter, the participants were informed that it would take 15 to 20 minutes to complete the questionnaires, and that some of the questions might touch on sensitive areas while some might seem unrelated. It was explained that the questionnaires should be completed by the grandparent who was considered the primary caregiver and that participation was entirely voluntary and anonymous. Participants were asked to return completed questionnaires in the stamped envelope provided. Members not in attendance also received questionnaires by mail. A reminder post card was sent out one week after the questionnaires.

Fifty five questionnaires were sent out originally and 28 were returned. Of those 28, 12 were not able to be used as they did not meet the criteria for inclusion, or important survey information was missing. One strategy to recover some of the data was to meet with the group leaders and determine, for example, how many meetings were attended if that was left blank. This was able to be done as some of the respondents put their return address on their envelope. Some of the married couples that were raising grandchildren did not want to credit one grandparent or another with being the 'primary' caregiver. They considered it to be a completely joint effort and put both down as primary caregiver. For the purpose of the study the grandmother was used for the data collection. The grandmother was chosen over the grandfather only because traditionally in our culture, the female is generally the one with more hands on, nurturing type of care while the male provides more instrumental care.

At subsequent meetings some grandparents indicated they had not returned their surveys yet, and some surveys were handed out to them personally. Some returned them through the mail and some filled them out and returned them before the end of the meeting. Two surveys were obtained from another grandparent group started by the same group leaders in the Lansing area. One return was obtained by picking it up from the grandparents' home with their permission.

CHAPTER 4

PRESENTATION OF FINDINGS

Data were collected from grandparents who had the responsibility for primary care of grandchildren for a period of time not less than 6 months, and who had attended at least two sessions of the Relatives as Parents Program. Demographic information was gathered and the Caregiver Reaction Assessment instrument was used to gather information on the grandparents' reactions to the caregiving situation. A series of Pearson correlations were used to determine if there was a relationship between number of support groups attended and reactions as measured by the subscales of caregiver esteem, caregiver health, family support, impact on schedule, and impact on finances. Data were analyzed using SPSSX statistical program.

Descriptive Statistics

Description of Sample

Data were collected from 25 grandparents, 24 grandmothers and one grandfather. They ranged in age from 40 to 84 years (M = 56.72, SD = 9.62). All but one of the grandparents were high school graduates (96%), 48% attended college, and 20% reported having a college degree.

The subjects were primarily caucasian (84%) with the exception of one African-American and two hispanic participants. Most of the group members were married (56%), 16% were divorced, 8% lived with a significant other, one subject was widowed, one was never married and one did not report marital status (see Table 1). The majority of the grandparents had grandchildren currently living with them (84%). Most of the households reported having 1 grandchild with them (36%), 28% reported 2 grandchildren living with them, 16% reported 3 grandchildren, and one family reported 4 grandchildren living with them. The most frequent age group of children receiving care from grandparents was the elementary age group with 14 families reporting having 5 to 12 year olds. Eight families reported having preschoolers (ages 1 to 4), three families reported 13 to 17 year olds, and one family reported having an infant under the age of one. The grandparents were asked if they were responsible for the care of any other minor children at the time, and two families were in this category. One family had 2 and one family had 1 other minor children to care for (see Table 1). The grandparents were also asked if they were caring for an elderly or disabled adult in their home at the time and only one family reported this additional responsibility. The length of time being responsible for the primary care of a grandchild ranged from 1 year to 15 years (M = 6.23, SD = 4.22).

Reasons for Assumption of Care

The grandparents were asked to identify reasons for the assumption of care from a list of nine. The most frequently reported reason was neglect by the parent (64%). Substance abuse by the parent was reported in 48% of the cases. Other reasons reported were: incarceration of the parent (36%), abuse by the parent (32%), parental unemployment (28%), parent divorce (24%), mental or physical illness of the parent (16%), death of the parent (16%), and the parent being a minor (8%). Three persons also checked the 'other' category and explained that caregiving was related to the parent's career choice (see Figure 3).

Table 1

Descriptive Statistics on Demographic Variables

Variable	Frequency	Percent
Age		
40-50	6	24
51-60	12	48
61-70	5	20
71-80	1	4
81-84	1	4
Marital Status		
Married	14	56
Divorced	4	16
Live with Sig. Other	2	8
Separated	2	8
Widowed	1	4
Never Married	1	4
Missing Data	1	4
Ethnicity		
Caucasian	21	84
Hispanic	2	8
African-American	1	4
Other	1	4
Education (highest level completed)		
Some High School	1	4
High School	12	48
Some College	7	28
College	5	2
Employment		
Full time	5	20
Part time	7	28
Not Employed/Retired	13	52

Table 1 (Continued)

Variable	Frequency	Percent
Household Income (thousands)		
<20	8	32
20-30	5	20
30-40	5	20
40-50	4	16
>50	2	8
Missing data	1	4
Financial Assistance		
None	8	32
Medicaid	8	32
ADC	6	24
Child Support	4	16
Other	4	16
Food Stamps	1	4
Legal Authority		
Adopted	8	32
Guardian	7	28
Temporary Guardian	3	12
Full Custody	3	12
State has Custody	1	4
No Legal Authority	3	12
Number of Grandchildren in the Home at Time of Study		
0	4	16
1	9	36
2	7	28
3	4	16
4	1	4
Ages of Grandchildren Receiving Care		
< 1 (infant)	1	2.5
1-4 (pre-school)	9	22.5
5-12(elementary, jr. high)	27	67.5
13-17 (high school)	3	7.5
Referral to Group		
Friend	9	36
Read about	6	24
Social Service Professional	2	8
Health Care Professional	1	4
Other	7	28

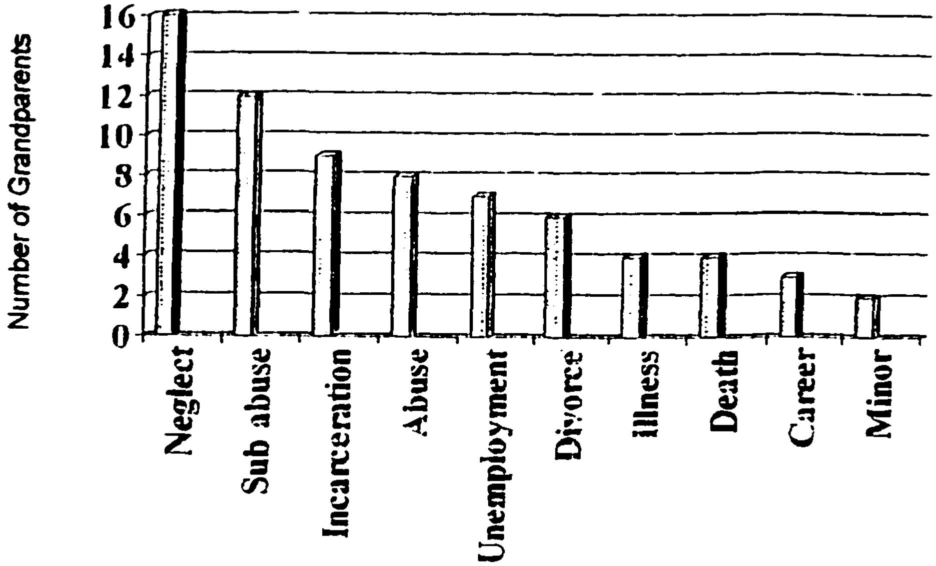


Figure 3. Reasons for assumption of care by grandparents.

Custody of the Grandchild

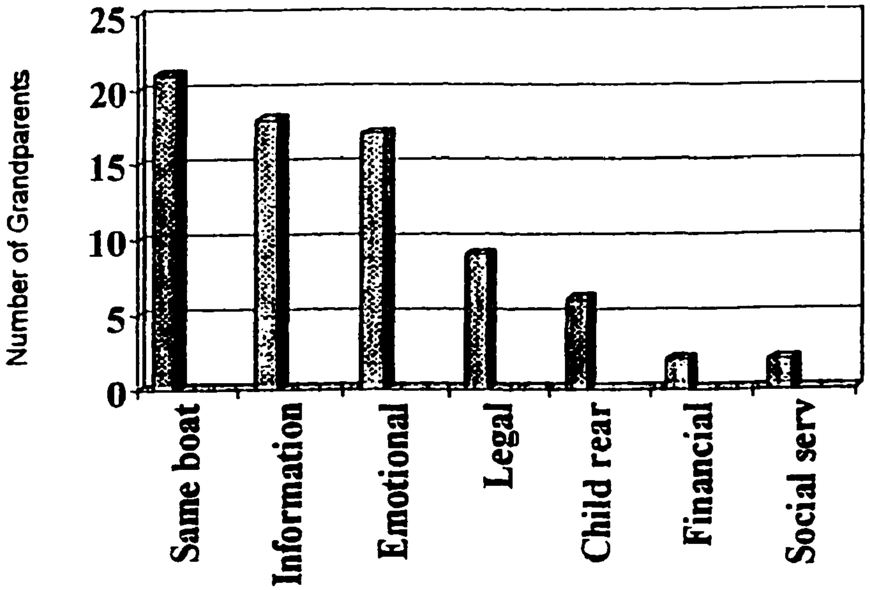
In this study 32% of the grandparents had adopted their grandchildren, 28% were full guardians, 12% had temporary guardianship, 12% had full custody, and one family reported that the state had custody and the grandchild was placed with them. The remaining 12% had no legal authority; the children were with them on an informal basis (see Table 1).

Finances

Over half of the respondents reported that they were unemployed or retired (52%), 24% reported working part time outside the home, and 16% reported working full time outside the home. One grandparent worked full time at home and one worked part time at home. Approximately one third of the families reported a household income of less than $20,000 a year (32%), 20% reported between 20 and 30 thousand, 20% reported 30 to 40 thousand, 16% reported 40 to 50 thousand, and only two families reported making over $50,000 a year. More than half of the grandparents received some additional financial assistance for care of the grandchildren (68%). These resources were in the form of medicaid (32%), aid to dependent children 24%), child support from parents (16%), food stamps (4%), and other (16%). Nearly a third (32%) received no assistance at all (see Table 1).

<u>Reasons for Seeking Support</u>

One item on the questionnaire listed seven reasons for seeking support from a support group. The most frequently chosen reason was to get others' ideas or to know others were "in the same boat" (84%). Other reasons chosen were: to get information (72%), to get emotional support (68%), to get help with the legal system (36%), to get help with childrearing (24%), to get help with the social service system (8%), and to get help with finances (8%)(see Figure 4). Five of the grandparents reported they were or had been involved in other support groups related to grandparenting as well.



<u>Figure 4.</u> Reasons grandparents sought support.

Referral to Group

When the grandparents were asked how they found out about their support group, 38% responded from a friend, 25% from reading about it, and 25% reported other sources. Of those who reported other sources, 2 of those had found out from Head Start, 1 from the police department, and 2 were founders of the support group. It was interesting to note that only 2 persons said they found out from a social service worker, and only one person was told about the group from a health care professional. This has implications for the group leaders regarding people and places that need more information about the support group.

Number of Groups Attended

The possible range for number of times attending the group was from 2 to 20. Those who had only attended once were not included in the study. The actual number of times the grandparents (N = 25) had attended this support group ranged from 2 to 20 (M = 11.28, SD = 7.13). Seven of the 25 which made up 28% of the total reported being there 20 times. The other responses were fairly evenly dispersed between 2 and 18.

Caregiver Reaction Assessment Subscales

The CRA has 24 items; 5 of those items needed to be reverse coded. The items were then placed into the five different subscales. Missing data were noted and handled according to suggestions from Polit and Hungler(1999). Four subjects had missing data on the instrument, one of the subjects missing one answer, and one missing two. For these subjects the percentage was small, 4% and 8% of the instrument respectively, so their missing data were handled by substituting the mean value for that item as the answer. The other two subjects missed 5 and 7 items. Those subjects were eliminated from the subscales where their missing data were because they missed more than 20% of the total instrument.

A Chronbach's alpha coefficient was obtained on all subscales to look for internal consistency reliability and compared with two previous studies (Dowdell, 1995; Given et al., 1992). Alpha coefficients, means, and standard deviations are also compared in Table 2.

Table 2

Caregiver Burden Subscales: Means, Standard Deviations, and Alphas

Subscales	Given Study			Dowdell Study			Rishel Study		
	M	SD	Alpha	M	SD	Alpha	M	SD	Alpha
Caregiver Esteem	3.61	.56	.90	3.72	.59	.80	4.18	.41	.59
Family Support	2.27	.54	.85	2.63	.84	.80	2.36	.68	.54
Finances	2.87	.60	.81	3.11	.59	.75	3.12	1.12	.75
Impact Schedule	3.11	.47	.82	3.65	.82	.80	3.72	.85	.79
Caregiver Health	2.56	.51	.80	2.48	.70	.70	2.60	.77	.78
	(N = 377)			(N = 104)			(N = 25)		

Caregiver Esteem

The subscale of caregiver esteem consists of 7 items. It is intended to "measure the extent to which caregiving imparts individual self-esteem "(Given et al., 1992). Higher scores indicate higher level of self-esteem from caregiving. The possible range for this subscale is from 7 to 35. The actual range for the participants (N = 24) was 23 to 35 (M = 29.29, SD = 2.91). The average answer was 4.18 (SD = .41) on a scale of 1 to 5 with 5 being strongly agree. This indicates that these grandparents do receive self-esteem from caregiving.

Family Support

The family support subscale consists of 5 items. It is designed to assess the "extent to which the family supports and works together with the caregiver" (Given et al., 1992). The higher the score on this scale the more the caregiver perceives a lack of family support. The possible range is 5 to 25. The actual range for the participants (N = 23) was 6 to 19 (M = 11.83, SD = 3.42). The average response on the scale of 1 to 5 was 2.36 (SD = .68). This response is mixed but it is evident that more feel supported by family than not supported.

Impact on Finances

This subscale consists of three items and is designed to "look at the adequacy, the difficulty, and the strain of the financial situation on the caregiver and the family" (Given et al., 1992, p. 275). It is constructed so that the higher the score the more the degree of difficulty and strain is felt. The possible range is 3 to 15. The actual range for the study (N = 23) is also 3 to 15 (M = 9.35, SD = 3.37). Although the scores were fairly evenly dispersed, 43% of the grandparents had average scores of 3.66 or more on a scale of 1 to 5 indicating difficulty with financial strain, and 35% had average scores on the items of 2.33 indicating lack of financial strain (M = 3.12, SD = 1.12).

Impact on Schedule

This subscale consists of five items that assess the degree to which activities center on caregiving by measuring the interruption of usual activities, the elimination of some activities, and interference with relaxation time (Given et al., 1992). Higher scores indicate caregiving has had a great deal of impact on or disrupted previous schedules. The possible range is 5 to 25. The actual range for this study (N = 24) was 9 to 25 (M = 18.58, SD = 4.25). More than half of the participants (58%) had average scores on the items of 3.6 or more, perceiving a definite impact on their schedule with the assumption of caregiving (M = 3.72, SD = .85).

Impact on Health

This subscale consists of 4 items. This scale measures physical health, capabilities, and energy in relation to the caregiving role (Given et al., 1992). Higher scores indicate an increased perception of negative impact on health. The possible range is 4 to 20. The range in this study (N = 25) was 4 to 16 (M = 10.4, SD = 3.06). Many of the caregivers in this study (76%) averaged scores of 2.4 or less on the scale of 1 - 5 indicating that they did not perceive much difficulty with regard to their health and how it had been affected. The highest score in this subscale was 16 which three grandparents checked. This is an average score of 4 on a scale of 1 - 5 indicating concern over negative impact on health (M = 2.6, SD = .77).

Correlation Analyses

A series of Pearson correlations were done relating the subscale scores to the number of support groups attended (see Table 3). These were done in an attempt to answer the following research questions:

1. Is there a relationship between the number of support group sessions attended and caregiver perceived impact on self esteem?

No relationship was found between number of support groups attended and self esteem (r = .07).

2. Is there a relationship between the number of support group sessions attended and caregiver perceived impact on family support?

A weak inverse relationship was found (r = -.25) so that as more support groups were attended, the total score on the family support subscale was less indicating the caregivers did not feel a high degree of abandonment by family. The results, however, did not reach a level that was found to be statistically significant.

3. Is there a relationship between the number of support groups attended and caregiver perceived impact on finances?

There was no relationship found between number of support groups attended and caregiver perceived impact on finances (r = -.02).

4. Is there a relationship between the number of support group sessions attended and caregiver perceived impact on schedule?

There was no relationship found between the number of support group sessions attended and caregiver perceived impact on schedule (r = -.08).

5. Is there a relationship between the number of support group sessions attended and caregiver perceived impact on health?

There was a weak positive relationship (r = .25) found between the number of support group sessions attended and caregiver perceived impact on health. As the number of groups attended increased, the scores on the subscale of impact on health increased indicating that caregivers perceived themselves as having more trouble with their health. This relationship, however, was not found to be statistically significant (see Table 3).

Table 3

Correlation of Number of Support Groups with CRA Sub-Scales

	Esteem	Support	Finance	Schedule	Health
Number of Support Groups	.07	-.25	-.02	-.08	.25
Significance (2-tailed)	.76	.26	.91	.71	.23
N	24	23	23	24	25

Other Findings of Interest

During the course of the study it was questioned whether the length of caregiving time would show any relationship to reactions to care. A Pearson's correlation ($r = -.58$) showed there was a moderate inverse relationship that was significant at the $p < .01$ level for caregiver esteem and length of time caring. As length of time increased the score on the caregiver esteem scale decreased indicating that caregivers felt less self-esteem as the years of caregiving increased. This was an unexpected finding as Dowdell (1993) using length of caregiving and the CRA subscale for esteem had a larger sample and did not find any significant correlation.

CHAPTER 5

DISCUSSION AND IMPLICATIONS

This chapter will discuss the findings in more detail, relating them to previous research and the conceptual framework. It will also discuss how the findings apply to practice. At the conclusion, the study's limitations and suggestions for further research will be addressed.

Discussion of Findings

The purpose of the study was to determine if there was a relationship between support group participation and caregivers' subjective perceptions and reactions to their caregiving situation. This research was based on information provided by 25 primarily caucasian grandparents who provided care for grandchildren over time periods ranging from 1 to 15 years. These grandparents were participants in a grandparent support group.

There have been numerous studies of grandparents as primary caregivers. There is difficulty, however, in making comparisons among studies due to differences in variables, study designs, measures, instruments, and purposes of the studies. Some similarities and differences of this study to others will be explored in an effort to clarify the data. With regard to the 5 research questions asked, none of the correlation results reached a level of statistical significance. Each question will be discussed along with related information.

No relationship was found between the number of support groups attended and perceived impact on caregiver esteem as measured by the CRA. This study's average score (4.18 on a scale of 1 - 5) for caregiver esteem was higher than the esteem score in two other studies. In Given et al.'s (1992) study of caregivers for elderly people the average score was 3.61, and in Dowdell's (1993) study of grandparents caring for high risk grandchildren the score was 3.72. Given's study did not report whether those caregivers were receiving support from a group, and Dowdell reported that some of her grandparents were in a support group. Although this study did not find a relationship between number of support groups attended and scores on the caregiver esteem subscale, it is possible that the higher average score in this study could have had some relation to the fact that they were all in a support group.

Another factor which may have influenced caregiver esteem was the security or the permanency of the caregiving arrangement. In this study 32% of the subjects had adopted their grandchildren. In the Dowdell (1993) study only 3.8% had adopted. This could affect caregiver esteem as the caregiving environment was more predictable giving the grandparent a greater sense of control without threat of having the child returned to an unsafe or less secure environment. This study is congruent with other studies that have found some positive rewards from caregiving. Despite the negative impacts of cargiving, Hayslip et al. (1998) found for some grandparents, raising grandchildren gives a sense of personal meaning and Burton (1992) found that the majority of grandparents in that study reported receiving blessings in raising their grandchildren.

Although it did not reach a level of significance, a weak inverse relationship ($r = -.25$) was found between support group participation and perceived lack of support from family so that as the number of support groups increased, the perception of lack of support from family decreased. Perhaps when involved in a support group, they feel less isolated and less dependent on family for support. Although the lack of significance may be related to sample size, it is also possible that the support received from family is independent of support received at a support group. The variables of family support and impact on schedule correlated with each other strongly ($r = .71$, $p <.01$). It is reasonable to contend that as a family was perceived to be more supportive there was less negative impact on schedule. And conversely, when a family was perceived as unsupportive there was increased negative impact on schedule. Given et al. (1992) also found interscale correlations of family support with schedule ($r = .32$, $p < .01$).

No relationship was found between the number of support groups attended and the perception of financial strain. Grandparent caregiving does have an impact on finances (Dowdell, 1993; Kelley, 1993; Strawbridge et al., 1997). In this study, the majority of the grandparents perceived that caregiving had a negative impact on finances. Perhaps no relationship was found because although finances were a problem, they were not one of the main reasons identified by this group for seeking support. In fact, only 2 of the 25 subjects reported that they had sought support for financial reasons. Ways to obtain financial assistance were frequently mentioned in this group, but it was not identified as a primary goal of this group.

Dowdell (1993) suggested that other studies look at reported financial status as well as perceived financial impact. In this study, 75% of the subjects were making under $40,000 per year. Those grandparents who made less than $40,000 perceived that caregiving had a negative impact on finances with an average score of 3.43 on a scale of 1 - 5 with 5 indicating greatest difficulty. The remaining 25% who made $40,000 and over perceived less impact on finances with an average score of 2.22. This indicates that perceptions were linked to actual status.

The variables of impact on finance and impact on health were found to correlate with each other ($r = .49$, $p < .05$) and support similar findings by Given et al. (1992) and Dowdell (1993). This is likely to mean that when financial resources are adequate, there is more access to medical care and resources to engage in healthy living practices. If financial resources are limited, the medical needs of the grandparent may be postponed, and the grandchild's needs placed above the needs of the grandparent. Another way to explain this relationship is to reason that declining health may impact finances by loss of hours from work or loss of job. Declining health may drain financial resources because of need for expensive medications, physician visits, or treatments. Impact on health and impact on schedule varied together ($r = .52$, $p < .01$). This was also found in the Given et al. (1992) caregiver study ($r = .45$, $p < .01$). This could be interpreted as the more health declines the less a person would be able to maintain their normal activities.

No relationship was found between number of support groups attended and caregiver perceived impact on schedule. Although the participants may attend out of their perceived need for help or to help others, it is still one more thing that has been added to their schedule since assuming the child caring role. Some respondents to the questionnaires in this study that did not meet the inclusion criteria of attending at least two support groups stated that they did not feel they had time to be involved in a support group due to their high level of activities with their grandchildren.

A weak positive relationship was found (r = .25) between number of support groups and impact on health so that as the number of support groups increased the perceived negative impact on health increased. This was not found to be statistically significant. The meaning of this is unclear but it might be that as health problems worsen, grandparents may feel more of a need to seek support.

Two studies of grandparent caregivers focused on African American grandmothers who were selected from urban areas and who were caring for grandchildren because of substance abuse (Burton, 1992; Minkler, Roe, & Price, 1992). Dowdell's study was also done in an urban area, and over 50% of the subjects were African American. The primary reason for assumption of care was substance abuse (80%), followed by child neglect (30%) and child abuse (16%). In contrast, the subjects of this study were primarily caucasian and the study was done in a rural or small town setting. This study did not select on the basis of drug use, and yet substance abuse as one of the reasons for assumption of care was reported in nearly half (48%) of the cases with the other reasons identified as neglect (64%), incarceration (36%), and abuse (32%). These figures bring deeper understanding of the scope of the problem. Finding these percentages in a primarily caucasian, small town area reveals that the disturbing reasons for assumption of care are not isolated to urban areas, or minority groups.

Discussion of Findings in Relationship to the Conceptual Framework

The Given et al. (1992) model was developed to examine how families respond to the challenge of caregiving for their elderly. The model provides a framework for explaining how the characteristics of the caregiver, the characteristics of the care receiver, and the level of involvement in the process of caring influence caregiver reactions (see Figure 1). In Dowdell's (1993) adapted model, the characteristics of grandmothers and the characteristics of the grandchildren affect the caregiving environment. That environment is also affected by caregiver social supports and formal assistance. The relationship among all of these directly or indirectly affect grandmother outcomes (see Figure 2). For the purpose of this study, the grandparent support group was identified as that part of the Dowdell model labeled Caregiver Social Support. The model stresses the importance of social support in influencing the caregiver environment which in turn influences perceived outcomes.

Although no relationships were found between support group attendance and outcomes, this does not mean that support groups do not have an important role in social support. There are various dimensions of support in a support group and the value or benefit received may not be closely related to the number of times a person goes to the group. Another factor pointed out by researchers (Billings & Moos, 1984; Dowdell, 1993, Monahan, Green, & Coleman, 1992) was that attendance at groups was related to the amount of stress perceived. In other words, people who are very stressed are more likely to seek support. This may cloud the helpfulness of support groups as measured by attendance because those who have received the help they needed may drop out of attendance while those still in a considerable amount of stress may continue. In addition, the sample size may have been too small to find significant variability in outcomes. The question still needs to be asked: does support group participation affect the caregiving environment enough to change grandparent perceived outcomes?

Application to Practice

Grandparent caregiving is an intergenerational phenomenon impacting persons at various ages and developmental levels. Being involved in nearly every aspect of healthcare, nurses are in a good position to be able to recognize this situation. Determining the needs of grandparent caregivers and the interventions that would be most effective would be essential in making referrals and developing future programs. In Kelley and Damato's (1995) study of grandparent caregivers, 85% of the subjects said that professional services such as financial assistance, legal services, mental health programs, and respite care were inadequate. The need for services today is frequently beyond what our human services systems can provide or what insurance will pay for. This is especially true for those with limited financial resources. Self help and other support groups can be a method of providing emotional support and information with little or no cost.

The need for more awareness of this resource on the part of healthcare professionals is evident. When the subjects of this study were asked how they found out about their support group, most responded they had heard about it from a friend (38%), from reading about it (25%), and from other sources (25%). Only one of the 24 who responded were told of the support group by a health care professional. Nurses need to talk with grandparents they find in this situation about their needs. Nurses are obligated to be aware of support programs in their area and investigate those resources directly to determine what they have to offer in order to make beneficial referrals.

Information from studies such as this one can be used by nurses and by grandparent groups as well to bring about recognition of need for policy change and to develop future programs. Many grandparent groups have become active politically in efforts to secure legal rights and more financial and support resources. There is a great amount of variation among the different states with regard to the legal rights of grandparents and financial options for those who are the primary caregivers of grandchildren. Educating legislators to the special needs of this population will help to bring about changes.

Limitations

The major limitation in this study was the small sample size. This was a logical group on which to use the CRA measurement tool, but the internal consistency reliability of the instrument subscales with this size of sample proved to be too low. The alpha coefficients for the 5 subscales ranged between .54 and .79 (see Table 1). A reliability of .80 is considered the lowest acceptable coefficient for a well-developed tool (Burns & Grove, 1993). Relationships were not found between support group participation and the CRA subscales. One has to take into consideration the large chance of type II error where the effect of support group participation on some of the subscales may have been there but may have been too small to identify with this size of study.

The cross sectional design was convenient for obtaining the data in a reasonable time period and was chosen as it would examine the grandparents at various levels of participation. The purpose was to see if some relationship could be found between the number of support groups attended and outcomes on the subscales of the CRA. A stronger design would be a longitudinal design that measured the subjects at different time intervals. This would accomodate individual differences across time that do not show up in cross sectional designs.

Since the study was not an experimental design involving random assignment of grandparents to support groups and control groups, there were many potential effects that could not be completely controlled. One example would be maturation. Even if there was a significant change in scores with the number of groups attended the effects of maturation over time could have been partially responsible for that change. A grandparent could learn and find ways to adapt to decrease stress independent of group participation.

Although the CRA had good reliability in the Given et al. (1992) caregiver study and the Dowdell (1993) caregiver study, it may not have been the best tool to determine the effectiveness of the support group. Most of the people who joined this support group were seeking emotional support and information. Receiving emotional support and information may not have anything to do with a change in the subjects' perceptions of health, esteem, finances, family support, or schedule.

Suggestions for Future Research

Researchers need to continue to explore ways of measuring how and in what circumstances support groups are helpful. The use of standardized measures is recommended as it is helpful when comparing research studies. Also, the addition of qualitative research to quantitative is recommended as it is a technique that adds richness, detail, and meaning to the quantitative data. Through attendance at the grandparent group meetings for nearly 2 years in preparation for this research study, the researcher noted that many grandfathers were also very involved in the care of the grandchildren. Studies need to include the grandfathers and their involvement as an area for research as many research studies to date rarely mention the role of the grandfather.

There is a recent proliferation of grandparent support groups yet much still needs to be learned about support group effectivness. The American Association of Retired People (AARP) reports their most frequent request from grandparent caregivers is for referral to support groups (Woodworth, 1996). Toseland, Rossiter, and Labrecque (1989) compared 29 support groups of family caregivers. In most cases the participants were extremely satisfied and reported improvement on standardized measures of functioning, but the researchers had difficulty linking those results with measurable behavioral outcomes. Perhaps in the caregiving environment there is little room for behavioral change. Research may want to focus on how the caregivers perceive themselves in their role as far as finding value and meaning in caregiving or finding ways to decrease stress and depression.

Summary

In the last decade an increasing amount of attention focused on the phenomenon of grandparents that had become primary caregivers for their grandchildren. Research has indicated that stress and burden for this caregiver group may be even greater than for other groups of caregivers. The purpose of this study was to determine if there was a relationship between support group participation by grandparent caregivers and reactions to their caregiving situation. Participation was measured by number of groups attended and caregiver reactions were measured by the 5 subscales of Given's Caregiver Reaction Assessment which included: caregiver esteem, family support, impact on finances, impact on schedule, and impact on health. A descriptive correlational design was used, and the conceptual framework was Dowdell's adaptation of Given's model on caregiver strain.

No statistically significant correlations were found between number of support groups attended and reactions as measured by the CRA subscales. A discussion of these results and other findings followed. Implications for nursing and for future research were identified as well.

APPENDICES

Appendix A

GRANDPARENT CAREGIVER QUESTIONNAIRE

(Adapted from Given's Caregiver Reaction Assessment)

Before starting this questionnaire, please indicate the number of times you have attended the *Levandusky's grandparent support group meetings.*

Please circle your one best estimate of the number of monthly support group meetings attended: 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20

(On the statements below, please circle the response that best represents your feelings.)

1. I feel privileged to care for my grandchild/grandchildren.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

2. Others have dumped caring for my grandchild/grandchildren onto me.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

3. My financial resources are adequate to pay for things that are required for caregiving.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

4. My activities are centered around care for my grandchild/grandchildren.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

5. Since caring for my grandchild/grandchildren, it seems like I'm tired all of the time.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

6. It is very difficult to get help from my family in taking care of my grandchild/grandchildren.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

7. I resent having to take care of my grandchild/grandchildren.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

8. Sometimes caring for my grandchild/grandchildren means I have to stop in the middle of my work activities.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

9. I really want to care for my grandchild/grandchildren.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

10. My health has gotten worse since I've been caring for my grandchild/grandchildren.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

11. I visit family and friends less since I have been caring for grandchild/grandchildren.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

12. I will never be able to do too much to help my grandchild/grandchildren.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

13. My family works together at caring for my grandchild/grandchildren.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

14. I have eliminated things from my schedule since caring for my grandchild/grandchildren.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

15. I have enough physical strength to care for my grandchild/grandchildren.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

16. Since caring for my grandchild/grandchildren, I feel my family has abandoned me.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

17. Caring for my grandchild/grandchildren makes me feel good.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

18. The constant interruptions make it difficult to find time for relaxation.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

19. I am healthy enough to care for my grandchild/grandchildren.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

20. Caring for my grandchild/grandchildren is important to me.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

21. Caring for my grandchild/grandchildren has put a financial strain on the family.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

22. My family (brothers, sisters, children, husband) left me alone to care for my grandchild/grandchildren.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

23. I enjoy caring for my grandchild/grandchildren.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

24. It's difficult to pay for my grandchild's/grandchildren's health needs and services.

Strongly disagree Disagree Neither agree or disagree Agree Strongly agree

Appendix B

DEMOGRAPHIC DATA

This survey should be filled out by the grandparent who attends the support group and who would be considered as the one who gives the most hands on care to the grandchild/grandchildren.

Please circle, check, or fill in the most accurate answer. Please feel free to write any comments on the survey.

1. Grandparent age____.

2. Grandparent sex: Male Female

3. Race: Caucasian____.
African-American_____.
Hispanic____.
Asian____.
Other___________.

4. Education: (Check highest level.)
Elementary____.
Some highschool_____.
Highschool graduate_____.
Some college_____.
College graduate_____.

5. Employment:
Full time outside the home_____.
Part time outside the home_____.
Full time home business____.
Part time home business_____.
Not employed_____.

6. Marital status:
Married____.
Live with significant other_____.
Divorced_____.
Widowed____.
Separated____.
Never married______.

7. Are you responsible for the care of any elderly or disabled adults in your home?
Yes _____. No _____.

8. Please fill in the number of grandchildren living in your home - _____.
How many under age one?_____.
How many from ages 1 to 4?______.
How many from ages 5 to 12?______.
How many from ages 13-17?_______.

9. Please fill in the number of any other minor children living with you______.
How many under age one?____.
How many from ages 1 to 4?_____.
How many from ages 5 to 12?______.
How many from ages 13 to 17?______.

10. Please check all of the reasons below that contributed to needing to care for your grandchild.
__a. death of parent
__b. drug/alcohol abuse of parent
__c. the parent is a minor
__d. neglect by parent
__e. abuse by parent
__e. incarceration of parent
__f. parent unemployment
__g. parent's divorce
__h. mental/physical illness of parent
__i. other_____________________________.

11. On a yearly basis this household's income is:
less that $20,000____.
$20,000- $30,000 ____.
$30,000- $40,000____.
$40,000- $50,000 ____.
over $50,000 ____.

12. Do you receive any financial assistance for the care of your grandchildren? Yes No

13. If yes, please indicate by checking any that apply:
__foster care payments
__aid to dependent children
__medicaid
__social security benefits
__food stamps
__child support from parents
__other______________________________.

14. How long has your grandchild (grandchildren) lived with you? Years____, Months
.
(If your grandchild has been in and out of your home, write in the estimated total time.)

15. Please identify your legal authority with respect to the grandchildren.
_____no legal authority
_____temporarly guardian
_____guardian
_____foster parent
_____informal custody (verbal agreement)
_____full custody
_____have adopted grandchild
_____the state has legal custody and the child is placed with me

16. How did you find out about your support group?
___health professional
___social service professional
___friend
___read about it
___other______________________________.

17. What was the primary reason you sought support?
a. to get others ideas/to know others were in the same boat
b. help with legal system
c. help with finances
d. emotional support
e. information
f. help with child rearing
g. help with social service system

18. Are you involved in any other support groups including phone or internet groups that would help you with the care of your grandchildren? (Please list any in the space below.)

Appendix C

GRAND VALLEY
STATE UNIVERSITY

1 CAMPUS DRIVE • ALLENDALE, MICHIGAN 49401-9403 • 616/895-6611

November 4, 1999

Karen Rishel
923 6th Ave.
Lake Odessa, MI 48849

Dear Karen:

The Human Research Review Committee of Grand Valley State University is charged to examine proposals with respect to protection of human subjects. The Committee has considered your proposal, **The Relationship Between Grandparent Caregiver Reactions and Support Group Participation**, and is satisfied that you have complied with the intent of the regulations published in the Federal Register 46(16)8386-8392, January 26, 1981.

Please note that Grand Valley State University letterhead may not be used for your letter to the grandparents, or the questionnaire.

Sincerely,

[redacted]

Paul A. Huizenga, Chair
Human Research Review Committee

Appendix D

To: Director of the School of Nursing
Grand Valley State University

From: Daniel and Glenda Levandusky
Founders and Coordinators of the Relatives as Parents Program of Eaton County

Subject: ***The Relationship Between Grandparent Caregiver Reactions and Support Group Participation***

We are happy to be able to facilitate Grandparent Caregiver Research by allowing Mrs. Rishel access to our support group mailing list. We understand that Mrs. Rishel is doing this research as her thesis for master's completion. We also understand that the questionaire responses are anonymous and that participation is voluntary.

We are attaching information about our program for your reference. Please feel free to contact us should you have any questions.

Sincerely,

Daniel and Glenda Levandusky

[redacted] - 10-19-99

517 - 663 - 2164

[redacted]

Appendix E

Dear Grandparent,

My name is Karen Rishel, I have been attending your Relatives as Parents group since spring and I would like to ask you to participate in a research study that I am doing as a requirement for completion of my masters program at Grand Valley State University. This research is titled: The Relationship Between Grandparent Caregiver Reactions and Support Group Participation. The purpose is to describe caregivers and their situations in this community, and the impact that a support group may have.

As a participant you will be asked to complete two questionnaires taking a total of 15 to 20 minutes to fill out. There will be only one set questionnaires per household and I would request that the grandparent who gives the most hands on care be the one to fill them out. The questionnaires contain questions about your particular situation and how you have been impacted by your situation. Your answers are anonymous. There is no expected risk to you except that some questions may touch on areas resulting in feelings of anxiety or distress. Your participation in this study is entirely voluntary, and you are free to refuse participation. On completion of the study, copies of the summary will be left with the group leaders for your review.

If you have any questions about your participation in this study please call me collect at 616-374-7618. You may also contact Professor Paul Huizinga, chairman of the Human Research Review Committee at Grand Valley State University, if you have any questions about your rights as a participant. That number is: 616-895-2472. Your consent to participate is your returned questionnaire. Please fill out and return in the enclosed envelope within the next week. A postcard will be sent out about 1 week later as a reminder.

Thank you so much for your help.

[redacted]

Karen Rishel R.N., B.S.N.

Appendix F

PERMISSION REQUEST FORM

Family Care Study

Name: Karen Rishel
Department: Nursing
Institution: Grand Valley State University
Mailing Address: 923 6th Ave, Lake Odessa, MI 48849
616 374-7018 [illegible]

••

Description of Research

Title: The Relationship Between Grandparent Caregiver Reactions and Support Group Participation

Dissertation: ____ Thesis: ✓ Other (specify): ____

Subjects (population and number): Grandparent Caregivers N=25

Location (where research will be carried out): Support group meets in Charlotte, Michigan

Brief description of study: Descriptive correlation study of variable of support group participation as measured by attendance with 5 subscales of CRA

Funded: Yes ____ No. ✓ If Yes, funding source: ____

[redacted]
Signature of investigator Date 4/12/00

Sharon Leder
Signature of faculty advisor (if investigator is a student) Date 4-12-00

••

1 Permission is requested to reproduce the scale(s) or data request indicated below for the research project described above:

✓ Caregiver Reaction Assessment
____ Involvement Scale
____ Patient Behaviors Scale
____ Health Services Utilization
____ Scales to Measure Beliefs of Diabetic Patients
✓ ~~Data request (specify)~~: May I use your figure of framework from "Family Caregivers of the Elderly and Reactions to Care" (1988)?
✓ Other (specify): May I put adapted assessment in appendix of thesis?

2 All data or scales will be used in accordance with the Code of Ethics of the American Psychological Association.

3. I agree to provide a detailed description of my procedures and results as soon as possible after the completion of the research.

4 I agree that whenever data is presented in any fashion that the grant title, funding agency, and principal investigator is cited.

••

✓ 5. Copyright Permission that Bell & Howard Informat may supply copies on demand. (formerly UMI dissertation services.)

Return completed form to:

Charles W Given, Ph.D
Michigan State University
Department of Family Practice
B109 Clinical Center
East Lansing, Michigan 48823-1313

FAX: (517) 355 7700
EMAIL: 20863cwg@msu.edu

Permission is granted.

[redacted]
Charles W Given, Ph.D
Principal Investigator

dd j [illegible] permiss.wpd (July 3 1997)

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