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A STUDY OF THE EFFECTS OF SHORT-TERM RESPITE CARE
ON CAREGIVERS AND THE RELATIONSHIP BETWEEN
RESPITE SATISFACTION AND SOCIAL SUPPORT

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Lisa San Filippo Di Matteo

June 2005

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Approved by:




Dr. Thomas Davis, Faculty Supervisor
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6/21/05
Date



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ABSTRACT

The goal of this research was to assess the effects of short-term respite care on caregivers of the elderly and brain-impaired adults. Two groups of caregivers were assessed. The first group was caregivers who received respite care in the last six months. The second group was caregivers who did not receive respite care in the last six months. The sample consisted of 30 participants who received respite services in the last six months and 22 who did not receive respite care in the last six months. Both groups of caregivers were assessed in terms of their depression levels, burden levels, and sense of role overload, sense of role capacity, social support and respite satisfaction. This study found no significant differences between short-term respite users and non-respite users' depression levels, burden levels, sense of role capacity or role overload. This study did find a significant relationship between respite use and increased levels of reported social support. This study also found a significant relationship between satisfaction with respite services and increased levels of social support.

ACKNOWLEDGMENTS

I would like to thank all the caregivers who voluntarily participated in this study and gave their time to complete this questionnaire. I would like to acknowledge the dedication and amazing care that family caregivers provided. I would also like to thank all of the staff at Inland Caregiver Resource Center for their support and for the opportunity to do this study.

I would like to thank my family. I would also like to thank Dr. Thomas Davis for his guidance and support with this project. I would also like to thank Dr. Janet Chang for her guidance in terms of helping this project develop.

DEDICATION

To my husband Carmelo and my two wonderful children
Domenico and Teresa. Thank you for being so understanding
and supportive.

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CHAPTER ONE

INTRODUCTION

This chapter will provide an overview of the problems facing caregivers. It will also provide a definition of respite and how it is used as an intervention strategy. This chapter will also discuss the purpose of this study and the implications of this study for social work practice.

Problem Statement

Informal caregiving is an increasing problem in today's society. The problem of informal caregiving has always existed. The need for informal caregivers has increased in the last few years because of the increased population of older adults and because older adults are living longer as a result of medical advances. Older adults will soon make up twenty percent of our population (Fried, 2003). Many older adults who are living longer suffer from limitations in their functioning. In many cases these older adults are mentally or physically impaired and therefore require assistance with everyday tasks. There is a need for more informal caregivers to provide this assistance. Currently there are 5 to 7

million informal caregivers providing assistance to persons 65 or older (Family Caregivers Alliance, 2004). The problem of informal caregiving is expected to increase in the future. According to Family Caregivers Alliance, it is estimated by the year 2007 that 39 million households in the US will be providing care for someone who is 50 years old or older (Family Caregivers Alliance, 2004). Unfortunately, many of these informal caregivers are unequipped to deal with the care receiver's illness because of a lack of knowledge, resources and support.

Services that address these caregivers' needs are limited and under funded. Limited resources and the strain associated with caregiving cause many of these caregivers to experience symptoms of depression. Studies have shown that among caregivers there is an estimated 46% to 50% who are considered clinically depressed (Family Caregivers Alliance, 2004). Many of these caregivers suffer from anxiety, depression and other forms of emotional stress. They are found to use prescription drugs for depression and anxiety more often than the average person (Family Caregivers Alliance, 2004). They are usually under a lot of strain and stress

due to the care receiver's constant need for care, and the behavioral problems the care receiver may display due to their illness. In many cases these caregivers have to modify their entire lives. They give up their jobs. They also give up time with their immediate family and friends to fill the role of providing full-time care. All these factors contribute to increased stress, strain and depression. In many cases this stress causes caregivers to suffer from health problems. This is why it is critical to examine what factors might help a caregiver deal with their role and relieve the strain associated with informal caregiving.

Unfortunately, there are not many services that address the needs of informal caregivers. One service that has been discussed at length but requires more research is respite services. Respite services have been defined in many ways. The term "Respite" means an interval of rest or relief (Merriam Webster, 2001). It is described in the literature generally as any service or services that help the caregiver receive relief or rest from the care receiver and their caregiving duties. The goal of the service is to provide relief for the caregiver (Kosloski & Montgomery, 1995; as cited in

Chappel, Colin, & Dow, 2001). Respite can also be defined as caregivers receiving help with caregiving duties. In some cases, respite can involve a care receiver being temporarily placed in a facility so the caregiver can have a break (Miller & Goldman, 1989).

There are many types of respite services. There is in-home respite, where someone comes in the home to take care of the care receiver. There is respite that is provided through adult day-care services. This is where the care receiver goes to day-care during the day. There is temporary placement of the care receiver in a facility, in order to provide respite for the caregiver. There is also emergency respite. This is when the

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caregiver's sense of burden and stress (Gottlieb & Johnson, 2002). Other studies show no significant difference in terms of burden and stress (Gottlieb & Johnson, 2002). There is a substantial need for continued research in this area, to examine whether respite is an effective intervention.

Many agencies providing these services are concerned about respite services and their effectiveness. Most of these agencies offer short-term respite services. Short-term respite services and their effectiveness have not been addressed widely in the literature. There is currently little data supporting its effectiveness. Many of these agencies that provide these services are under increased pressure to show positive outcomes in order to maintain funding for their services. This is a big issue in these times of budgetary crisis. That is why it is essential for agencies that are providing these services to justify the need for respite services and justify the effectiveness of their respite programs. Further research in this area is desperately needed in order to clarify whether respite services are effective for caregivers.

Policy Context

As the next generation of older adults gets older, there is an increased demand for aging and adult services. One of the main services provided to caregivers is respite service. Respite services are under funded and usually time limited. There is lack of research to support respite services as an effective intervention. There also exists a lack of consideration for older adult services. The current state of funding is influenced by politics. Funding for social services, in general, is being cut. This also reduces funding for older adult services. Inland Caregivers Resource Center in Colton falls under the category of Adult and Aging services. From a conservative perspective, services for older adults are not a priority.

Conservatives view the problem of caregiving as a family problem, not a governmental or social problem. They also feel that older adults are retired and are no longer paying into the system. Older adults are not contributing to free enterprise. Free enterprise is valued highly by conservatives. They do not generally view funding for social services as a priority because it does not produce revenue. This political ideology has

caused cuts in funding and reductions in resources for this population.

When one realizes most caregivers are female, the conservative gender roles associated with the expectations of women becomes an explanation of why services for caregivers have been discounted for so long. According to Family Caregivers Alliance, females spend 50% more time providing care than males. Twenty six point six percent of caregivers are daughters, 17.5% of caregivers are another female relative, and 13.4% are wives of the care receiver. Another 5.7% of caregivers are not relatives of the care receivers but still are female (Family Caregivers Alliance, 2004). Policy makers are just not focused on this population. However the increasing needs of this group will become important as the population of older adults increases.

Practice Context

Social workers approach caregiving at the macro and micro levels. The specific intervention of respite is viewed from both these levels. From a macro practice level, administrators view respite care as an intervention that helps the care receiver remain in the home. Administrators see respite services as an

intervention that helps the caregivers avoid placement or institutionalization of the care receiver. This intervention saves the government money since it postpones institutionalization. Administrators feel that it is more economic to provide clients with short-term respite grants. Administrators would rather give caregivers breaks from their caregiving duties, than pay for nursing home placement. They also feel that it benefits the care receiver by allowing them to remain in the least restrictive environment.

At a micro practice level, respite care is used as an intervention by social workers to provide caregivers with relief from their caregiving duties. This break from caregiving allows the caregivers to take care of themselves. This break is thought to reduce the psychological and physical effects of caregiving. This includes depression, strain, sense of burden and overall health.

Purpose of the Study

The purpose of this study is to examine the effects of short-term respite on caregivers' strain, depression, role overload and role capacity. This study also sought

to examine the role that social support plays in determining satisfaction with respite care. This study obtained its participants from Inland Caregiver's Resource Center (ICRC) in Colton California. This resource center is one of eleven caregiver resource centers throughout the state of California. It provides services to caregivers of older adults and caregivers of brain impaired adults. It also offers a variety of services, case management, counseling, legal consultation and respite grants.

ICRC provides short-term respite grants to the caregivers it serves. These grants can range from a few hundred dollars to a few thousand dollars depending on eligibility and funding. ICRC relies on funding through grants it receives from the Department of Mental Health and through the National Family Caregivers Alliance. Since ICRC is funded by grants, it must show positive outcomes for its services. If it does not show that services are effective, it is at risk of losing funding. Currently, there is a lack of research on the effectiveness of short-term respite services for caregivers. That is why the issue of short-term respite has been especially important to this agency.

This agency is concerned about the short-term respite services they are providing. They are also concerned with the benefits to caregivers. This study provided them with essential data to determine if short-term respite care reduces depression, burden, role overload and role capacity of caregivers. It also provided them with information about the role social support plays in caregivers' satisfaction with respite care. This study also provided valuable data to this agency that assisted them in evaluating their respite program. This study also assisted this agency by providing significant data. This data contributed to ICRC's ability to develop appropriate and effective interventions, programs, and policies to benefit caregivers.

This study employed a quantitative exploratory survey design. The survey examined whether respite affects caregivers' depression, burden, role overload, and role capacity. It also examined how social support plays a role in caregivers' satisfaction with respite care. The instruments this study used consisted of several standardized surveys. Standardized surveys usually have high validity and reliability.

There were two groups of caregivers surveyed. The first group was caregivers of elderly and brain impaired adults who had received and utilized a respite grant in the last six months. The second group was caregivers of elderly and brain impaired adults who had not received a respite grant in the last six months. The sample was taken from Inland Caregivers Resource Center in Colton. The sample consisted of male and female caregivers. The sample consisted mostly of female caregivers. Female caregivers are over represented within this population.

The study employed a convenience sample. The study had a comparative design that included two groups of caregivers. The first group consisted of 30 participants who had received respite services in the last six months. The second group consisted of 22 caregivers who had not received respite services in the last six months. The participants were taken from support groups and educational groups. The participants were also taken from a respite list provided by ICRC. They completed the instrument in person or via phone. A telephone method was used so caregivers who did not attend support groups would still have the opportunity to participate in this study.

Significance of the Project for Social Work

This research is significant to social work practice on many levels. The first significant contribution this research makes is that it allows caregivers an opportunity to provide feedback about respite services. From an empowerment perspective, this is very important. This empowers caregivers by allowing them to give feedback about the respite services they receive and the benefits derived from these respite services. This is very empowering because it allows them to have a large role in whether these services continue and how they can be improved. This research will also provide the families' caregiving for their loved ones, with information about whether this intervention is effective or not. This will affect their decision-making processes in terms of whether they seek short-term respite services.

This research will be a valuable contribution to the social work profession at a micro and macro practice level. It will provide these agencies, which are employed and run by social workers, the opportunity to get feedback on whether these services are effective. It will also help them recognize what factors can make this

service more effective and what they can do to help facilitate better implementation of services. In terms of micro social work practice, this research can provide social workers with feedback about the services they have been providing. This research will provide social workers who are working directly with caregivers the information they need to make the best choices for the caregivers they are serving. It will provide them with information about what type of respite services were helpful and what kind of benefits can be derived from these services.

This study will also provide information that can be extremely valuable in terms of program evaluations and improving services for caregivers. This research can affect program and policy changes at Inland Caregivers Resource Center and within similar agencies. It also can affect whether respite services are increased or decreased. It can affect how these services are provided, in terms of whether they are short-term or long-term. It also can affect whether these respite programs are funded in the future.

In the case of Inland Caregivers Resource Center, this research can affect whether they receive more grants for respite services or not. This research can also

affect whether Inland Caregiver Resource Center allocates more money towards respite services. If they find that this intervention is not as beneficial as they thought, they might need to change programs and allocate resources towards different interventions for caregivers. This research could also provide information, which will justify increasing funding for respite services. This research will play an essential role in establishing support for these services or expose the need to reconsider providing these services. This research will also assist Inland Caregiver Resource Center and agencies like it, by helping them prepare for the increase in the older adult population and the needs of caregivers.

This study will also make a valuable contribution to research in the area of respite. Research on respite is desperately needed in order to clarify whether respite services are effective for caregivers. This is especially true for short-term respite services. The research on short-term respite services is lacking. There is a lack of data supporting the effects of short-term respite services on caregivers' well being. This research will also assist in generating other research questions for future research projects.

This project seeks to examine whether short-term respite is effective in reducing caregivers' depression levels, sense of burden, role overload and role capacity. This study also seeks to examine whether social support plays a role in caregivers' satisfaction with respite services. This project seeks to answer questions like: Is short-term respite effective in reducing depression levels? Is short-term respite effective in relieving caregivers' sense of burden? Does short-term respite care affect caregivers' sense of role capacity and role overload? What role does social support play in terms of caregivers' satisfaction with respite care?

CHAPTER TWO
LITERATURE REVIEW

Introduction

This chapter will consist of a discussion about relevant literature in terms of caregiving, components of caregiving, and how they relate to respite care use. This chapter will also examine components of caregivers' satisfaction. This literature review will examine several components of caregiving and respite care. Chapter two will begin with a discussion about components related to caregivers' burden. This will provide a better understanding of what leads caregivers to use respite services. The literature about informal and formal support and how that affects caregivers' use of respite services will be discussed in the second subsection. The third subsection will examine the dynamics of social support and respite care, providing an overview of the relationship between these two variables. The fourth subsections will address components involved in utilization of respite services. The last two final subsections will provide a review of the findings

involving the effects of respite services on caregivers and caregivers' satisfaction with respite care.

Components Related to Caregivers' Burden

It is important when examining the problems caregivers experience to determine what factors contribute to caregivers' perceptions of stress and burden. The variables that contribute to caregivers' sense of strain and burden have not been identified clearly within the literature. Some patterns have been established but they have proven to be inconsistent. Gilleard, Gilleard, Gledhill, and Whittick (1984), examined the variables associated with increased reports of stress and burden with caregivers of people who were considered mentally infirm. The participants were 129 caregivers of mentally infirm elderly adults who had been referred for day care services within their homes (Gilleard, Gilleard, Gledhill, & Whittick, 1984).

The participants were caregivers of patients admitted for day care services at four day hospitals in the Lothian between July 1981 and July of 1982. The caregivers had to either live with the care receiver or visit them a minimal of three times per week to be

included in this study. The participants were interviewed and administered several questionnaires. The questionnaires measured strain, burden and psychiatric symptoms. The interview also assessed past and present relationships with the care receiver and problems experienced by caregivers (Gillerard et al., 1984).

During the interview, questions were asked about source of illness, help they have sought/received and expectations about the future in terms of their caregiving role. This study was a longitudinal study, but the information in this article only focused on the information that was collected the day before day the hospital services were rendered. The results indicated that the caregivers age was a factor in the perceived stress and burden associated with caregiving. Younger caregivers reported more stress and burden. The limitations of the care receivers were also a factor in the perceived stress and burden of the caregiver. The sex of the care receiver was also found to be a significant factor in how the caregivers' experienced burden and stress. Caregivers of male care receivers were found to report an increase in burden and stress. Formal and informal supports were not found to be significant

factors in terms of caregiver reports of stress and burden in this study (Gillerard et al., 1984).

The scales used in this study were unpublished. This affects the reliability and validity of these scales. The reliability and validity of the scales used were not present in the method section of this article. This is a major limitation in terms of this study. Generalizability is also an issue when you consider the sample was obtained from previous admissions for day hospital care in a specific geographic area. This study did not examine caregivers who did not receive hospital services previously.

Informal and Formal Support and Its Effects on Caregiving

Gillerard et al. (1984) did not find a correlation between informal and formal support in relation to burden. Many other studies have found informal and formal support to be factors in how caregivers' perceive their caregiving role and the services they seek. According to Cotrell and Engel (1998), informal and formal support impacts whether caregivers will seek formal services like respite. Formal and informal mediators were the primary

focus of this study in terms of whether caregivers sought formal support services (Cotrell & Engel, 1998).

Cotrell and Engel (1998) interviewed 100 caregivers and asked them to identify people who had encouraged them to utilize formal support services. The sample of 100 caregivers was obtained through mailing lists and telephone logs of local Alzheimer's support groups. Participants were also obtained through the Alzheimer's Association contact information and through other agencies that offered services to older adults. The interviews lasted from two and a half hours to four hours. They examined two types of mediators. The first categories of mediators examined were formal mediators. Examples of formal mediators were doctors and other professionals. The second categories examined were informal mediators like family, friends and relatives. Respite was available to all participants (Cotrell & Engel, 1998).

The results of this study found that caregivers with mediators were 72% more likely to use respite services than caregivers without mediators. It was found that mediators provide caregivers with information, encouragement and other activities that encourage the

usage of formal services. Formal mediators were effective in facilitating caregivers to use services like in-home respite. Formal mediators were not as effective in facilitating usage of day-care services. Informal mediators were able to influence usage of services but did not give the same referral information as formal mediators (Cotrell & Engel, 1998).

One limitation in terms of this study was the potential for bias because the sample was taken mostly from the Alzheimer's Association. The Alzheimer's Association provides its members with referrals for formal services like respite and acts as a formal mediator. This can affect the validity of the findings of this study, if the participants were already connected with a formal mediator. The findings of this study are difficult to generalize. Caregivers associated with the Alzheimer's Association are not totally representative of the whole population of caregivers. This makes it difficult to generalize the findings of this study to all caregivers. Many caregivers do not care for someone with Alzheimers and many caregivers do not seek help or belong to organizations like the Alzheimer's Association.

Informal support was also examined by Kosloski, Montgomery, and Youngerbauer (2001). Kosloski et al. (2001) found that informal support was a significant predictor in whether a caregiver would seek and utilize formal services. They also found that the availability of a substitute caregiver was a significant predictor in whether a caregiver would seek and utilize formal services. They interviewed 458 caregivers of Alzheimer's patients in Michigan. In this study 176 of the participants were using respite. Another 128 participants had inquired about respite services. The remaining 154 participants were not using respite services and had not inquired about services. The goal of the study was to examine the characteristics of non-respite users. The participants were obtained from 26 counties in Michigan. The users and seekers were identified through county programs, personnel and staff. The non-seekers were identified through other service providers, who felt there was a need for these caregivers to utilize respite services (Kosloski et al., 2001).

The caregivers were interviewed by trained interviewers. The interviewers assessed several variables. The variables they assessed were need for

assistance, background, demographics, beliefs about personal responsibilities, and aspects of services delivery (Kosloski et al., 2001).

This study found that the need for services made caregivers seek respite services but not utilize the services. Informal support was a predictor of whether someone would seek and utilize respite services. The study also found that caregivers' degree of burden was associated with seeking services but not with utilizing respite services. According to this study, the characteristics of the respite services did mediate whether caregivers would utilize the services (Kosloski et al., 2001)

The reliability of this study is high because it utilizes many standardized scales with fairly high reliability. The sample size of this study was significant. It is difficult to generalize the findings of this study because the participants were obtained in one state. Yet the sample size and instruments make these findings significant to the literature.

Social Support and Respite Services

Formal support and informal support appears to affect caregivers in many diverse ways. It is important to examine the findings of the literature in reference to social support and respite use. Nicoll, Ashworth, and McNally (2002) chose to examine whether social support affected caregivers' satisfaction with respite services. They also examined whether depression, strain and burden were correlated with social support. They provided a questionnaire via mail to 140 caregivers who were caring for someone with dementia. The questionnaire consisted of several scales measuring social support, caregivers' strain, depression, and satisfaction with respite care (Nicoll et al., 2002).

The participants were obtained through support groups, nursing homes, day centers and district nursing services. This study was carried out in the United Kingdom. This study found that social support was a factor in caregivers' satisfaction with respite care. Caregivers who reported having more social support were more likely to report higher levels of satisfaction with respite services. There were no correlations found

between depression, strain, burden and social support (Nicoll et al., 2002).

Another study that examined social support and its relationship to respite services was Strang and Haughey (1999). They found that social support was a factor in terms of caregivers' experience of respite. They interviewed 10 family caregivers to see how they experienced respite services. The participants were obtained through different self-help groups, various home care agencies, and other community connections. The samples of participants were taken from an urban area. The caregivers were interviewed twice, two months apart. The interviews lasted 90 minute each. They identified three dimensions that were connected to the experiencing of coping with respite. One of these dimensions was having a social support network to encourage the caregiver to remove themselves from the caregiving role (Strang & Haughey 1999).

Components Involved in Utilization of Respite Services

Respite care is one of the most demanded services, yet utilization is reported to be low (Gottlieb & Johnson, 2000). It is important to examine why some

caregivers utilize respite services and some do not. According to Kosloski, Montgomery, and Youngerbauer (2001) the need for respite was not a factor in whether a caregiver utilized respite services. Yet an alternative caregiver was a predictor whether someone would utilize respite services. They also found that characteristics of the respite service were a factor in whether caregivers would utilize respite services (Kosloski et al., 2001).

Some researchers have chosen to examine why respite services are utilized and why caregivers do not utilize them. According to Strang and Haughey, (1999) caregivers coped better with the respite process if they were able to recognize that there was a need to remove themselves from the caregiving world. They also coped better with respite if they had the ability to give themselves permission to temporarily get out of the caregiving role. As mentioned earlier, the third component they identified was social support network, which encouraged them to remove themselves from the caregiving role (Strang & Haughey, 1999).

Kosloski and Montgomery (1993b) also examined why caregivers utilize respite services. They studied 114 caregivers who were eligible for respite services and

were caregiving for someone with Alzheimer's disease. The participants were informed about the study by support groups, newspaper articles, health providers, and social service providers. One half of the caregivers had used respite services. They interviewed caregivers and asked them how many times they utilized respite services. They also developed questions designed to measure convenience, quality, perceived utility, caregivers' health, ADL's of the care receiver, and instrumental activities of daily living. They also assessed whether the family was using other services. This study found that levels of respite use were affected by caregivers' beliefs about quality, convenience, and usefulness. It was also affected by other preexisting attitudes. Other variables that affected use were health of the caregivers' and use of other support services (Kosloski & Montgomery, 1993b).

Effects of Respite Services

It is important to know the components that lead a caregiver to utilize respite services. It is also important to know whether these services are helpful to caregivers in terms of relieving stress, burden and depression. It is also essential to assess whether

caregivers feel satisfied with the services they are receiving. Kosloski and Montgomery did another study in 1993 evaluating the effects respite care had on informal caregivers of Alzheimer's patients. They assessed seventy-two caregivers. Forty-seven of the caregivers were in the treatment group and twenty-five were in the control group. This was a longitudinal study of the Michigan's Model of respite care. They did a pretest when the caregivers were admitted into the study and a posttest at six months (Kosloski & Montgomery, 1993a).

They assessed subjective burden, objective burden, and morale using several scales from the literature. This study found that caregivers who received respite had lower levels of subjective burden and higher morale. They did not find any differences in terms of objective burden (Kosloski & Montgomery, 1993a).

In 1998 Zarit, Stephen, Towensend, and Greene did a study with caregivers whose care receivers suffered from dementia. They had two panels: one three-month panel and one twelve-month panel. In the three-month panel, there were 121 caregivers in the treatment group. These caregivers were using respite services. There were 203 participants in the control group. The treatment group

was composed of caregivers who had been involved in day care services in New Jersey. The control group participants were obtained from Ohio and two counties in Pennsylvania (Zarit et al., 1998).

This study used several scales to assess stressors, role capacity, overload, worry, strain, depression, anger and positive effects. In terms of the twelve-month panel, there were seventy-three caregivers in the treatment group who were using respite services and one hundred and twenty in the control group. In the three-month panel, caregivers in the treatment group reported lower levels of overload, strain, depression and anger. In terms of the twelve-month panel, the treatment group reported lower levels of overload and depression (Zarit et al., 1998).

Gottlieb and Johnson (2000), did a review of the literature on respite programs for caregivers with dementia. Within this review they discussed several studies that showed respite as having an effect on problems experienced by caregivers.

The first study Gottlieb and Johnson (2000), discussed in their literature review is Montgomery and Borgatta's (1989) study. Montgomery and Borgatta found

significant reductions in caregivers' subjective burden. They also found delays in placement rates of caregivers who utilized respite care. They had 183 participants in their study. They assigned caregivers of elderly adults to six groups. One group was a control group that featured eighty-five caregivers. The five other groups were treatment groups. The treatment groups incorporated a combination of respite, seminars, support groups and family consultation. The caregivers in these groups had access to different types of respite services and other support services. The last group had access to only respite services. The results were that all the participants in the treatment groups reported lower levels of subjective burden and were less likely to place their care receiver (Montgomery & Borgatta, 1989; as cited in Gottlieb & Johnson, 2000).

It is difficult to assess the generalizability of this study due to the fact that the information about this study is from a secondary source. This study is unpublished. Yet it is considered a valuable study, because it is frequently mentioned in the literature about respite care.

Gottlieb and Johnson in their (2000) study chose to include a description of their (1995) study. Gottlieb and Johnson (1995) did a study with 103 caregivers caring for care receivers with dementia. They used several scales to assess anxiety, somatization, perceived stress, depression and life satisfaction. Significant effects were found in the areas of anxiety, somatization and perceived stress (Gottlieb & Johnson, 1995; as cited Gottlieb & Johnson, 2000).

Satisfaction with Respite Services

Satisfaction is also an important component to examine when considering whether respite services are effective for caregivers. As mentioned earlier, Nicoll et al., (2002) found that social support was a factor in caregivers' satisfaction with respite care (Nicoll et al., 2002).

Townsend and Kosloski (2002) also did a study on caregivers' satisfaction with respite care and found several components that related to satisfaction. This study analyzed interviews with 1183 caregivers. They examined satisfaction rates of caregivers who received respite services through the Demonstration Grants to

State Program. This program was designed to serve caregivers of Alzheimer's patients, who were minorities and lived in rural areas. They analyzed two major variables. They analyzed the characteristics of the clients' family and the caregivers' perception of service delivery. They found several factors that influenced satisfaction with in-home respite services. The factors they found were the care receivers ADL's, ethnicity and expectations of what the person providing respite care would do and not do. They also found that access to services, and the red tape involved in getting services influenced caregivers' satisfaction with in-home services. In terms of user satisfaction with day care services, factors that correlated with satisfaction were caregivers' age, health, ethnicity and expectations of what the person providing respite services would do and not do. They also found that access to services, and the red tape involved in getting services were factors in caregivers' satisfaction with day care services (Townsend & Kosloski, 2002).

There has been a lack of literature examining the effects of short-term respite services and caregivers' satisfaction. Miller and Goldman (1989) did a study on

caregivers who had arranged short-term respite services. They found that the caregivers would utilize the services again and that they felt that it benefited them mentally. The study was done with 48 family caregivers who had arranged respite care for care receivers who were elderly and frail. The respite was short-term and used for vacations, personal business and surgery. The care receivers were placed in a facility during the respite period. The participants were given a questionnaire to measure how they felt about the respite services. This questionnaire measured the caregivers' perceptions and the care receivers' perceptions. Seventy-eight percent of the caregivers indicated that they would use the respite services again and that it helped them with their mental health (Miller & Goldman, 1989). This study has several limitations including the sample size and the use of an instrument that did not appear to be standardized.

From a review of the literature, it is clear to see that the literature on respite care is mixed. These studies have examined respite care qualitatively and quantitatively. This study will contribute to the literature by examining several variables. It will examine the effects that short-term respite has on

caregivers' burden, depression, role overload and role capacity. It will also examine the role social support plays in terms of caregivers' satisfaction with respite services. This study will provide clarity for social workers and other professions working with this population.

Theories Guiding Conceptualization

There were several models discussed in the literature in relation to respite care. The one directly related to respite as an intervention for caregivers is the stress-processing model (Gottlieb & Johnson, 2000). This model indicates that respite should be a good intervention for caregivers because it alleviates role capacity and overload among caregivers. It states that role capacity and overload are indicators of role strain. Role strain is experienced widely by caregivers. The model states that role strain can be reduced by a substantial amount of respite. The respite would need to be timed just right to help the caregiver avoid the outcomes of such role strain like anger, hostility and giving up the caregiving role (Gottlieb & Johnson, 2000).

Another theoretical model mentioned within the literature is respite as a coping strategy (Gottlieb & Johnson, 2000). This theoretical model believes that respite users who are unable to remove themselves from caregiving and who experience troubling thoughts, are unlikely to seek respite services. They are also unlikely to utilize them properly. This model holds that it may be necessary for caregivers to receive education about distancing themselves from the situation when they receive respite services. This model subscribes to the idea of respite as a break that allows caregivers to withdraw from a situation that causes emotional and physical arousal (Gottlieb & Johnson, 2000).

This theory believes that breaks for caregivers provide caregivers the opportunity to return to a state of homeostasis and relieve stress that has built up due to the demands of caregiving. Breaks help them cope with the situation by removing them from the situation, so they can recuperate mentally and physically (Gottlieb & Johnson, 2000).

CHAPTER THREE

METHODS

Introduction

This section will provide an overview of the study design, sampling method, and research procedures. The processes involved in the data collection and data analysis will be discussed in this section. The steps involved in the protection of the human participants will also be discussed.

Study Design

This study explored the effects of short-term respite care on caregivers of elderly and brain-impaired adults. The information obtained from this study has attempted to assess whether short-term respite services being provided by Inland Caregivers Resource Center are effective in relieving some of the problems experienced by caregivers. This study also examined how social support plays a role in caregivers' satisfaction with respite services. The aspects of burden, depression, role overload, role capacity, respite care satisfaction, and social support, were explored using a quantitative survey design. Two groups were assessed. Caregivers who had

received short-term respite services in the last six months, and caregivers who had not received respite services in the last six months. Participants were obtained through caregiver support groups, educational groups and phone calls. Most of the instruments utilized in this survey were standardized. This method of assessment requires a limited amount of time to complete and is convenient for study participants. The participants were all clients of Inland Caregivers Resource Center in Colton California.

The purpose of this study was to answer several research questions. Is short-term respite effective in reducing depression levels? How are role capacity and role overload affected by short-term respite? Is short-term respite effective in relieving caregivers' sense of burden? What role does social support play in terms of caregivers' satisfaction with respite care?

A limitation in this study is the reliability of the reports of the participants. In many cases, participants fail to report everything due to concerns about being evaluated. In many cases, participants do not always report their feelings honestly. This may be due to

concerns about what others will think or to avoid stigmas attached to reports of certain behaviors or feelings.

Another limitation to this study is the sample size. When assessing multiple variables, it is important to obtain a large number of participants. This study obtained a limited number of participants, which makes the results of the study difficult to generalize. Another limitation of this study was the fact that this study is assessing clients from one particular agency. This affects this study's generalizability.

Sampling

Caregivers participating in this study were obtained from Inland Caregivers Resource Center in Colton. The caregivers this agency serves are caregivers of brain-impaired adults and elderly adults. Inland Caregivers Resource Center serves San Bernardino County, Riverside County, Inyo, and Mono County. A list of both caregivers who had received respite in the last six months and caregivers who had not received respite within the last six months was provided by Inland Caregivers Resource Center. From these lists a convenience sample was taken. There were 30 caregivers who had received respite in the

last six months and 22 caregivers who had not received respite services in the last six months. Participants were randomly selected.

Data Collection and Instruments

The data was collected through self-administered questionnaires. The independent variables were respite care satisfaction and respite care use. The dependent variables were depression, burden, social support, role capacity and role overload. All the dependent variables were measured with standardized instruments.

The variable of depression was measured by the Center For Epidemiological Studies-Depression Mood Scale (CES-D). This standardized scale was developed to measure depression. This scale consists of 20 questions on a four-point Likert scale. In terms of reliability, the CES-D has an internal consistency alpha .85 in the general population. In a psychiatric population it has an alpha of .90. The validity of this instrument is good. It is able to discriminate between the inpatient psychiatric clients and the general population. It is also a good instrument in terms of measuring levels of severity (Radloff, 1977). This instrument is standardized and is

currently being used within the CRC system to measure depression levels among caregivers.

Burden was measured using a shortened version of Zarit's Burden Interview (2001). The original scale was 22 items and the shortened version contains 12 items. This shorter version is on a five-point Likert scale ranging from *Never* to *Nearly Always*. The shortened version has a Cronbach alpha level of 0.88. In terms of measuring personal strain the scale has a Cronbach alpha level of 0.89. When measuring the strain associated with roles, the scale has an alpha level of 0.77 (Bédard et al., 2001).

Social Support was measured by the Social Support Questionnaire (1982). This is a six-item scale that measures social support. This scale is on a five-point Likert scale ranging from *Almost Always* to *None of the Time*. According to Sarason, Levine, Basham, and Sarason, (1982), this is a standardized instrument that measures levels of social support. It has a reliability of 0.83. This scale has been adapted for the purposes of this study. The questions have been revised slightly to fit the purpose of this study (Sarason et al., 1982).

The variables of role capacity were measured by a scale taken from Pearlin, Mullian, Semple, and Shaff, (1990). This scale has been used in other studies to measure caregivers' role capacity. It is a three-item scale on a four-point Likert scale ranging from *Very Much* to *Not At All*. It has a reliability of 0.83 (Pearlin et al., 1990).

The variable of role overload was measured by a scale taken from Pearlin, et al. (1990). This scale has also been used in the literature to measure caregivers' role overload. It is a four-item scale set on a four-point Likert scale ranging from *Very Much* to *Not At All*. It has a reliability of 0.80 (Pearlin et al., 1990).

Respite satisfaction was measured using questions taken from Nicoll et al. (2002). They used these questions to examine the relationship between social support and respite satisfaction. This was a three-item scale, which was developed for the purpose of their study. The first question they asked was "*How satisfied are you with the respite care that the person you are caring for received?*" This question was placed on a five-point Likert scale. The responses ranged from "*Very Dissatisfied*" to "*Very Satisfied*". The other two

questions used by Nicoll et al.; (2002) were "Do you feel you benefited from the Respite care period?" and "Do you feel the person you care for benefited from the respite care period?" These two questions were also placed on a five-point Likert scale. The responses ranged from "Not at all" to "Yes, Very Much". These three levels of respite satisfaction examined correlated closely and had a p value of $> .60$ and a P value of < 0.001 . Satisfaction correlated with benefits to the caregivers $p = 0.68$, $P < 0.001$ (Nicoll et al., 2002).

Procedures

Permission was obtained to conduct this study at Inland Caregiver's Resource Center in Colton, California. The caregivers for this study were obtained from a list of respite users and non-users from Inland Caregiver Resource Center. The survey questionnaires were administered at caregiver support groups, caregiver education classes and via phone. The group facilitator, under the guidance of the researcher, administered the questionnaire. Questionnaires were also administered via phone by the researcher. The phone method was used to avoid any bias in terms of caregivers who may not be able

to attend these functions due to their caregiving duties. Permission was obtained through a letter of approval from a representative at Inland Caregivers Resource Center. The questionnaires were administered from January of 2005 to March of 2005. IRB clearance was obtained in January of 2005.

Participants were provided with an informed consent form prior to completing the questionnaire. If the participants agreed to the information provided to them on the consent form, they marked an X in the appropriate box. This study did not collect names to protect caregivers' confidentiality. After the participants completed the questionnaire they returned the questionnaire to the researcher. Participants who were administered the questionnaire via phone provided verbal consent to the facilitator. The participants were provided with a debriefing statement after the administration of the questionnaire. These debriefing statements informed them about the purpose of the study they participated in and provided them with information about obtaining the results of the study if desired. Names of mental health agencies were also provided on the

debriefing statement in case a participant became distressed.

Protection of Human Subjects

Several measures were taken to protect the confidentiality of the participants in this study. All participants in this study were voluntary. The questionnaires did not contain names of the participants. Each questionnaire was assigned an identification number to identify it. The information collected in the demographic portion of the survey was limited. It did not ask for specific information like the disability of the care receiver or the care receiver's functioning level.

Participants were provided with an informed consent form. If they agreed with the information provided on the consent form they placed an X in the appropriate box. This was done to maintain the participants' confidentiality. The confidentiality of the participants was maintained and only the researcher and researcher's advisor had access to the study's data. The data was kept under lock and key by the researcher when not being evaluated. It was locked at the researcher's home or in a locked brief case when it was being transported from the

site of collection to the area where it was analyzed. Once the information on the questionnaires was entered into SPSS the questionnaires were destroyed via shredding.

The participants were informed prior to completing the questionnaire that if questions were too personal or made them feel uncomfortable, they had the right not to answer these questions. They also were informed that participation in the study was voluntary and that they could stop filling out the questionnaire at any time. They also were informed that their responses were confidential and would be used only for research purposes. Debriefing statements were provided to the participants with information about the study and with information about how to obtain the results. Names and numbers of mental health agencies were provided on the debriefing statement, in case participants became distressed.

Data Analysis

This study employed a quantitative questionnaire design. The sample collected was a non-probability sample. The questionnaires were coded. The data analysis

method used descriptive and inferential statistics. Inferential statistics were used to evaluate relationships between the independent and dependent variables. The dependent variables of depression, burden, social support, role overload, and role capacity, were measured using ordinal levels of measurement. Respite satisfaction measurements utilized ordinal levels of measurement. Demographic variables utilized both nominal and ordinal levels of measurement.

Bivariate analysis was conducted between variables. There were evaluations performed between the dependent variables and independent variables. These evaluations showed the significance of the relationships between the variables. There were several variables evaluated. The relationship between depression and usage of short-term respite services was evaluated. The relationship between burden and usage of short-term respite services was evaluated. The relationship between role capacity and usage of short-term respite services was evaluated. The correlational relationships between role overload and usage of short-term respite services were also examined. Social support was also examined in terms of its relationship to usage of short-term respite service. The

explored the role that social support plays in terms of caregivers' satisfaction with short-term respite services. This methods section provided a description of how this study obtained its participants, the kind of participants included and the research questions posed.

CHAPTER FOUR

RESULTS

Introduction

Chapter four will be a presentation of this study's the results.

Results

The eligible participants consisted of 52 caregivers from Inland Caregiver Resource Center. Thirty of the participants had used respite care in the last six months, and twenty-two had not received respite care in the last six months. In terms of gender, 78% of the participants were female and 15% of the participants were male. Another 5% were unknown. The mean age was 65 years old. A majority of the participants (61%) reported that they had more than a high school diploma. Approximately 44% of the participants had a yearly income of forty thousand dollars or more. The sample was composed of 75% Caucasian caregivers. Another 11% reported that they were Hispanic. African American caregivers made up 6% of the sample and another 4% indicated that they were Asian American. Over half of the caregivers reported being married (67%). Single caregivers made up 11% of the

sample. Divorced caregivers consisted of 12% of the participants. Another 8% of the participants were widowed and 2% were separated. In terms of the relationship between the caregivers and the care receivers, 23% stated that they were the care receivers' husbands. Another 23% of the participants stated that they were the care receivers' children. Caregivers who reported that they were the care receivers' wives consisted of 21% of the sample. Another 19% reported that they were the care receiver's parent. Approximately 8% of the participants reported that they were another family member. Another 4% reported that they were a grandparent and 2% reported that they were not a family member. The majority of the caregivers in this sample reported that they had been caregiving for five years or more (36%). In terms of the type of respite care used, the caregivers in this study reported that they used Adult Day Care services (33%). The participants reported that 21% of them received respite care for 2 months or less. Another 56% of the participants did not provide an answer for this question. The participants were also asked about respite benefits they received. The majority of the participants reported receiving grants and aid benefits (25%). Another 42% of

the participants failed to give a response to this question. In terms of health, 52 % of the caregivers in this study rated their health as good. Another 29% of the participants rated their health as fair. Caregivers who reported having excellent health consisted of 13% of the sample. Another 6% of the participants rated their health as poor.

An independent T test was performed to compare the differences between caregivers who used respite care in the last six months and caregivers who did not. There were no significant differences found between caregivers who received respite care in the last six months and those who had not in terms of depression, burden, role overload, and role capacity. There were however, differences in terms of social support. Caregivers who received respite services in the last six months reported higher levels of social support than caregivers who did not. (Please refer to Table 5 for details).

An independent T test was conducted to evaluate the differences between the burden levels of caregivers who had received respite care in the last six months and caregivers who did not receive respite care in the last six months. The test was not significant $t(52) = -.724$,

$p = .472$, and the results were counter to this study's research hypothesis. Caregivers who received respite care in the last six months had a burden level ($\underline{M} = 19.17$, $\underline{SD} = 8.840$), which was not significantly lower than caregivers who had not received respite in the last six months. (Please refer to Table 1 for details).

An independent T test was conducted to evaluate the difference between depression levels of caregivers who had received respite care in the last six months and caregivers who had not. The test was not significant $\underline{t} (52) = -1.304, p = .199$ and the results were counter to this study's research hypothesis. Caregivers who received respite care in the last six months had depression levels ($\underline{M} = 32.78, \underline{SD} = 11.473$) (Please refer to Table 2 for details).

An independent T test was conducted to evaluate the differences between caregivers who had received respite care in the last six months and caregivers who had not received respite in the last six months. The t-test was significant $\underline{t} (52) = 2.622, p = .012$. Caregivers who had received respite in the last six months reported higher levels of social support ($\underline{M} = 17.6, \underline{SD} = 2.44$). (Please refer to Table 3 for details).

An independent T test was conducted to evaluate the difference between reports of role overload by caregivers who received respite care in the last six months and caregivers who had not received respite care in the last six months. The t test was not significant $t(52) = -.148, p = .883$. Caregivers who had received respite care in the last six months ($M = 7.28, SD = 3.168$) reported similar levels of role overload to caregivers who did not receive respite care in the last six months ($M = 7.41, SD = 3.202$) (Please refer to Table 4 for details).

An independent T test was conducted to evaluate the differences between reports of role capacity by caregivers who received respite care in the last six months and caregivers who had not received respite care in the last six months. The t test was not significant $t(52) = -.200, p = .842$. Caregivers who had received respite care in the last six months ($M = 8.83, SD = 2.9$) reported similar levels of role capacity to caregivers who did not receive respite in the last six months ($M = 9.00, SD = 3.1$) (Please refer to Table 5 for details).

Pearson R correlations were performed for the variables of depression, burden, role overload, role capacity, social support, and respite satisfaction. Total scores were evaluated and individual scores for specific questions were also correlated. There were correlations found between total scores for depression and burden. There were also correlations found between depression and role overload. Burden and role overload also had a significant correlation. There was also a correlation between role overload and role capacity. There were also correlations found between respite satisfaction and social support.

There was a correlation relationship found between total depression levels and burden levels. The correlation between depression and burden was significant $r(52) = .643, p < .01$ (Please refer to Table 6 for details).

A Pearson R correlation was performed for the total scores of depression and role overload. There was a significant correlation found between the two variables. The correlation between depression and role overload was significant $r(52) = .491, p < .01$ (Please refer to Table 7 for details).

A Pearson's R correlation was performed for the total scores of burden and role overload. The result indicated a significant correlation between the two variables. The correlation between burden and role overload was significant $r(52) = .775$; $p < .01$. (Please refer to Table 8 for details).

A Pearson's R correlation was performed on the total scores of role overload and role capacity. There was a significant correlation between these two variables. The correlation between the total scores for role overload and role capacity was significant $r(52) = .455$, $p < .001$ (Please refer to Table 9 for details).

A Pearson's R correlation was performed for the total scores of respite satisfaction and social support. There was a significant correlation found between social support and respite satisfaction. The correlation between the total scores for respite satisfaction and social support was significant $r(52) = .520$, $p < .01$ (Please refer to Table 10 for details).

Individual correlations were performed on specific questions from each scale. Several significant findings are presented.

Depression Question 1: *During the past week, I was
bothered by things that don't usually bother me.*

Burden Question 3: *Do you feel angry when you are around
the care receiver?*

The correlation between depression 1 and burden 3
was significant at $r(52) = .548, p > .000$.

Depression Question 1: *During the past week, I was
bothered by things that do not usually bother me.*

Burden Question 9: *Do you feel like you have lost control
of your life since the care receiver illness?*

There was a significant correlation between
depression question 1 and burden question 9
 $r(52) = .643, p < .000$.

Depression Question 20: *During the past week, I could not
get going?*

Role Overload Question 3: *You don't have enough time for
yourself?*

There was a significant correlation between
depression question 20 and role overload question 3
 $r(52) = .564, p < .000$.

Role Capacity Question 2: *How much do you feel trapped by
your relatives illness?*

Burden Question 2: *Do you feel stressed between caring for the care receiver and trying to meet other responsibilities (work/family)?*

There was a significant correlation between role capacity question 2 and burden question 2 $r(52) = .555$, $p < .000$.

Role Overload Question 2: *You have more things to do than you can handle.*

Burden Question 8: *Do you feel your social life has suffered because you are involved with the care receiver?*

There was a significant correlation between role overload question 2 and burden question 2 $r(52) = .711$, $p < .000$

Role Overload Question 1- *You are exhausted when you go to bed at night.*

Burden Question 9: *Do you feel like you have lost control of your life since the care receiver's illness?*

There was a significant correlation between role overload question 1 and burden question 9 $r(52) = .687$, $p < .000$.

Respite Satisfaction Question 2: *Do you feel that you benefited from the respite care period?*

Social Support Question 6: *There are people you can totally be yourself with?*

There was a significant correlation between respite satisfaction question 2 and social support question 6 $r(52) = .494, p < .000$.

Summary

Chapter four reviewed the results of this research project. Data was obtained on caregivers who received respite care in the last six months and caregivers who did not receive respite care. Respite users reported having more social support than non-respite users. There was a high correlation between burden, depression, role overload and role capacity. There were also found to be several correlations between independent questions related to the perceptions of caregivers.

CHAPTER FIVE

DISCUSSION

Introduction

This chapter will discuss the findings from this project and how they are essential to understanding the experiences of caregivers. It will also discuss the limitations of the data. This chapter will also provide recommendations for social work practice. Policy and research practices will also be addressed. This chapter will close with a final conclusion section.

Discussion

In this study, a significant relation between respite use and social support was found. The independent T test performed indicated that caregivers who had received respite services in the last six months reported higher levels of social support. These findings could indicate that social support is a determining factor in whether caregivers utilize respite services. Caregivers who already have friends and family who are supportive, might be more inclined to have respite breaks from caregiving. Relatives and friends who are supportive might help the caregiver get a break when they see that

they are overwhelmed. Caregivers who have support networks also might be encouraged to utilize formal respite services more often than caregivers who have no support.

This study also found correlations between caregivers' respite satisfaction and higher levels of social support. This study supports the findings of Nicoll, Ashworth, and McNally (2002) who found that social support was a factor in caregivers' satisfaction with respite care (Nicoll et al., 2002). Social support could not only be a reason why caregivers obtain respite services through informal or formal means, but a reason why they are satisfied with the service. Caregivers who have social support networks might benefit more from respite because they remove themselves from their caregiving role completely when they spend their respite time with friends and relatives. Caregivers without social support networks might feel uncomfortable receiving respite services and therefore rate the service lower. According to Strang and Haughey (1999), in their study on respite as a coping strategy, one dimension that helps caregivers cope with times of respite is having a social support network to encourage them to come out of

their caregiving role (Strang and Haughey, 1999).

Findings from this study could possibly support Strang and Haughey's findings and highlight the importance of caregivers having a social support network.

This study also found significant correlations between depression and burden. It is possible that caregivers experience extreme degrees of burden due to their caregiving role. This sense of burden, in turn, causes them to feel symptoms of depression. Depression and burden could possibly be the result of role overload since some of the caregivers' role overload correlated with depression and burden. Caregivers could possibly become so overloaded with the role they play that they begin to feel like their caregiving role is a burden. This perceived burden causes them to become depressed and they report higher levels of depression. Higher degrees of role overload could then possibly lead to the caregiver reporting higher levels of role capacity. Caregivers who feel overloaded, depressed and burdened might experience role capacity. They might feel like they are trapped. They also might feel the need to run away and live their own life. This highlights the fact that there needs to be interventions to reduce caregivers'

role overload and provide them with breaks from their roles. They need breaks from their roles so they do not become burdened, depressed and reach their role capacity.

This study also found correlations between individual questions that appeared to be significant in terms of understanding caregivers. Being a caregiver is difficult when you have other responsibilities other than caregiving. According to the results of this study, caregivers who have multiple things to do tended to feel that their social life had suffered. It is possible that caregiving duties limit the social activities of the caregiver. These activities usually provide people with breaks from the routine of their daily lives. Caregivers who do not participate in social activities and do not experience social breaks may possibly become stressed. They become stressed trying to perform multiple roles and not having any breaks from these roles. Caregivers who feel stressed between all these responsibilities may also feel trapped by the care receiver's illness. They may possibly feel overwhelmed, trying to meet all these needs. Caregivers' ability to cope with stress may explain why some caregivers feel angry with the care receiver. This anger directed at the care receiver also

is projected on to other things. This accounts for caregivers' reports that they were bothered more by things that do not usually bother them. This sense of feeling bothered could account for why they reported that they felt out of control. If one is constantly angry and bothered by everything they might have a sense that they are losing control of their emotions. The process of being angry and sensing that your losing control, can be quite emotionally and physically exhausting. This could account for the correlation between loss of control and feeling exhausted. Caregivers who feel exhausted might also find it difficult to get going. Caregivers are less motivated to get going because they have no time to themselves. They cannot envision any time away from their responsibilities. This could account for the correlation between lack of motivation to get going and feeling they do not have enough time for themselves. Caregivers who receive respite breaks might have more time to themselves and more time to spend with others. This time allows them to be free from their caregiving role. Caregivers who have someone to spend this free time with might report higher levels of satisfaction with respite services. This

might account for why caregivers with social support appear to be more satisfied with respite services.

This does not account for why we did not see differences between the group of caregivers who utilized respite care and caregivers who did not utilize respite care. There were no significant differences found in terms of depression levels, burden level, sense of role overload and role capacity. There were differences found but not statistically significant differences. This makes it hard to assess the effects of respite care services on caregivers. One reason why the effects of respite care are difficult to assess is that there are so many variables involved in how respite use affects an individual caregiver. One variable that has not been examined is substitute caregivers who provide respite breaks for the regular caregiver. This could be a friend, a neighbor or a relative who watches the care receiver for a set period of time while the normal caregiver performs some chore or task. These breaks provide a break from caregiving that allows the caregiver to think about something other than the care receiver's needs. These short-term breaks may be looked forward to weekly by caregivers who normally receive no respite services.

These breaks are difficult to account for using a quantitative survey. Caregivers who report receiving no respite breaks could possibly be receiving mini respite breaks from friends, relatives and neighbors. These breaks could affect these caregivers' burden levels and sense of role overload. These caregivers therefore report similar levels of depression, burden, role capacity and role overload, compared to caregivers who receive short-term respite services. Until these breaks are considered within the literature, it will continue to be difficult to show accurately the effects respite services have on caregivers burden, depression, role overload and role capacity.

Limitations

There are several limitations in terms of this study. The first limitation is the study's sample size. The sample size only consisted of 52 caregivers. It is difficult based on the responses of 52 caregivers to generalize these findings to the rest of this population. There are also limitations in terms of the participants' self-reporting. In many cases participants do not report their feelings honestly. In many cases they do not reveal

everything because they are being evaluated. They might be concerned about the stigma attached to reporting certain feelings and behaviors. Another limitation to this project is that the participants were obtained at one agency at a specific point and time. It is difficult to generalize the findings of caregivers from one agency to the entire caregiving population.

Recommendations for Social Work Practice, Policy and Research

The research about respite care and its effects is very mixed. This project found differences in respite users' depression levels, burden levels, sense of role overload and role capacity but these differences failed to be statistically significant. It appears to be difficult to assess the exact benefits caregivers are receiving from short-term respite periods. A variable that is not being considered is the presence of informal respite care by relatives, neighbors and friends of the caregiver. In many cases caregivers fail to report these breaks in caregiving because they do not view them as respite periods. The definition of respite care needs to be defined to consider these breaks in caregiving by informal caregivers. Many caregivers have respite breaks

without having formal respite services. These breaks, may reduce caregivers' depression levels, burden levels, sense of role overload and role capacity. These breaks are short yet may be effective in reducing the effects of continuous caregiving. These breaks and their effects are not being examined within the literature. It is this researcher's view that these small breaks in caregiving experienced by caregivers labeled as non-respite users account for the lack of empirical data showing the effectiveness of formal respite services. A qualitative interview may allow a researcher to determine the amount of informal respite care being provided by relatives and others. This might allow the researcher to rule out the effects of informal respite services by others people. This could allow the researcher to thoroughly examine the effects formal short-term respite services have on caregivers. Informal breaks in caregiving by caregiver are problematic in a comparative design study like this project. A qualitative study might rule out this bias. Further studies might also be needed to examine why respite users reported higher levels of social support than respite non-users. A qualitative study measuring the caregivers' perception of social support and how that

relates to usage of formal respite services might need to be explored further.

Conclusion

The purpose of this study was to examine the effects short-term respite care had on caregivers of elderly and brain-impaired adults. This study examined how short-term respite care affected depression levels, burden levels, role overload, role capacity and social support. This study also examined the relationships between respite care satisfaction and social support. There was a significant relationship found between respite use and increased reports of social support. Respite users reported that they had a significant level of social support. A significant relationship was also found between reports of respite satisfaction and perceived social support. Respite users with more social support reported higher levels of respite satisfaction. It is important to examine the variables affecting respite use and satisfaction to help caregivers fulfill their responsibilities without becoming overwhelmed. This is especially important because the population of older adults continues to increase. Many of these adults will

need an informal family caregiver to assist them. The population of family caregivers will continue to increase. It is important to examine what services these caregivers will need to help them be successful as caregivers. Lack of services for caregivers will lead to increases in placements of older adults in facilities. Short-term respite use needs to be examined further in terms of its affects on caregivers.

APPENDIX A
QUESTIONNAIRE

Caregiver Survey

Section I. The following questions are designed to understand how you see yourself. This is not a test so there are no right or wrong answers. Please answer each item as careful and accurately as you can. Please tell me how often you feel this way

<i>Do you feel...</i>	NEVER	RARELY	SOMETIMES	QUITE FREQUENTLY	NEARLY ALWAYS
that because of the time you spend with care receiver] that you don't have enough time for yourself?	0	1	2	3	4
stressed between caring for care receiver and trying to meet other responsibilities (work/family)?	0	1	2	3	4
angry when you are around the care receiver?	0	1	2	3	4
that care receiver currently affects your relationship with family members or friends in a negative way?	0	1	2	3	4
strained when you are around care receiver?	0	1	2	3	4
that your health has suffered because of your involvement with care receiver?	0	1	2	3	4
that you don't have as much privacy as you would like because of care receiver?	0	1	2	3	4
that your social life has suffered because you are caring for care receiver?	0	1	2	3	4
that you have lost control of your life since care receiver's illness?	0	1	2	3	4
uncertain about what to do about care receivers?	0	1	2	3	4
you should be doing more for care receivers?	0	1	2	3	4
you could do a better job in caring for care receiver ?	0	1	2	3	4

Section II: The following questions are about the respite care you may have received

Have you received respite care in the last 6 months? yes no

If the answer to last question was no please skip to Section III

	Very Dissatisfied	Dissatisfied	Some What Dissatisfied	Satisfied	Very Satisfied
How satisfied are you with the respite care that the person your caring for received	0	1	2	3	4
	Not at all	A little bit	Somewhat	Yes	Yes, Very Much
Do you feel you benefited from the respite care period?	0	1	2	3	4
Do you feel the person you care for benefited from the respite care period	0	1	2	3	4

Section III: The next few questions are about the social support available to you.

	Almost always	Most of the time	Some of the time	Little of the time	None of the time
There are people you can count on to listen to you when you need to talk	1	2	3	4	5
There are people you can count on to console when you are very upset	1	2	3	4	5
There are people you can count on to provide care when you are sick	1	2	3	4	5
There are people you can count on to help financial when you need it	1	2	3	4	5
There are people who appreciate you as a person	1	2	3	4	5
There are people whom you can totally be yourself with	1	2	3	4	5

Below is a list of the ways you may have felt or behaved recently. For each statement, check the box that best describes how often you have felt this way during the past week.

During the Past Week:	Rarely or None of the Time	Some of the Time	Occasionally	Most of the Time
	(Less than 1 day)	(1-2 days)	(3-4 days)	(5-7 days)
A. I was bothered by things that don't usually bother me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B. I did not feel like eating; my appetite was poor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C. I felt that I could not shake the blues even with help from my family and friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D. I felt that I was just as good as other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E. I had trouble keeping my mind on what I was doing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F. I felt depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G. I felt that everything I did was an effort.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H. I felt hopeful about the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I. I thought my life had been a failure.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J. I felt fearful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K. My sleep was restless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L. I was happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
M. I talked less than usual.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
N. I felt lonely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
O. People were unfriendly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
P. I enjoyed life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Q. I had crying spells.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
R. I felt sad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
S. I felt that people disliked me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
T. I could not get "going."	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Here are some statements about your energy level and the time it takes to do the things you have to do. How much does each statement describe you?

	Completely	Quite a bit	Somewhat	Not at all
You are exhausted when you go to bed at night.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
You have more things to do than you can handle	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
You don't have time for yourself	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
You work hard as a caregiver but never seem to make any progress	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Here are some thoughts and feelings that people sometimes have about themselves as caregivers. How much does each statement describe your thoughts about your caregiving?

	Very much	Somewhat	Just a little	Not at all
How much do you wish you were free to lead a life of your own.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
How much do you feel trapped by your (relative's) illness.	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
How much do you wish you could run away?	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Demographic: The following questions are intended to get some background information about you and your experience as a caregiver (Please circle one number below)

1. Gender (Circle One): 1) Male 2) Female

2. Age (Circle One):
1) 40 or younger 2) 41-51 3) 51-60 4) 61-70 5) 71-80 6) 80 or older

3. Education: (Circle One):
1) Less than or Equal to H.S. 2) Greater than H.S.

4. Income Level: (Circle One):
1) \$20,000 or less 2) \$20,000-\$40,000 3) \$40,000 or more

5. Ethnicity: (Circle One):
1) African-American 2) White 3) Hispanic 4) Asian 5) American Indian 6) Other

6. Marital Status:

1) Single 2) Married 3) Divorced 4) Widowed 5) Separated

7. Relationship to Care Receiver: (Circle One):
1) Wife 2) Husband 3) Child 4) Grandparent 5) Parent 6) Other Family 7) Non-Family

8. How Long Have You Been a Caregiver? (Circle One):
1) Less than 1Year 2) 1-2 Years 3) 2-4 Years 4) 4-5 Years 5) 5+ Years

9. What kind of respite benefit did you use?
1) In-Home 2) Adult Day Care 3) Residential Facility 5) Grant & Aid

10. How long was your respite benefit? (Circle One):
1) 2 Months 2) 4 Months 3) 1 Year 4) More Than 1Year

11. Did you use an agency-based or grant-in-aid respite benefit? (Circle One)
1) Agency-Based 2) Grant-In-Aid 3) Day Care

12. How would you rate your health? (Circle one)
1) Excellent 2) Good 3) Fair 4) Poor

APPENDIX B
INFORMED CONSENT

INFORMED CONSENT

This study that you are being asked to participate in is designed to examine the effect short term respite care has on caregivers. This study is being conducted by Lisa San Filippo Di Matteo, under the supervision of Assistant Professor Dr. Thomas Davis Dept of Social Work at California State University San Bernardino. This study has been approved by the Social Worker subcommittee of the Institutional Review Board, at California State University San Bernardino.

In this study you will be asked some questions about the feelings you have experienced as a caregiver and your feelings about respite care. Some of the questions ask about your satisfaction with respite care services. The Caregiver Survey you are about to fill out takes 10-15 minutes to complete. All of your responses will be held in the strictest of confidence by the researcher. Your name will not be reported with your responses. All data will be reported in-group form only. You may receive the group results of this study upon completion on July 22, 2005 at the Pfau Library.

Your participation in this study is totally voluntary. You are free not to answer any questions and withdraw at anytime during this study without penalty. After you complete the Caregiver's Questionnaire you will be provided with a debriefing statement that describes the study in more detail. This study is intended to provide the participant with an opportunity to give feed back about their experience as caregivers. This questionnaire measures several variables that are usually personal to caregivers. This questionnaire contains personal questions about your caregiving experience if you feel distressed in any way by a question you can chose not to answer it or withdraw from the study at any time. This study will survey several caregivers so, in order to ensure the validity of this study we ask that you do not discuss the study with other participants.

If you have any questions about this study, please feel free to contact Dr. Thomas Davis at 1 (909) 880-5000

By placing a mark in the box below, I acknowledge that I have been informed of, and that I understand, the nature and purpose of this study and I freely consent to participate. I also acknowledge that I am at least 18 year old.

Place check mark here _____
Today's date

APPENDIX C
DEBRIEFING STATEMENT

Debriefing Statement

This study was designed to specifically examine the effects that short term respite care has on caregivers depression levels, sense of burden, role overload and role capacity. This study also set out to examine the effects social support has on short-term respite care satisfaction.

Thank you for participating in this project and for not discussing the contents of this study with other participants. If you feel distressed in any way from participating in this study. You may contact your Family consultant at Inland Caregivers Resource Center for assistance. You can also contact these mental health service providers, Family Services Agency at (909) 822-3533 or Crest Forest Family Services at (909) 338-4689.

Your participation in this study will help add to the knowledge about the effect short term respite has on caregivers. If you have any questions about the study feel free to contact Lisa San Filippo Di Matteo or Dr. Thomas Davis at (909) 880-5000. If you would like to obtain a copy of the group results of this study, please contact Professor Dr. Thomas Davis at (909) 880-5000 at the end of July of 2005.

APPENDIX D

LETTER



Inland Caregiver
Resource Center

November 30, 2004

1420 E. COOLEY DRIVE
SUITE 100
COLTON, CA
92324
(909) 514-1404
(800) 675-6694

Institutional Review Board
California State University, San Bernardino
5500 University Parkway
San Bernardino, California 92407-2397

To Whom It May Concern:

Inland Caregiver Resource Center (ICRC) is a non-profit social service organization focused on supporting family members caring for a dependant loved one. Our mission is to help families and communities master the challenges of caregiving. Since 1985 Inland Caregiver Resource Center (ICRC) has been the leading provider of supportive services to family caregivers in the Inland area encompassing Riverside, San Bernardino, Inyo and Mono Counties.

In addition to our work with caregivers, we are dedicated to supporting and promotion education in caregiving issues. Lisa Di Matteo has approached this agency with a proposal for a project. She proposed to investigate the effects of respite on caregiver's burden and depression. ICRC is prepared to assist with the proposed research topic. With the approval of the IRB, we will assist her in reaching the target population.

A NONPROFIT
TAX-EXEMPT
CORPORATION, PART
OF A STATEWIDE
SYSTEM OF REGIONAL
RESOURCE CENTERS
SERVING FAMILIES
AND CAREGIVERS OF
ADULTS WITH
BRAIN IMPAIRMENTS.

Sincerely,

Debbie Townson, LCSW
Clinical Consultant

APPENDIX E

TABLES

Table 1. Independent t Test

	Levene's Test for Equality of Variances		T test for Equality of Means						
	F	Sig	t	df	Sig (2-tailed)	Mean Difference	Std.Error	95% Confidence Interval of the Difference	
								lower	upper
Burden	.071	.791	-7.24	49	.472	-1.918	2.649	-7.241	3.404
			-7.12	42.088	.481	-1.918	2.696	-7.358	3.521

Table 2. Independent T test

	Levene's Test for Equality of Variances		T test for Equality of Means						
	F	Sig	t	df	Sig (2-tailed)	Mean Difference	Std.Error	95% Confidence Interval of the Difference	
								lower	upper
Depres	.329	.569	-1.304	45	.199	-4.772	3.660	-12.144	2.559
			-1.271	36.875	.212	-4.772	3.754	-12.380	2.835

Table 3. Independent T test

	Levene's Test for Equality of Variances		T test for Equality of Means						
	F	Sig	t	df	Sig (2-tailed)	Mean Difference	Std.Error	95% Confidence Interval of the Difference	
								lower	upper
Social tot	7.169	0.011	2.622	41	0.012	2.82222	1.07637	0.64844	4.996
			2.39	24.069	0.025	2.82222	1.18066	0.38583	5.25861

Table 4. Independent T Test

	Levene's Test for Equality of Variances		T test for Equality of Means					95% Confidence Interval of the Difference	
	F	Sig	t	df	Sig (2-tailed)	Mean Difference	Std.Error	lower	upper
Roleo	.013	.910	-200	49	.842	.861-	.89	-1.902	1.557
				-198	43.412	.844	.870-	.90	-1.927

Table 5. Independent T test

	Levene's Test for Equality of Variances		T test for Equality of Means					95% Confidence Interval of the Difference	
	F	Sig	t	df	Sig (2-tailed)	Mean Difference	Std.Error	lower	upper
Rolec	.011	.918	-.148	49	.883	-133	.899	-1.939	1.673
				-.148	45.059	.883	-133	.90	-1.947

Table 6

		TotalDEP	Total bur
Total Dep	Pearson Correlation	1	.455**
	Sig. (2-tailed)		.000
Total BUR		47	46
	Pearsons Correlation	.643**	1
	Sig (2-tailed)	.000	.
	N	46	51

Correlation is significant at 0.01 level

Table 7

		TotalDep	roleo
TotalDep	Pearson Correlation	1	.491**
	Sig. (2- tailed)	.47	.001
	N		46
Roleo	Pearson Correlation	.491**	1
	Sig (2-tailed)	.001	.
	N	46	51

Correlation is significant at 0.01 level

Table 8

		rolec	roleo
Total Burd	Pearson Correlation	1	.775**
	Sig. (2- tailed)	51	.000
	N		50
Rolec	Pearson Correlation	.755**	1
	Sig (2-tailed)	.000	.
	N	50	51

Correlation is significant at 0.01 level

Table 9

		rolec	roleo
Rolec	Pearson Correlation		.455**
	Sig. (2- tailed)	1	.001
	N	51	51
Roleo	Pearson Correlation	.455**	1
	Sig (2-tailed)	.001	.
	N	51	51

Correlation is significant at 0.01 level

Table 10

		totalRS	socialtot
totalRS	Pearson Correlation	1	.520(**)
	Sig. (2-tailed)	.	.009
	N	30	24
socialtot	Pearson Correlation	.520(**)	1
	Sig. (2-tailed)	.009	.
	N	24	43

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

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