

CALIFORNIA STATE UNIVERSITY, NORTHRIDGE

Measuring the Effectiveness of Support Groups for
Caregivers of Individuals Suffering from Alzheimer's

A graduate project submitted in partial fulfillment of the requirements

For the degree of Master of Social Work

By

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in collaboration with Sarah Perdiguerra

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Abstract

Measuring the Effectiveness of Support Groups for Caregivers of Individuals suffering from Alzheimer's

By

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Purpose: The purpose of this study was to explore the effect of support groups on caregivers of individuals over the age of 60 suffering from Alzheimer's/Dementia to gain insight on the population being served in order to improve the intervention for those that participate and further understand barriers for those that do not. The researchers found that a significant relationship between attendance and the amount of anxiety participants reported. This study used a quantitative research method by utilizing a questionnaire based on one from Oliveira et al.'s (2015) study which was based off of Beck's inventories for anxiety and depression, the Duke Religion Index, a short form health survey, and the Zarit Caregiver Burden Interview. The study used the members of Alzheimer/Dementia caregiver support groups located in Southern California, who are non-paid caregivers.

Introduction

The journey of a caregiver can be challenging, stressful and emotionally draining as they watch their relative or friend's health decline. In fact, clinicians have coined the term "caregiver's burden" and have defined elder care one of the most contributing factors of chronic stress among non-paid caregivers (Hornillos & Crespo, 2012).

Although it is important to connect caregivers with educational and economic resources, it is also important that they are encouraged to care for their own emotional well-being along with coping skills for their stress (Hornillos & Crespo, 2012). While much research has been conducted focusing on caregiver stress, there is still a lack of research involving the effectiveness support groups for this population (Cooper, Balamurali, Livingston, 2007; Iavarone Et al, 2014; Kannan Et al., 2011; Von Känel Et al., 2003).

The objective of this quantitative study was to explore the effectiveness of the support groups from the caregiver perspective. Another goal for this study was to analyze stress levels, risk for depression and anxiety and declining health of the caregivers, as well as the demographics of the members of the support groups. The researchers evaluated the usefulness of caregiver support groups to non-paid caregivers by answering the following questions: 1) Have the members of the support groups experienced a decline in their health over the past 12 months? 2) Do the caregivers rely on any faith base support, in conjunction with the support group? 3) What are is the stress levels of the caregiver at the time of the survey?

Literature review

Becoming a caregiver has been shown to come with issues which decrease quality of life. Fitzpatrick and Vacha-Haase (2010) state that the higher

level of burden perceived by those who are caregivers often results in lower satisfaction in their relationship with their spouse. Increased impairment in those who they are responsible for also leads to a decrease in relationship satisfaction. Another study found an association between being a caregiver and an overall decrease in health/well-being (Bank et al., 2006).

Caregiver support groups aim to assist caregivers in numerous ways emotionally and socially. One study states, “Support groups combine different forms of intervention such as psychoeducational, skills training, and emotional support.” (Chu et. Al., 2011, p. 228). Another article which developed a program of therapy for those with progressive aphasia found it necessary to incorporate a support group which shared among participant’s education, successes and failures, as well as coping methods for the therapy program to produce better results for the care receivers.

Studies have indicated that caregiver support groups have shown to be beneficial to caregivers and care recipients alike in a variety of ways. A study by Jokel et al. (2017) states that support groups are a necessary part of treatment for caregivers which subsequently benefits those whom they care for by increasing their health and well-being. Research has found that caregivers themselves benefit from attending support groups by lowering levels of depression (Chu et al. 2011). Another study yielded results which support the idea that families whose caregivers attend support groups tend to require less medical care and thereby decrease medical costs (Peak, Toseland, and Banks, 1995).

Other articles also discuss the personal experiences of caregivers who attend support groups and how they felt they have benefited from the service. One study by Beerman (2003) found there were common themes among 5 women who were caregivers who created a support group. These women reported that the support group benefited them by allowing them to share without being judged, that they found relief, and they also had found acceptance in their support group. Another article by Vann (2013) describes his experience as a caregiver in a support group because of his wife having Alzheimer's. He said about the group, "Regardless of age or sex, we all 'got it' in my spouse caregiver group. We were addressing many, if not all, of the same behaviors, and although each of our individual situations was somewhat different, it was helpful to learn how others were handling similar situations." (Vann, 2013, p. 1413).

There is still more to be understood and known about the benefits and effects of caregiver support groups on caregivers and their care recipients. Chu et al. (2011) states previous studies had mixed results as to whether caregiver burden is decreased with attendance of a caregiver support group. Every support group and caregiver situation also differs from one another, which creates a need to understand further how to best implement the service. One study found that caregivers who found it difficult to attend support groups in person benefitted in similar ways by participating in a support group via telephone (Bank et al., 2006). A gap in service had been supported by creating a group for caregivers who found it difficult to find someone to take over caregiving responsibilities which would allow to attend support groups in-person.

Another study by Valentino and Bulmer (2005) utilized ‘cognitive mapping’ to better understand women's’ experiences as caregivers. This process yielded findings that while there were plenty of similarities among their experiences, there were significant amounts of unique situations among the participants which made every caregiving experience unique.

Further research and study will assist medical and mental health providers to better improve their services in therapy and caregiver support groups to better improve the lives of the growing population of care receivers and their families.

Method

The following methods were approved by the California State University Northridge IRB committee. This study asked the participants to engage in a single questionnaire at the end of their group therapy session. The questionnaire was developed by the researchers as a method of gathering data about participants to gain insight of how support groups affect individuals of varying characteristics. The questionnaire was adapted from a previous study by Oliveira et al. (2015) in which the researchers created a tool to measure socio-demographics, depression, anxiety, quality of life, religiosity, and caregiver burden from widely known and used scales of measurement.

Participants

This study's population included non-paid caregivers (N=30) of individuals who are suffering from Alzheimer's and Dementia. Incumbents were eligible to participate in this study if they were at least 18 years of age or older, and are the primary non-paid caregiver of an individual suffering from Alzheimer's or Dementia. Non-paid caregivers of individuals who are not suffering from Alzheimer's were excluded from participation. Eligible participants were recruited through local senior centers serving the Los Angeles county. Recruitment for this study occurred in two ways. Participants were informed of the study through an announcement by the group facilitator and flyer. This announcement was made for several weeks, ensuring that all group members are aware of the study. Researchers used purposive sampling to reach out to caregiver group facilitators to encourage participation in the researcher questionnaire. Ten (N=10) of the group participants identified as male. Twenty (N=20) of the participants identified as female. Twenty-eight (N=28) of the participants were aged 55 or older. Eleven of the participants

indicated they were single. Fourteen reported they were married. Three participants were divorced while the remaining two stated they were widowed.

Measures

The results measured categories of depression, caregiver burden, anxiety, health and well-being across bio-social-spiritual variables. The twenty-two item survey was developed off a previous scale utilized in a study by Oliveira et al. (2015). The survey utilized two sections. The first section was used to survey demographics. The second section was used to measure variables of anxiety, depression, health/well-being, and caregiver burden. The researchers created the questionnaire based on the literature.

Demographics. Researchers created questions to appropriately measure demographic variables of gender, age, caregiver status, income, and relationship status. These questions were designed to utilize nominal and ordinal measurements.

Spirituality. The questionnaire utilized prompts and responses taken from the Duke Religiosity Index. Participants reported their self-perceived level of engagement and commitment using ordinal measurements ranging on a five-point scale from (1) definitely not true to (5) definitely true. Higher scores reflect increased levels of spirituality for the participant.

Depression. The survey also allowed participants to report their levels of depression using samples of questions from Beck's Inventory of Depression. Questions asked participants to state their self-perceived levels of sadness, guilt, and satisfaction along ordinal measurements on four-point scales. Questions ranged from (1) I do not feel sad to (4) I am so sad and unhappy that I can't stand it, (1) I get as much satisfaction out of things as I used to (4) I am dissatisfied or bored with everything, and (1) I don't feel

particularly guilty to (4) I feel guilty all the time. Higher scores indicate higher levels of depression reported by participants.

Anxiety. The questionnaire inquired about participants' feelings of anxiety by implementing questions from Beck's Inventory of Anxiety. These questions allowed participants to report their self-perceived levels of anxiety by answering utilizing ordinal categories on a four-point scale ranging from (1) Not at all to (4) Severely. Higher scores report higher feelings of anxiety answered by participants.

Health/Well-being. Participants were asked to rate their health using questions developed from a short form health survey as described in the study by Oliveira et al. (2015). The questions used five-point ordinal measurements with higher scores establishing poorer health as stated by participants.

Caregiver Burden. The questionnaire prompted participants self-perceived levels of caregiver burden by responding to questions developed from the Zarit Caregiver Interview. Responses were recorded using five-point ordinal measurements ranging from (1) Never to (5) Nearly Always. Higher scores reported by the participants indicate higher levels of caregiver burden.

Research Design

This research used a survey/correlational design to measure multiple self-reported variables about emotional, mental, and health status against demographic variables to determine correlations.

Intervention

The intervention of the support groups inquired of in the questionnaire as well as utilized to implement the survey share basic similarities among therapy groups. The

groups used clinically licensed mental health facilitators to encourage engagement of group members amongst one-another to share thoughts, feelings, and advice pertaining to their role as a caregiver. The groups are held in their respective agency locations and are open to the public for participation. Each group is voluntary as well as expense-free for participation.

Procedure

This study asked participants to engage in a single questionnaire at the end of the group therapy session being examined. A cover letter to the questionnaire shared researcher's credentials as well as contact information. The cover letter explained the purpose of the study as well as describing confidentiality and potential risk exposures. This questionnaire took approximately 10-15 minutes to complete. After completion of the session, the questionnaire was handed out and reminded group members that participation was voluntary. The questionnaire asked questions regarding non-identifying biographical information, how group therapy has affected their physical health, how group therapy has affected their emotional health, and how group therapy has impacted their social life.

Results

The demographic variables of the study, including amount of caregiver support group sessions attended, were measured against variables rating anxiety, depression, health/well-being, spirituality, and depression using a category of questions. A significant relationship was found between attendance and the amount of anxiety participants reported. When N= 30 and the standard deviation of participant attendance is ~.504, the relationship between attendance and anxiety for participants is significant ($r=.386$) at the .05 level as indicated by Table 1.

Table I Correlations of Attendance and Caregiver Burden, Depression, Anxiety, and Health/Well-being

		Attendance	Burden, Stress, and Obligation	Level of Depression	Level of Anxiety	Level of Health/ Well- being
Attendance	Pearson Correlation	1	-.330	-.023	.386*	.093
	Sig. (2-tailed)		.087	.903	.042	.638
	N	30	28	30	28	28
Burden, Stress, and Obligation	Pearson Correlation	-.330	1	.150	-.116	.002
	Sig. (2-tailed)	.087		.446	.556	.993
	N	28	28	28	28	28
Level of Depression	Pearson Correlation	-.023	.150	1	.287	.085
	Sig. (2-tailed)	.903	.446		.138	.667
	N	30	28	30	28	28
Level of Anxiety	Pearson Correlation	.386*	-.116	.287	1	.526**
	Sig. (2-tailed)	.042	.556	.138		.004
	N	28	28	28	28	28
	Pearson Correlation	.093	.002	.085	.526**	1

Level of	Sig. (2-tailed)	.638	.993	.667	.004	
Health/Well-being	N	28	28	28	28	28

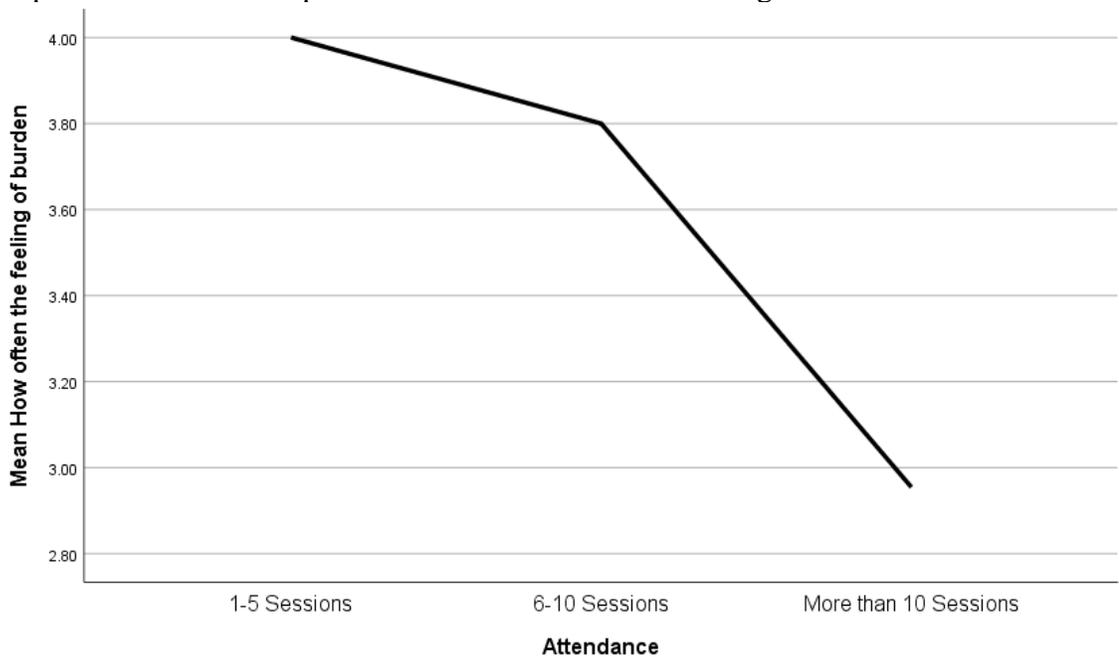
*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

No other significant relationships were found between demographic variables and the other variables measuring depression, caregiver burden, and health/well-being when the variables were measured as a group.

Researchers did find that when variables were measured by their individual questions, a significant relationship was found between attendance and the question about caregiver burden. This relationship is illustrated in Graph A.

Graph A. The relationship between attendance and the feeling of burden



Graph A illustrates a relationship whereas the attendance of the caregiver to a support group increases, the feeling of caregiver burden decreases. This is further described in Table II. when the negative correlation between attendance (N=30 and the SD= \sim .504)

and Caregiver Burden (N=28 and SD= .756) has a moderately significant relationship ($r = -.473$) at the .05 level.

Table II. Correlation between participant attendance and how often the participant rates their feeling of burden

		Attendance	How often the feeling of burden
Attendance	Pearson Correlation	1	-.473*
	Sig. (2-tailed)		.011
	N	30	28
How often the feeling of burden	Pearson Correlation	-.473*	1
	Sig. (2-tailed)	.011	
	N	28	28

*. Correlation is significant at the 0.05 level (2-tailed).

When the scores between two questions of caregiver burden were combined, particularly questions identifying burden and strain, there remains a significant relationship ($r = -.449$) between caregiver support group attendance and caregiver burden. This relationship is detailed in Table III.

Table III. Correlation between caregiver support group attendance and caregiver burden

		Attendance	Burden and Stress
Attendance	Pearson Correlation	1	-.449*
	Sig. (2-tailed)		.017
	N	30	28
Burden and Stress	Pearson Correlation	-.449*	1
	Sig. (2-tailed)	.017	
	N	28	28

*. Correlation is significant at the 0.05 level (2-tailed).

Discussion

The results of our survey neither validate or invalidate previous findings by past studies. The findings of our study have shown that there is a relationship to be explored between attendance of a caregiver support group and the level of anxiety caregivers feel. The cause of this anxiety remains to be explored by future studies as to why an increase of attendance of a caregiver support group correlates to an increase in anxiety. Chut et al. (2011) stated there were mixed results regarding the attendance of a support group and the level of caregiver burden. The results of our study reflects the mixed history of previous studies' findings. Attendance to a caregiver group did not demonstrate a significant relationship to caregiver burden when caregiver burden used a small category of three questions as whole to measure burden. When one of the three questions were removed from the measurement, a significant relationship was found. The question, "Do you feel you should be doing more for your relative?", is the difference between having a correlation between caregiver support group attendance and caregiver burden. This leads the researchers to wonder if identifying the emotion of burden amongst caregivers needs a clearer definition to produce clearer results in studies. Limitations of our survey that might have weakened the ability to validate or invalidate previous studies findings might be the number of variables being measured using shortened tools of index to identify participant's feelings. Using more inclusive questionnaires with thorough measuring tools might support reliable findings.

Conclusion

As identified through the results of this study and previous research, caregiver's experience many challenges, stress and emotional burden as they watch their relative or friend's health decline. Although the results of our study did not produce more insight into experience of a non-paid caregiver, it is important that they are encouraged to care for their own emotional well-being along with coping skills for their stress (Hornillos & Crespo, 2012). We hope that this study brings shed light on the experience of the non-paid caregiver and more resources are developed to support their own needs.

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Addendum

ADDENDUM – **Measuring the Effectiveness of Support Groups for Caregivers of Individuals Suffering from Alzheimer’s**

Project Title is a joint graduate project between Nicholas Ferreira and Sarah Perdiguerra. This document will explain the division of responsibilities between the two parties. Any additional information can be included in a separate document attached to this Addendum page.

Nicholas Ferreira is responsible for all the following tasks/document sections:

- Quantitative data processing (data denormalization, loading to SPSS)
- Design of Study
- Sample

Sarah Perdiguerra is responsible for all the following tasks/document sections:

- Quantitative data analysis (descriptive statistics and correlations)
- Data collection procedures
- Limitations

Both parties shared responsibilities for the following tasks/document sections:

- IRB creation and approval
- Data Collection
- Abstract, Introductions & Literature Review
- Results
- Discussion & Conclusion

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