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BELIEFS ABOUT RESPITE AMONG CAREGIVERS

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BELIEFS ABOUT RESPITE AMONG CAREGIVERS

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

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by

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ABSTRACT

The emphasis of this research was to evaluate the beliefs about respite among caregivers of the clients associated with Inland Caregiver Resource Center. The caregivers of the elderly and those who suffer from Alzheimer’s and dementia, or suffer from traumatic brain injury that was organic in nature were the population of interest. These caregivers were unpaid persons who help to keep those with such conditions at home as long as possible. This study used an exploratory pilot survey instrument to assess the perception of benefit of respite used as seen from the view of the caregiver. The primary theory used to support this project was Abraham H. Maslow’s Hierarchy of Needs. Data analysis used standard statistical methodology. The benefit to the profession of social work was seen in the addition of knowledge to the fast growing field of organizational respite services. The results of the research indicated that when respite was seen as beneficial the caregiver was more able to complete activities while using respite, the caregiver believed the person or agency who cared for their loved one was professional and trusting, and the care receiver was treaded well and was more easier to care for after being cared for by another person or agency.

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DEDICATION

This work is dedicated to all of the caregivers of those who help friends, family, and loved ones. Your caregiving sacrifice is a thankless effort that you have chosen. Having been witness to the service of caregiving personally I feel connected to this population. Also to my mother Genevieve Nunez for never giving up on me and believing in me. I am forever grateful for all the love and support you have given me over a lifetime of trials and successes.

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CHAPTER ONE

INTRODUCTION

This section is intended to provide an overview of the population of interest within the specialization of Gerontological studies and social work practice. This will include a national and local scope of the target population. Appropriate background information on the population the agency serves is given, and the agency of interest where the study takes place is also provided. A problem statement that includes the purpose of this study and the significance this study will have on the practice of social work is also included, as well as the research question

Problem Statement

Respite is best defined as, “Short-term care of long-term sick person(s) in order to give regular caregiver(s) a brief rest” (“Respite care - Oxford Reference,” n.d.). The effects of respite on caregivers are best described as the perceived benefit as a result of respite use. The caregiver perception of benefit to self and the care receiver are vital properties in program development for the agencies who provide respite services, case management and other support services that the caregiver may utilize in their effort to maintain a stable environment for themselves and those they care for.

The caregivers who receive services from the Caregiver Resource Center (CRC) system are unpaid. The system of CRC’s structure program services by utilizing evidence based research. This is consistent with the original legislative act in that research be conducted to help improve services and to inform the legislative body who will then implement change to increase the impact the CRC system will have on the population that is served (California Caregivers Resource Center, 2006).

As the nation grows older more attention is being given to the care of our elderly. Informal care of the elderly is becoming a reality as the trends of aging are moving to the graying of our population. It is common knowledge that this trend of aging has seen the life span of the population increase. According to, Arden et al., (2015) Life expectancy in 1951 was estimated to be 68.1 years. In 2011 the average age of death was 79. Family and friends who are unpaid caregivers are responsible for the care of this growing population. It has been reported that “In 2014 17.9 billion hours” (“Latest Facts & Figures Report | Alzheimer’s Association,” n.d.) of unpaid services have been provided to the care receivers. There is growing evidence that rates of incidence for Alzheimer’s and Dementia are increasing. According to Gottlieb and Johnson, (2000) the prevalence of these diseases will increase in proportion to the growth of this age group over the next 30 years. Currently there are an estimated 5.1 million adults suffering from Alzheimer’s. By the year 2025 the number at the national level is estimated to reach 7.1 million and by 2050 the estimated national number will reach 13.8 million adults who are 65 and older. (“Latest Facts and Figures Report | Alzheimer’s Association,” n.d.) It is estimated between 2010 and 2020 the number of adults 65 and up will grow from 4.4 million to 6.35 million and by 2030 the estimate is 9 million seniors (AB, 2013).

According to the Alzheimer's Association California Alzheimer's Data Report the rate of reported cases in California is expected to double by 2030 while total growth is expected grow by one-third. For those Californians at the age of 55 or more who suffer from Alzheimer's the increase is expected to be; "15% from 2008 to 2015, there were 588,208 to 678,446 afflicted (Ross, Brennan, Nazareno, & Fox, 2009). Between 2015 and 2030, the percent of individuals 55 years of age and over living with Alzheimer's disease is projected to increase by 69%, from 678,446 to 1,149,560" (Ross et al., 2009, p. 5). Also from the same source the prevalence in San Bernardino in 2008 was at 23,680, in 2015 is was at 29,922, and in 2030 is estimated at 56,591; further, Riverside in 2008 was, 31,992, in 2015 was at 37,025, and in 2030 is estimated at 60,116 counties will reach (Ross et al., 2009, p. 6).

There is no exact date when social workers actively worked with this population, yet it is believed that some of the activities that social workers do were performed in the assessment process of individuals who were believed to suffer from this disease. An assessment reveals quality results if conducted in the home of a patent. The assessment was done by a professional versed in psychiatry and other human services related fields, for these professionals were part of a multidisciplinary team (Maurer et al., 2006).

It was not until 1965 that we see a federal attempt in the form of legislation to create a formal agency that was tasked with the creation of federal institutions that were specific to the care and treatment of the elderly. In the Older Americans Act of 1965, the foundation and legal authorization allows states to legislate appropriate programs that best meet the needs of their populations (“42 USC 3030s-1: Program authorized,” n.d.). within this act there is specific language related to social workers and how they are tasked to work with this segment of the population, ‘‘(A) ensure access by older individuals in the project area to community-based health and social services consisting of— ‘‘(i) case management, case assistance, and social work services;” (Older Americans Act Amendments of 1965, 2006). It is through this act that social work, and social workers take a significant role in social services at the state, county, and local level in the form of public and private agencies.

There has been a growing need to insure these individuals are cared for and not forced into a care facility environment. Accordingly, this responsibility falls on the family and friends of the individuals who are no longer capable of caring for themselves. This creates the need for service providers in the Gerontological field of practice. In the Field of Social Work, the micro practice area recognizes these individuals are in need of qualified social workers who can manage diverse caseloads, as well as insure proper personal support in the form of counseling and group psychoeducational programs that teach and support individuals and those who care for the individuals within this population group who suffer from Alzheimer's or Traumatic Brain Injury, (TBI).

Caregiver is defined as, "Any person, usually a family member, friend, or less often a health professional, who cares for a dependent sick person or persons, emphasizing compassionate personal care." ("Caregiver - Oxford Reference," n.d.). These caregivers help in a number of ways including personal care, homemaking, light housekeeping, and other task related to the care receivers activities of daily living, (ADL) and instrumental activities of daily living (IADL), (AB, 2013).

The purpose of the CRC's and ICRC is to give temporary relief to the caregivers in the form of respite. The caregiver may be enduring physical strain that lessens the quality of care given to the care receiver, and mental stress due to the constant care of another without a break in routine; consequently, respite for the caregiver is a support system. (AB, 2013) Respite for the caregiver comes in the form of in the home service, day care for the care receiver, and placement for the care receiver. The support comes in the form of a third party contractor who is paid by an agency like ICRC through a grant process. At IRC the caregiver receives short term services understands that respite grants are not intended to be an ongoing option at this time. Respite is also not intended to be an ongoing supplemental form of care for the caregiver who is receiving services from other agencies who provide care to the care receiver that is similar in nature to the services at ICRC, and not meant as a way to provide for care while a caregiver works. (California Caregivers Resource Center, 2006)

When looking at the belief the caregiver has about respite, the question of the effects of respite on caregiver burden must be explore as well to better understand the respite options used. The type of respite used by the caregiver for relief include; emergency, counseling, doctors' appointments, classes and support groups, high levels of depression, high levels of burden, and other unspecified areas. The actual number of hours respite hours used is important for this suggest program viability.

Purpose of the Study

The purpose of this study is to get a better understanding of the beliefs the caregiver has about respite used among caregivers in Riverside County who use the respite services at Inland Caregiver Resource Center (ICRC). Caregiver burden is best defined as; "a multidimensional response to the negative appraisal and perceived stress resulting from taking care of an ill individual. (this burden) threatens the physical, psychological, emotional and functional health of caregivers" (Kim, Chang, Rose, & Kim, 2012, p. 846).

The target agency of this research is Inland Caregiver Resource Center (ICRC) who serves the San Bernardino Riverside county region. (Inland Caregiver Resource Center, 2009; AB 753, CA, 2013) They in turn are funded through the National Foundation of Caregivers, (NFC) and Senior Support

Services through San Bernardino County Department of Adult and Aging Services, as well as the Riverside County Office on Aging, and through other philanthropic entities that have an interest in the wellbeing of those who care for this specific population. All of the mentioned agencies who support ICRC have an interest in this type of information, for they serve this population and are the primary source of funding for ICRC. The mission of the CRC and ICRC is unique in that the emphasis of service is “Helping families and the community cope with and manage the challenge of caregiving” (Inland Caregiver Resource Center, 2009) for the health and wellbeing of the caregiver is the goal the agency and their service has a positive cumulative effect on the care receiver and the greater community.

This study is also interested in assessing how the time of the caregiver is spent while the respite provider is providing the respite service, as well as, the perception of wellbeing that is related to physical activity, interest in friends, happiness, memory acuity, restfulness during the day and at night, and enjoyment while alone. As important as the perception of trust as it relates to the benefit of respite including the quality of service provider for both the contracted respite provider and ICRC. A belief that expectations were met, the effects the respite had on the care receiver, the perception of enjoyment of respite by the care receiver, and the safety of the care receiver.

It is believed there are factors in the form of feelings that are positive that influence the use of respite and in turn influence the perception of respite use. For example, care receiver enjoyment and positive manner may either contribute or diminish the guilt the caregiver may have. A caregiver may feel a relief of mental and physical stress, or may believe there is no benefit incurred from the use of respite

There is a need to know what services the caregiver has utilized, so measuring in frequency what services the caregiver uses helps to clarify the overall intent of the study. The program of interest for this study is respite service used by the caregiver. The caregiver works with the staff of ICRC to assess the best possible fit of service to be utilized. The CRC system and ICRC also offers support groups, psychoeducational training, family consultation, short-term counseling for the caregiver, and bereavement groups for those whose care receiver has passed away (Inland Caregiver Resource Center, 2009). This support is provided by the trained personnel who work for the agency the caregiver is associated with.

A way of determining benefit is through an assessment of benefit as it relates to the desire to repeat respite use, the caregivers needs being met by the use of respite, the caregivers use of respite hours offered, the caregivers willingness to use respite again, the caregivers gender and the use of respite, and the care receivers gender and the use of respite, and as it relates to demographic variables based on the caregiver and the care receiver that include ADL totals, IADL totals, years of caregiving, caregiver age, and care receiver age.

To receive respite service from ICRC the caregiver must not be receiving payment for caring for someone who meets the criteria of; the care recipient must be at least 60 years of age and have at least two activities of daily living (ADL) and instrumental activities of daily living (IADL) impairment, or persons with Alzheimer’s, Demetria, or a traumatic brain injury (Inland Caregiver Resource Center, 2009). Accordingly, respite cannot be used to supplement those who are paid for caregiving services. The respite offered by ICRC is temporary.

Significance to Social Work Practice

There are several reasons why respite is important, to those who utilize the services and for those who administer the services. The perception of the caregivers who used respite drives the current system. It is believed this work will contribute to the general knowledge base of social work by helping the agency assess current program services. With this knowledge the agency can modify program services to expand those services that are seen as beneficial to the caregiver. ICRC and the CRC program along with the service provider will have a better understanding how the caregivers at ICRC perceives the benefit of respite services the caregiver has used when assessing and implementing interventions that the caregiver deems useful.

Another benefit to the field of social work will be seen when respite is used by the caregiver to reduce the burden and stress of caregiving. The family of the care receiver will delay the institutionalization of the care receiver.

It is commonly believed that respite helps to lessen the burden of cost of permanent placement, increase the quality of life of the caregiver and care receiver, and helps to keep the family together (California Caregivers Resource Center, 2006 p. 2-7). A beneficial consequence of this work may be seen at the macro level of practice. With this data the agency will be more able to advocate for increased funding at the state and federal level. The agency will be well informed with respect to the type of respite services used by the caregiver and the perceived benefit of the services used. This will allow ICRC and the other CCRC's to assess the relationships and the quality of services provided of those agencies they contact with. It is known that the legislative body at the state and federal level take more seriously proposed request for budget increases that are evidence based.

Research Question

The question of belief about respite among caregivers is driven by the perceived benefit of respite received and used from the point of view of the caregiver is of interest to many who serve in the CRC system and the target agency ICRC. Specifically, the staff of ICRC and the agency as a whole would benefit from knowing if the respite service they provide to their clients is well received and whether the respite service being used by the caregivers is seen as a benefit. The research question asks, are the respite services used in the past by the caregiver of ICRC perceived as a benefit to the caregiver?

Summary

This chapter looked at the problem statement as it relates to the graying of America and the prevalence of Alzheimer’s and dementia. The purpose of this study as it relates to the perception of respite on caregiver burden. The significance to the field of social work as it relates to macro and micro practice. Last is the research question.

CHAPTER TWO

LITERATURE REVIEW

Introduction

The intent of this chapter is to briefly look at the history of Alzheimer’s, and the creation of the CRC system. Second is caregiver need and the perception of trust and feelings when utilizing respite service and caregiver burden and the relief of said burden. Statistical data on home respite used is presented, and influencing factors as they related to respite are also present. Influencing factors as they related to trust, perception, and safety are explored as they relate to the benefit of respite. There are barriers the caregiver faces that influence the decision to use respite. The theoretical conceptualizations that drive this work that will be explored are the life span model, and Abraham Maslow’s Hierarchy of Needs model. This model explains how the basic needs must be met first before any benefit can be realized. In conjunction to Maslow, Ronald Anderson's Behavioral Model of Service Use looks at the service provider in terms of positive and negative experience in relation to access to services. Last the limitations and gaps in the literature are presented.

History

Alois Alzheimer is credited with the discoverer of Alzheimer’s. In Small and Cappai, (2006) mini review of the history of Dr. Alois Alzheimer’s presentation of a post mortem autopsy of a 51-year-old patient’s brain who suffered from a “progressive prehensile dementia” (Small & Cappai, 2006 p. 708) This event is recognized as a starting point where senile dementia was classified as a disease that had the potential to be treated rather than a stage of aging.

When providing care for people with Alzheimer’s Maurer, McKeith, Cummings, Ames, and Burns, (2006) described the the care of and quality of treatment in the early 20th century as similar to treatment used today. There was an emphasis to treat dementia in a clinical setting that centered on tolerance of the unusual behavior. Special consideration was given to an environment that was supportive and stimulating for those patients. It is further stated that both MD and Psychiatrist played a role in the treatment of the patient. Institutionalization was a last resort then as it is now (Maurer et al., 2006). History has shown how over time society has learned the treatment and care of those who have Alzheimer’s or a Traumatic Brain Injury (TBI) is best done in a home environment where the caregiver and care receiver live as this environment is less stressful for both the caregiver and the care recipient.

Consequently, a legislative push was made in the 1980s to help support the efforts of those who care for the elderly, those who care for persons with Alzheimer’s, Dementia, and those who have suffered a TBI injury due to an organic or physical brain injury. The Caregiver Resource Center (CRC) system in California was “first authorized through the legislation process in California when Governor Deukmejian signed AB 2913 in 1984” (AB, 2013, p. E).

The work of Blake, (2008) was a review of the literature that focused on the caregiver who attends to the needs of those who have TBI's. The review supports the interventions related to the alleviation of caregiver burden and stress. Interventions including; "the provision of information, support groups and self-help resources, family support and counselling, caregiver training and respite care." (Blake, 2008, p. 269) ICRC's caregivers who use respite care for those who have Alzheimer's, Dementia, and TBI"s also have the opportunity to lean coping skills through these support and educational programs, as well as receiving respite grants.

Caregiver Need

The literature on caregiving is growing as the need for respite service grows more relevant with regard to the aging trend of the population in the United States. In a study conducted by, Rizzo, Gomes, and Chalfy (2013) the average age of a caregiver was between 50 and 64. It is also reported that daily activities of the caregiver included immediate family responsibilities, possible employment for those not retired, significant time spent attending to the needs of those clients who are dependent for Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) The concerns of the caregiver also included protection and safety for those they were caring for (Rizzo et al., 2013).

When assessing the beliefs about respite among caregivers the effects of burden on the caregiver was the driving force for utilizing respite, so knowing if respite was seen as a positive means of avoiding burnout then an understanding of how useful the respite a caregiver used was depended on how useful the activity engaged in by the caregiver during the time of respite was to the caregiver as this consideration was as important as the respite. The research of Lund, Utz, Caserta, Wright, Llanque, Lindfelt, Shon, Whitlatch, and Montoro-Rodriguez, (2014) has asserted the positive outcome from using respite occurs when the caregiver engages in activities that they believed were important to them. Caregiver satisfaction with the respite used and the perception of wellbeing was an essential element related to the perception that respite was beneficial. The researchers were able to show a positive relationship of this concept.

The relationship between engaging in meaningful activity and benefit, witch respite use provided was better understood through a pilot intervention protocol that was created and administered to 14 caregivers who were in the experimental group and six caregivers who were in a control group. Both participant groups were selected from a diverse racial and cultural background; the name of the intervention was “Time for Living and Caring (TLC)” (Lund et al., 2014, p. 162). The instrument focused on the caregiver. The goal of TLC was to help caregivers become sensitive to their use of respite as it related to an effective use of time and realistic activities that could be completed during the respite period. These activities would be of high value to the caregiver with the value of respite use seen in satisfaction. What was measured was the “missing component—what caregivers do during their respite time” (Lund et al., 2014, p. 162). This research has shown there was an increase of satisfaction related to respite use after receiving the intervention.

The TLC intervention consisted of a continuing interactive process where “three interrelated tasks: assessment, goal setting, and goal attainment” (Lund et al., 2014, p. 164) occurred over time. The assessment of the caregiver is similar to that of ICRC’s as the TLC study’s use of assessment addressed circumstances, priorities, resources, and changing needs as they related to self and caregiving. The goal setting stage included prioritizing and selection of activities for the allotted time of respite. The third part of the intervention centered on how the goal was attained through an evaluation of the successes and obstacles incurred during the activity and at the completion of the activity (Lund et al., 2014).

There are contrasting data on, out of home respite use that was generated in Australia. Phillipson, Magee, and Jones, (2013) sampled caregivers who used out of home services for their care receivers. What was learned was of all caregivers sampled at 19.5% did not use out of home respite. Also 44.2% of the caregivers at the time of the intervention were not using respite services even though 45.1% stated they had an unmet need. For residential overnight placement 60.2% said they were not using this service and 58.4% said there was an unmet need (Phillipson et al., 2013).

The work of Phillipson and Jones, (2011) described how in Australia respite was underutilized. With the nonuse of respite so high in Australia the belief system the caregiver had about the respite provider was seen as a determinate in the decision to use or not use respite services. For example, if the caregiver had beliefs about the the respite provider that were negative like not being convenient or having to travel long distances to a day care center, the caregiver in most cases did not use respite or did not see the respite used as not being beneficial (Phillipson, & Jones, 2011). A consequence of non-use of respite may be seen as it the increase of institutionalization of the care receiver.

As has been mentioned supporting the caregiver is the goal of ICRC. Respite provides the caregiver with a much needed break from caregiving duties with respite services provided in the form of in home services, day care services, and temporary placement (“42 USC 3030s-1: Program authorized,” n.d.). Caregivers work with minimal outside support to care for those afflicted with degenerative illnesses, and in most instances the caregiver is unpaid. Roberto and Jarrott, (2008) explained that at least one in four caregivers sees to the needs of persons with Alzheimer’s and dementia.

With the work of O’Connell, Hawkins, Ostaszkiewicz, and Millar (2012) an evaluative study of short term respite usage where the caregiver was provided a break from the responsibility of caregiving was completed to show the relationship of respite use and caregiver wellbeing; consequently, 95 percent of those surveyed reported a positive outcome when able to access respite services, and “four out of five carers reported lower stress” (O’Connell et al., 2012, p. 115). Further benefit was reported if the caregiver believed the care receivers who received day care services enjoyed themselves as the care receiver were then able to socialize with others at day care centers.

Influencing Factors

There are many internal cognitive processes that affect the decision to utilize respite; accordingly, the more positive the internal perception of factors as they relate to the decision to use respite influence the caregivers emotions, feelings and thoughts related to the perception of benefit as described by Stirling, Dwan, and McKenzie, (2014). As an emerging area of study in the Gerontological field of study the focus has centered on the caregivers perception of trust, beliefs, and feelings the caregiver has about the respite service, and the perception the caregiver has about the effects the respite has on the care receiver. The research of Stirling et al., (2014) has acknowledged that the care receiver must trust in the caregiver to insure the respite provider provides a safe and satisfying experience. This was true for in home and adult daycare respite services. If this condition was met it was reported that 80% of caregivers would reuse the services of the agency again; consequently 12% felt some guilt at using respite services (Stirling et al., 2014).

The research literature has moved toward the presentation of more information on how partnerships among caregivers and respite providers have been leading to more positive interactions and more positive beliefs about the service provider. It is believed this has contributed to a positive perception of benefit the caregiver has had about the respite services (Lévesque et al., (2010). The authors addressed caregiver trust as part of the interactive process with providers with the results of their study having shown that trust will increase as the partnership with the respite provider grows in understanding of the caregiver environment, the ability to communicate caregiver need, and an understanding the caregiver has about the limitations of the respite provider to meet all of the caregivers needs. What was learned was that with time and patience that the provider gave to the caregiver, the caregiver was able to express unmet needs. The communication was a two-way interaction that allowed for unrealized concerns to be explored more fully (Lévesque et al., 2010).

Another factor that has influenced the perception of respite care was the attitude the caregiver had from the beginning of the relationship with the respite provider. Stirling et al., (2014) has shown that positive preconceived ideas and beliefs have an impact on both the caregiver and the care receiver that is expressed in better sleeping habits for the caregiver and a lessening of behavioral problems that the care receiver displays. Positive attitudes about the respite provider the caregiver used to describe the respite provider were “caring, friendly, attentive, patient and professional” (Stirling et al., 2014, p. 5)

In a concept analysis by Evans, (2013) the perceived benefit by the caregiver was related to the belief that the care receiver was not being harmed and the care receiver exhibited or stated a willingness to participate or accept other respite providers, thus lessening the idea of abandonment of the care receiver on the caregiver's part. The time away from the caregiver allows the care receiver to socialize and participate in meaningful activity (Evans, 2013), yet this is dependent on the health, wellbeing, and cognitive ability of the care receiver to participate and understand what is occurring in their environment. The health and the wellbeing of the care receiver is related to their ability to function independently in activities of daily living and instrumental activities of daily living.

There is a segment of the population who have used respite who have not had a positive experience Lund et al., (2014) reported that for those who said respite was the service they were seeking above all other services. What was learned was this did not mean the respite used was well accepted even though respite hours provided were used fully. It would be presumptuous to infer that the caregiver reaction to the respite was automatically going to be positive. The researchers found, "46% of the caregivers were not very satisfied with how they had spent their respite time" (Lund et al., 2014, p. 161). It is believed and supported by the researcher's study that caregiver dissatisfaction was associated with high levels of depression and burden that was related to the duties of caregiving. Essentially if the time spent during the respite period was not seen as productive the perception of dissatisfaction with the respite was mirrored; conversely, this meant those who reported satisfaction reported doing things and completing activates the caregiver placed a high value on (Lund et al., 2014).

Evans, (2013) described several activities engaged in by the caregiver that were seen as a productive use of respite time. These activities included disengagement or separation from of responsibilities of caregiving for short periods of time, freedom away from the caregiving environment to enjoy personal space or time alone, stimulation of mind and body through meaningful and pleasurable activities like exercise, hobbies, and friends, and meeting personal needs by making and keeping appointments with medical and other professionals.

The care receiver was an important element when assessing the caregiver’s belief about respite services used as it is understood the caregiver has assumed responsibility for the wellbeing of the care receiver. The research of Evans, (2013) has addressed both the caregiver and the care receiver. The benefit the care receiver has gotten from receiving day care services, temporary placement, or personal care is realized in reports the care receiver gives to the caregiver about the services used or in the behavior of the care receiver after having gone to day care or after having received personal care from a provider of personal care. If the care receiver is unable to communicate coherently then nonverbal cues like smiling is an indicator of a positive experience (Evans, 2013).

Potential barriers to a positive outcome of respite use are related to external factors that may be out of the caregiver’s control. For example, if the repute provider is not well trained or the day care center services are not appropteate or are unsuitable for the care receiver the caregiver will associate a perception of the respite to the reaction of the care receiver (Evans, 2013). Depending on the reaction the care receiver has to the respite provider the outcome of respite is then either negative or positive, and it is likely to be continued if the outcome is positive (Phillipson et al., 2013).

Research shows that a caregiver who has a negative experience with a care provider will likely be resistant to use respite and will perceive the use of respite service as unproductive resulting in nonuse (Phillipson et al., 2013). The researchers have asserted the nonuse of respite by the caregiver in the form of day care or residential placement for the care receiver was directly tied to the behavioral outcome of a negative experience by the care receiver that were tied to the care receiver who was experiencing limitations related to biological, cognitive, and behavioral deterioration and functional ability. These limitations were seen as embarrassing and contributed to a negative or embarrassing stigma for the caregiver that resulted in nonuse of respite services (Phillipson et al., 2013).

One of the largest factors influencing the perception of the caregiver was the caregiver’s relinquishing of control and responsibility of caregiving to an agency based respite provider or other non-relative respite provider. In a qualitative study conducted by Stirling et al., (2014) the caregivers assumed a high level of personal responsibility when choosing service providers. The personality of the respite provider was a factor that affected the outcome. It was further believed the out of pocket cost had an effect on the outcome of respite use. Research has shown that those who took the time to carefully research the respite provider by interviewing in home providers, visiting day care and residential providers had more positive respite experiences for both the caregiver and the care recipient. This research also validates the argument that the caregiver takes into account the needs of the care receiver (Stirling et al., 2014).

Theory Guiding Conceptualization

The process of becoming a caregiver occurs over time as was described by Roberto and Jarrott, (2008). With the health and wellbeing of the caregiver being greatly influenced by the needs of the care receiver; consequently, the abilities of the caregiver to perform those associated task as they correspond to the age of both the care giver and care receiver are reliant on adaptive skills, learned behaviors, and learned coping skills (Roberto & Jarrott, 2008).

Lifespan Approach

According to Roberto and Jarrott, (2008) life span approach it is understood that the act of caregiving is fluid with change occurring in all areas of a person’s life. The areas of change are related to the biopsychosocial environment. These internal and external influences have had both negative and positive influence and outcomes on the diversity of experiences the caregiver has, as well as the experiences acquired over time. This is also true for the care receiver. The four main components of the life span model are “individual development is a lifelong endeavor… (M)ultidimensional and multidirectional, (development) including both improvement and decline… (I)ndividuals encounter historical and societal forces that shape the course of their development… (P)lasticity, refers to intra-individual variability and suggests a capacity for differential behavior” (Roberto & Jarrott, 2008, p. 101).

The agency that provides respite will have to be sensitive to life span elements, and have the ability to understand and address unforeseen instances that may hamper the relationship of the dyad, for it is this perception that influences the perceived benefit (Roberto & Jarrott, 2008). Essentially the life span model is not a standalone model, yet the four main considerations when working with this specific population provide a broad base and foundation to build on.

Maslow’s Hierarchy of Needs

Maslow’s hierarchy of needs (Stirling et al., 2014) is a theory that allows for quality of life issues to be explained, for the theory accounts for physiological and biological needs, as well as perceptions of belongingness, safety, and love. Although there are components like love and esteem that are difficult to quantify it is possible to construct meaning, so they should not be overlooked when assessing perceived benefit. (Stirling, Dwan, & McKenzie, 2014b)

A central theme of this work is trust. The perceived benefit is based on this trust in the services utilized by the caregiver. The service provider whether it is in home service, day care, or placement the caregiver will not use any service for any period of time if there is no trust (Stirling et al., 2014). Trust is associated to the primary physiological needs of the body, and is addressed in the caring for the care receiver and the self-care of the caregiver. Then safety of the care receiver is insured by providing an environment that is free of potential hazard, and where proper supervision ensures protection. It is understood that caregivers seek and expect the highest levels of service for their care recipient for these first two levels. (Stirling et al., 2014)

At level three, belongingness, the caregiver will have a positive outlook on respite if there are indicators that the care receiver is accepted by other and interacts with others by establishing friendships (Stirling et al., 2014). These behaviors occur in an out of home center, as well as in a one-to-one relationship where the respite occurs in the home. Finally, the fourth level is centered on esteem where the caregiver perceives the care recipient is being treated with respect, and where the activities the care receiver participates in are meaningful and enjoyed (Stirling et al., 2014). Given that respite is more than a dyad between the respite provider and the caregiver the caregiver who perceives the respite as a benefit will have less feelings of guilt when giving over responsibility of care to the respite provider (Stirling et al., 2014).

Anderson's Behavioral Model of Service Use

The acceptance of caregiving is growing; consequently, there is more to the concept of perceived benefit that can be explained with Maslow’s hierarchy of needs. According to Roberto and Jarrott, (2008) functioning of the caregiver goes beyond the basic interpretations of the mental and physical wellbeing of the caregiver and care receiver. Phillipson, Jones, and Magee, (2014) review the Andersen ‘Behavioral Model of Service Use’ where service access is as important as the service providers. We believe the components of the Anderson model that include; “demographic, social structure and health beliefs (that are ether) enabling or impeding factors (like) community and personal resources” (Phillipson et al., 2014, p. 2) help to answer the question; are the respite services used in the past by the caregiver of ICRC perceived as a benefit to the caregiver?

The main reason for using the Anderson model with Maslow’s hierarchy of needs is this model assesses the policy of the agency that provides the respite. Further the assessment from the point of view of the service provider is also influential on the perceived benefit the caregiver has about the agency and the respite the agency provides (Phillipson, Jones, & Magee, 2014). This agency perspective takes into account the attitude, mannerism, and genuineness of the agency provider who is in direct contact with the caregiver.

Limitation and Gaps in the Research

In Phillipson et al., (2014) one of the limitations in this area of study was centered on the type of study used. The authors asserted there are relatively few comprehensive studies; consequently, most researchers conducted samples of convenience and cross sectional surveys. Although the research on respite services is growing there are limits related the the size of the samples with the majority of the samples being small. Also there is a question related to generalizability with many samples being single study approaches. “Furthermore, findings of studies are difficult to compare owing to differences in design and methodologies. It seems that the literature is lacking in rigorous, controlled studies, conducted prospectively over longer periods of time and measuring outcome using standardized assessment tools” (Blake, 2008, p. 269).

In addition, those empirical longitudinal research projects lacked control or had non-equivalent controls (Phillipson et al., 2014). These authors also asserted the lack of community level respite service data, as well as how the lack of personal resources of the caregiver impedes the use of respite. These variables are recognized as part of the client system and that to separate them from the analysis would skew the results, for it is commonly understood that perception of benefit is affected and is sensitive to poverty. What the author's state concerning income is, "having a low carer income or living in an area of low population density (i.e. n < 50 000) was associated specifically with the nonuse of in-home services" (Phillipson et al., 2014, p. 6)

In Stirling, Dwan, and McKenzie, (2014) the researchers were concerned about the high rate of responses that were positive. The researchers believe this was due to the 40% response rate to the survey. They believe this created a bias with only the most involved caregivers who had a positive perception of the respite provider as they were the only ones to take the time to participate. (Stirling et al., 2014) Another limitation is, this was a single case study of a group of caregivers from one respite provider. It was stated that the conclusions had low generalizability, and that additional research on the expectations of caregivers who used day care was necessary to prove reliability of previous work. (Stirling et al., 2014a)

A final gap in the literature was expressed by Phillipson et al., (2014). The gap was related to the quest to understand the heterogeneity of the caregivers. The researchers believed the predisposing reasons for no-use would shed light beyond the stated reasons that were currently being studied. It was furthered that agency that provided respite needs this type of data to form policy. We agree the community organization would benefit, for the mandate of the CRC system requires the eleven CRC agency’s in California to further the effectiveness of the CRC system by actively supporting and assisting with the study to enhance the service of the agency in a system that is research driven.

Summary

This section has introduced the concept of beliefs about respite among caregivers and how these beliefs have an effect on caregiver burden. The history of Alzheimer’s and the legislative effort to create a system of caregiver support was addressed. The need of relief was explored as it relates to the burden of caregiving. Along with assessment of the effects of respite as effects relate to the influencing factors on caregivers and the caregivers perception of trust in the respite provider for those who use respite, and for those who will not have a positive experience even though respite was the most needed resource that was sought. Theory Guiding Conceptualization including the life span theory, Maslow’s Hierarchy of Needs, and Anderson's Behavioral Model of Service Use. Last was the limitation and gaps in the research.

CHAPTER THREE

METHODS

Introduction

This section gives an overview of the study design, an explanation of the sampling method, and research procedures. Further the procedures used in the collection of data and the data analysis were addressed in this chapter. Also the steps taken to insure those who participate in this study were protected from any undue harm as human participants and the dissemination of the research results was covered.

Study Design

This study was interested in the caregivers who have taken on the responsibility of caring for those who suffer from Alzheimer's, dementia and TBI. This interest was centered on the use of respite and how the caregiver's beliefs and satisfaction affect the perception of respite they have used and expect to use. This study used an exploratory design to answer the question: was the respite services used in the past by the caregivers of ICRC perceived as a benefit to the caregivers? Benefit was operationally defined as the perceived positive satisfaction of respite use by the caregiver, and was measured in feelings of usefulness, trust in the respite provider, and belief that time spent away from care receiver, as well as the safety of the care receiver, caregivers reduction of stress, and an increase in wellbeing as described by Stirling et al., (2014) and Phillipson and Jones, (2011).

This study was a quantitative pilot survey that sought to explore the relationship of respite used by the clients in Riverside County who used the services of ICRC, and to assess their belief that respite was a valuable resource. This study was intended to gain knowledge of belief trends specific to ICRC and was not intended as a means to generalize to the CRC system in California.

A belief was seen in terms of an internal construct related to trust, faith, and confidence. The survey was a self-administered questionnaire, for this appeared to be the best and most expedient method for our caregivers who agreed to participate in this study. The instrument contained closed ended questions where the respondent either placed a mark inside a box or circle a given response, and one question that asked for a specific diagnosis of the CR’s illness.

It was hypothesized that the caregiver would benefit from services used at Inland Caregiver Resource Center, and that there would be a significance between the respite service of the agency that include; the caregivers needs being met by the use of respite, the caregivers use of respite hours offered, the caregivers willingness to use respite again, the caregivers gender and the use of respite, and the care receivers gender and the use of respite, and as it relates to demographic variables based on the caregiver and the care receiver that include ADL totals, IADL totals, years of caregiving, caregiver age, and care receiver age.

Sampling

The data for this study came from the population of caregivers who have used the services of ICRC. As previously stated a caregiver was a person who cares for another who was dependent on the caregiver for their care, the caregiver provided companionate and supportive care in keeping the care receiver in a home environment as long as possible. The caregiver engaged in providing all manner of care for the care receiver, for the caregiver duties included aspects of insuring safety and wellbeing, maintaining stability of the care environment, and modeling psychological wellbeing.

Given the attributes of the caregiver population the caregivers were considered to be most effective in providing the data to answer the research question about the respite services used in the past by the caregiver of ICRC and how the use of respite was perceived as a benefit to the caregiver given they are the consumers of respite survives at ICRC.

A survey instrument was administered to both male and female caregivers of ICRC who have used services of ICRC since July of 2015 through December of 2015. The respondents were unpaid caregivers, and were considered to be the primary caregiver to the care receiver. The caregivers were at least 18 years of age. The participant population was drawn from agency records of those who used respite. The initial search excluded those clients who did not use respite. A second filter of the selection process limited the population by selecting only those clients who used ICRC respite services in the prescribed time frame.

The total number of surveys sent to the selected caregiver population was 135. It was determined this large number was needed to offset the predictable nature of low response rates that have been seen in other similar type studies (Stirling et al., 2014). We believed between 30 and 40 percent of surveys would be returned.

Data Collection and Instruments

The information gathered from this work was data that assess the belief, perception, and satisfaction of respite services used as seen from the perspective of the caregiver. The data was collected by way of a self-administered questionnaire instrument. This tool was administered by this researcher to the clients of ICRC who are caregivers who live in Riverside County.

The survey instrument that was used in this study was developed in part by this researchers use of literature and by utilizing a survey from Stirling, Dwan, and McKenzie (2014). The original intent of the author’s survey was to assess the perception of benefit the care receiver had from attending a day care center in Australia from the perspective of the caregiver. We adapted from the original survey questions that sought to understand respite benefit from those who used day care respite, to all respite services offered and used at ICRC.

Stirling, Dwan, and McKenzie (2014) accented to the use of their work and supplied this researcher with a copy of their work. The survey was original and based on a comprehensive literature review and prior qualitative investigations. The researches stated their survey was original using both open-ended questions and Likert scale questions in assessing; “emotional gains, social gains and meaningful activity, however the researchers noted how well these mapped against Maslow’s theory of hierarchy of needs” (Stirling, Dwan, & McKenzie, 2014, p. 6)

In assessing the perception of benefit of respite use the survey for this study looked at the caregiver’s perception of their own and the care receivers sociability, physical activity, belief, and feelings physical health. The instrument measured beliefs and perceptions the caregiver had about respite services in terms of satisfaction of respite services. We had a high confidence that perception of respite care was measured along with the attitude the caregiver had about the respite provider (Stirling, Dwan, & McKenzie, 2014).

In our benefit and satisfaction survey we asked in section one questions related to the use of respite and how this use has influenced activities related to the health and well-being of the caregiver. These questions were first rated on a four point Likert scale with; never equaling one, hardly ever equaling two, sometimes equaling three, and all the time equaling four. It was later determined that an interval scale would reflect a higher variability with the same one through four rating of never, hardly ever, sometime, and all the time were more accurate in assessing emotions, feelings, and thoughts of the caregiver.

Section one questions included (I am more physically active, more interested in friends, more happy, and able to remember things etc.). The questions asked if the caregiver was more able to engage in physical, emotional, and mental activities in a positive way after having used respite. There were two questions that were reversed scored due the negative quality of the question with never equaling four, hardly ever equaling three, sometime equaling two, and all the time equaling one. The questions that were reversed scored were interested in the caregiver’s guilt and burden after respite use.

In section two we asked questions that sought to understand internal cognitive constructs about the caregivers respite experience (the quality of respite service received, my loved one was treated with respect by the respite provider, the respite provider was always on time etc.) were asked to assess belief in the respite provider. These were measured on a Likert scale that was converted to an interval scale like section one. Section three sought to understand feelings about the respite (the respite provider was caring, my care receiver liked the respite provider, my care receiver appeared to be happy after the use of respite etc.). This section and section two were based on

Abraham Maslow’s Hierarchy of Needs. It also used a Likert scale that was converted to an interval scale like section one and two.

Section four looked at respite service used by the caregiver (respite type, how many times respite was used, what the respite was used for, etc.) This section helped to explain the correlation related to benefit and use. This section used a nominal scale. There was one question that askes for the number of years of caregiving. Section five is demographic information on both the caregiver and care receiver. Also there were two interval continuous scale questions that asked for caregiver and care receiver age, and one interval scale question that asked for the year of the diagnosis for the care receiver.

There was a sub section for the care receiver’s activities of daily living (ADL) and instrumental activities of daily living (IADL) that was taken directly from an assessment tool used at ICRC. The section on ADL and IADL were used to assess care receiver function. As this section and the other sections were considered to be predictor (independent) variables it was believed that these data were significant to understanding the critical-outcome (dependent) variable. The critical outcome variable was, the benefit of respite used as seen in satisfaction of respite use as measured by the survey. The predictor variables include, health and wellbeing, belief about respite, feelings related to respite and demographic data for the caregiver and care receiver. The ADL and IADL were grouped independently and were scored at the nominal level, but were changed to interval scale level so a total score for both groups could be used in the final analyses.

The strength of the instrument was that it was not a long survey and the respondents do not need a lot of time to complete (fifteen minutes or less). The survey was written in a clear and concise manner that was devoid of professional jargon, for it was designed to be understood by caregivers of all educational and cultural backgrounds who had a basic ability to read English. Additionally, the survey asked questions the caregiver would recognize as the questions were based on the caregiving experience. We understood the time of the caregiver was limited.

There was a weakness in this instrument. This survey was not a standardized instrument that has not been extensively tested for validity and reliability; consequently, a reliability test was completed for this survey using SPSS 23. The reliability of the Benefit Satisfaction survey was based on the scale used for the items that measured the perception of the caregiver in sub-groups 1, 2, and 3. There were 22 variables that were tested for reliability. The results of the reliability test for the three groups together were 0.796. Sub-group 1 had 8 variables. The reliability score was 0.704, sub-group 2 had 5 variables. The reliability score was 0.904, and sub-group 3 score had 9. The reliability score was 0.561.

Procedures

This researcher used ICRC data base to select the respondents for this survey. The sample was comprised of all caregivers who have used respite services from ICRC who live in Riverside County. The time period that was decided upon was for a six-month period starting from July, 2015 through December. 2015. It was felt this time frame was most suitable for this population. There is a general belief that those who have just recently used respite services were more likely to respond and report their respite experiences.

There were two mailed survey instrument sent to the selected respondents to the address that were on file for the caregiver. Each mailer occurred one week apart. It was believed that by repeating the mailer the response rate would be higher. Also cold calls were made to the target population with the caller informing the potential respondent of the survey they were about to receive in the mail. The respondents were informed of their rights of confidentiality and their right to not participate in this research. They were asked to send in only one of the surveys mailed to them, and they were thanked for their time and participation.

Mailed with the survey were instructions for completing the survey instrument. It was made clear to the participant the purpose and intent of the study in the instructions and informed consent sheet that was attached to the front of the survey. Also on the survey instrument there were specific and clear instructions on how to complete the survey. There was a special mention concerning the time frame for completion and mail back to the researcher. Concerning the return of the survey a self-addressed and stamped envelope was provided along with the instrument. The time limit for completion was one month for both surveys that were mailed. This study anticipated a four-month period for gathering and analyzing of data.

Protection of Human Subjects

The confidentially and anonymity of all caregivers who participate in this research was protected by insuring that no individual identifying information like name or social security for both the caregiver and care receiver, or address of caregiver or care receiver were asked for on the survey. Concerning all sensitive data steps were taken to ensure it was stored in a secure lock box when not in use. All data that was entered into a computer system was protected by a password protected system, and the data files were not named with a specific identifier that would lead to disclosure of sample members.

The participant was given a separate page labeled Informed Consent with information that addressed participant confidentially that was attached to the front of the survey instrument. Also in the informed consent was language with who the researcher was and the reason for the study, risk and benefits, expected duration of participant involvement, and how confidentiality or anonymity was to be maintained. There was also a statement related to the voluntary nature of participation, Information about foreseeable risks and benefits, and contact information for questions or additional information. Also a signed and dated seal with the name of the institution (CSUSB) that was overseeing the research was on this consent form.

Data Analysis

This study used SPSS to examine and explore frequencies, percentages and t-tests. Several t-test were done to determent if there was any significant differences for the these categorical independent variables; caregivers needs were met, caregiver was able to use all respite hours, caregiver would use respite again, caregiver gender and care receiver gender were tested with these continues dependent variables; ADL totals, IADL totals, years of caregiving, caregiver age, and care receiver age. Relationships within and between the independent variables of health and wellbeing, belief about respite, and feelings related to respite as they relate to the dependent variable were assessed. All significant and common relationships that were revealed as important and noteworthy between the various variable were reported and discussed.

Dissemination

The clients who participated in the study were given separate debriefing information sheet that included: recognition and thanks for assisting the research effort, the goal of this study to assess the perception of benefit of respite service from the perspective of the caregiver, how the data collected could possibly contribute to the improvement of services available to caregivers, and who the caregiver should contact if additional support from ICRC was needed was included. Last contact information about the results of the study or for any questions about the study where the caregiver could receive desired information was given as well. This included the location where the study results could be accessed through the Pfau Library.

Summary

This study was designed to evaluate the perceived benefit to the caregiver who used the respite services of ICRC. The instrument was carefully created from reliable sources of information to assess the belief and satisfaction as perceived by the caregiver. The sample of caregivers was accessible allowing for a reasonable time frame of four months to complete the data collection and analysis. The confidentiality and protection of the participants was insured and planned for. We hoped that through the successful completion of this study the knowledge base for those who work with the caregivers of the elderly, those who suffer from Alzheimer’s, and TBI were well informed and better able to provide services that will ensure the relief of burden the caregiver may have from caregiving.

CHAPTER FOUR

RESULTS

Introduction

The results of this study are described using frequencies, percent’s, and t-table results. The frequency of services used by the respondent are also presented along with demographic information for the caregiver and the care receiver.

Findings

In section one of the questionnaire the caregivers were asked to rate the activities that they engaged in while using respite. It was believed if the respite was beneficial then the answer would be reflected ether as sometimes or all the time. There were eight questions. The statement “I was more…” was associated to all questions in this section. If the respondent did believe the respite allowed for completion of the activity (I was more able to make and keep appointments, or I was more happy etc.) they marked one of four choices. The choices represented a frequency of times the caregiver believed there was a benefit.

Table 1. Caregiver Activities and Functions Facilitated by Function

Variable	Never	Almost Never	Sometimes	All the Time
I was more…	N, (%)	N, (%)	N, (%)	N, (%)
To keep appointments	3, (6.4%)	0, (0.0%)	10, (20.8%)	34, (70.8%)
Physically active	1, (2.2%)	4, (8.9%)	19, (42.2%)	21, (46.7%)
To visit friends	0, (0.0%)	3, (6.7%)	19, (42.2%)	23, (51.1%)
Happy	0, (0.0%)	3, (6.8%)	17, (38.8%)	24, (54.5%)
Able to remember things	2, (4.5%)	2, (4.5%)	16, (36.4%)	24, (54.5%)
Restless during the day	14, (30.4%)	11, (23.9%)	14, (30.4%)	7, (15.2%)
Restless at night	13, (29.5%)	7, (15.9%)	15, (36.4%)	8, (18.2%)
To enjoy time alone	5, (10.9%)	5, (10.9%)	14, (30.4%)	22, (47.8%)

The caregivers who indicated they used the time away from their caregiving duties to make and keep appointments valued the respite given to accomplish this activity all the time received the highest number of responses at 70.8%. There were 20.8% of the caregivers who said this benefit occurred sometimes. There were 46.7% of the caregivers who believed physical activity was meaningful as a respite activity all the time and 42.2% said this belief occurred sometimes. More than half the caregivers 51.1% said visiting with friends was an activity they would do all the time and 42.2% said they liked to visit with friends some of the time. The caregivers who stated they were happier all the time responded at 54.5% of the time, and 38.8% said they were happy sometimes after using respite. Those who were more able to remember things after using respite also responded at 54.5% of the time and 36.4% said they could remember things better sometimes. Caregivers indicated they were never restless during the day 30.4% the data also reveals the same percentage 30.4% of the caregivers were sometimes restless during the day. Caregivers were sometimes restless during the night 36.4% of the time and were never restless at night 29.5% of the time. The caregivers stated they were able to enjoy time alone 47.8% of the time and sometimes enjoyed time alone 30.4% of the time.

In section two of the questionnaire the caregivers were asked to rate their own belief about the care and treatment the care receiver received by another person or agency as part of the respite service provided by Inland Caregiver Resource Center. There were five questions in this section. The statement “I believe…” was associated to (the quality of respite service received was good, my loved one was treated with respect by the respite provider, etc.” were rated in the same manner as section one. The choices represent a frequency of times the caregiver believed there was a benefit.

Table 2. Caregiver Beliefs about Past Respite Experience

Variable	Never	Almost Never	Sometimes	All the Time
I believe…	N, (%)	N, (%)	N, (%)	N, (%)
Respite services was good	0, (0.0%)	1, (2.2%)	5, (10.9%)	40, (87.0%)
CR was treated with respect	0, (0.0%)	1, (2.2%)	1, (2.2%)	43, (95.6%)
Respite provider was on time	1, (2.1%)	7, (14.9%)	0, (0.0%)	39, (83.0%)
CR was safe	0, (0.0%)	0, (0.0%)	5, (10.9%)	41, (89.1%)
Respite provider well trained	0, (0.0%)	3, (6.5%)	4, (8.7%)	39, (84.8%)

The caregiver believed the respite provider treaded the care receiver with respect 95.6% all of the time, and there were no responses where the caregiver thought the respite provider was disrespectful to the care receiver. The caregiver indicated the respite service received was good 87.0% all the time and 10.9% sometimes. The respite provider was always on time 83.0% of the time; conversely, 14.9% believed the respite provider was almost never on time. The caregiver believed the care receiver was always safe 89.1% of the time and 10.9% said they believed the care receiver was safe some of the time. The respite provider who worked with the care receiver was believed to be well trained 84.8% all the time and 8.7% of the caregivers believed the respite provider was sometimes trained.

In section three of the questionnaire the respondents were asked to rate their own feelings about the respite services used by choosing the best answer. There were nine questions. The statement “I felt that…” was associated to (the respite provider was caring, my CR appeared to be happy after the use of respite, my care receivers acceptance of the respite provider influenced my use of respite, etc.). There were two reversed scores (I experienced guilt after using respite and I did not benefit from respite at all). The response choices for the revered questions were; (never = 4, hardly ever = 3, sometimes = 2, and all the time = 1). All other responses for this section were the same as the previous sections.

Table 3. Caregiver Feelings about Past Respite Experience

Variable	Never	Almost Never	Sometimes	All the Time
I felt that the …	N, (%)	N, (%)	N, (%)	N, (%)
Provider was caring	0, (0.0%)	0, (0.0%)	1, (2.2%)	45, (97.8%)
CR liked provider	0, (0.0%)	1, (2.3%)	8, (18.2%)	35. (79.5%)
CR happy after respite.	0, (0.0%)	2, (4.5%)	10, (22.7%)	32, (72.7%)
CR easier to care for	2, (4.5%)	3, (6.8%)	10, (22.7%)	29, (65.9 %)
CR influence my choice	2, (4.5%)	4, (9.1%)	4, (9.1%)	34, (77.3%)
I had guilt after respite	22, (51.2%)	9, (20.9%)	11, (25.6%)	1, (2.3%)
CG less tired	3, (6.5%)	4, (8.7%)	15, (32.6%)	24, (52.2%)
CG more relaxed	0, (0.0%)	1, (2.2%)	10, (22.2%)	34, (75.8%)
I had no benefit after respite	32, (72.2%)	2, (4.5%)	5, (11.4%)	5, (11.4%)

The caregiver felt the respite service provider who worked directly with the care receiver was caring all the time 97.8% of the time. The caregivers felt they liked the provider all the time 79.5% of the time and the provider was liked sometimes 18.2% of the time. The the caregiver indicated the care receiver was happy all the time after working with a respite provider 72.7% of the time and there were 22.7% who agreed with this statement some of the time. Caregivers indicated care receivers were easier to care for all the time after respite use 65.9% of the time and for the same category 22.7% said they agreed with this statement some of the time. The care receiver influenced the choice of the caregiver to use respite all the time 77.3% of the time and for the same question the caregiver was influenced some of the time 9.1% of the time. The caregiver was less tired after using respite all the time 52.2% of the time 32.6% some of the time. The caregivers said they were more relaxed all the time after respite use 75.8% of the time and sometimes they were more relaxed 22.2% of the time. There were 51.2% of the caregivers who said they never experience guilt after using respite, and 20.9% who experienced guilt almost never after respite use. The caregivers never had feelings that there was no benefit 72.2% of the time.

In section four of the questionnaire the respondents were asked to provide responses for ICRC related service type used (placement, in home services, and adult daycare). Four questions ask for specific information on hours used by the caregiver. Would the caregiver use respite again. Was the staff of Inland Caregiver Resource Center courteous, and did Inland Caregiver Resource Center meet the needs of the caregiver. The caregiver was asked to indicate other non-respite services available at Inland Caregiver Resource Center like information and referral, family consultation, short-term counseling, and groups. Caregivers were asked how many times they used respite services at Inland Caregiver Resource Center.

In assessing ICRC respite services 70.8% of the caregiver responses indicated they used in home services. Day care use was used 29.2% of the time, and placement was the lowest score at at 8.3%. Also 88.9% of the caregivers used all respite hours, and 97.9% would use respite again. All respondents, 100%, said they would use respite again, and 78.8% indicated that ICRC met their respite needs; further, of those surveyed, more than one-half, 54.2%, of the respondents used respite to attend support/educational groups and classes. A total of 45.8% reported using respite for doctor appointments and just under one-half 47.9% used respite to relieve overwhelming feelings. The lowest number of use was for emergencies at 6.3%.

Of the other non-respite services ICRC offers, one-half of the respondents received information and referrals, and 27.1% of caregivers used educational workshops. Family consultation was used by 16.7% of the respondents, and the percentage of respondents who used senior support programs was 20.8%. The caregivers utilization of respite at ICRC is ongoing, so many will use respite as often as possible; consequently, respite can be used more than once 37.5% of the caregivers used respite five to six times. The second highest group was 33.3% of the caregivers used respite one to two times.

Demographics

The sample of caregiver respondents was 48. There were 36 female caregivers and 11 male caregivers. There was one response to the gender question that was missing. The mean age of those caregivers who responded was 67 years old with the youngest at age 35 years and the oldest at 89 years. The mean years of caregiving was 9.6 years with the mode at 6 caregivers providing care for 6 years for those who responded to this question. The range of caregiving years was from 0 to 53 years for those who responded. There were 24 reports of good health, 16 reports of fair health, four reports of poor health, and two reports of excellent heath, and two missing responses. There were 26 caregivers who were retired, and there were 11 caregivers who were not formally employed. Of the choices for the relationship of caregiver to the care recipient, there were nine husbands, 16 wives, two mothers, one daughter, three sons, one sister, 12 other relatives, four friends, and two missing responses.

The care receiver demographics include 23 male and 23 female with two missing responses to the gender question. The mean age of the care recipient was 76 years old with the minimum age at 32 and the maximum age at 102 years. Most care recipients had poor or fair health with 16 responses for each group. There were 11 care recipients who had good health and one reported having excellent health. Of the 48 care recipients 46 had received a diagnosis made by a doctor. The top two primary diagnoses were “Dementia” with 12 cases and “Alzheimer’s” with 9 cases, ”Strokes” with four cases, “Alzheimer’s & Dementia” with four cases, and “Dementia & Parkinson’s” with three cases.

The caregiver was asked to rate the dependence the care receiver has on another to complete Activities of Daily Living (ADL) these activities include five tasks eating, bathing, toileting, transferring, walking, and dressing.

Table 4. Activities of Daily Living

	Independent	Verbal Assistance	Some Human Help	Lots of Human Help	Dependent	Declined to State
Variable	N, (%)	N, (%)	N, (%)	N, (%)	N, (%)	N, (%)
Eating	20, (43.5%)	2, (4.3%)	4, (8.7%)	8, (17.4%)	9, (19.6%)	3, (6.5%)
Bathing	4, (8.5%)	4, (8.5%)	5, (10.6%)	14, (29.8%)	16, (34.0%)	4, (8.5%)
Toileting	8, (17.4%)	3, (6.5%)	8, (17.4%)	9, (19.6%)	15, (32.5%)	3, (6.5%)
Transferring	10, (22.2%)	1, (2.2%)	11, (24.4%)	7, (15.6%)	14, (31.3%)	2, (4.4%)
Walking	12, (27.9%)	3, (7.0%)	5, (11.6%)	7, (16.3%)	12, (27.9%)	4, (9.3%)
Dressing	5, (11.1%)	4, (8.9%)	10, (22.2%)	8, (17.8%)	15, (33.3%)	3, (6.7%)

There were 20 care receivers who could feed themselves. There were 16 care receivers who are dependent on another to help them with bathing, yet there were 14 who needed lots of human help. There were 15 care receivers who are dependent on other to help with toileting, and there were eight care receivers who needed some human help or were independent to complete this activity. For those care receivers who needed help transferring from the bed to a chair there were 14 care receivers who were dependent on another to complete this activity. The care receiver's ability to walk was evenly split with 12 care receivers being independent and 12 care receivers being dependent on another. Dressing had 15 care receivers dependent on another and 10 caregivers needing some human help

The caregiver was asked to rate the dependence the care receiver has on another to complete Instrumental Activities of Daily Living (ADL) these activities include eight tasks meal preparation, shopping, medication management, money management, using telephone, heavy housework, light housework, and transportation.

Table 5. Instrumental Activities of Daily Living

Variable	Independent	Verbal Assistance	Some Human Help	Lots of Human Help	Dependent	Declined to State
N, (%)	N, (%)	N, (%)	N, (%)	N, (%)	N, (%)	N, (%)
Meal Preparation	1, (2.1%)	0, (0.0%)	4, (8.5%)	7, (14.9%)	33, (70.2%)	2, (4.3%)
Shopping	1, (2.1%)	0, (0.0%)	1, (2.1%)	8, (17.0%)	35, (74.5%)	2, (4.3%)
Medication Management	2, (4.3%)	0, (0.0%)	2, (4.3%)	7, (14.9%)	35, (74.5%)	1, (2.1%)
Money Management	2, (4.3%)	0, (0.0%)	3, (6.4%)	5, (10.6%)	35, (74.5%)	2, (4.3%)
Using Telephone	6, (12.8%)	0, (0.0%)	7, (14.9%)	3, (6.4%)	29, (61.7%)	2, (4.3%)
Heavy Housework	0, (0.0%)	0, (0.0%)	1, (2.2%)	2, (4.3%)	37, (80.4%)	6, (13.0%)
Light Housework	0, (0.0%)	0, (0.0%)	2, (4.3%)	5, (10.9%)	34, (73.9%)	5, (10.9%)
Transportation	2, (4.3%)	0, (0.0%)	1, (2.1%)	4, (8.5%)	37, (78.7%)	3, (6.4%)

The largest grouping of responses for the section on IADL activities was in the dependent on another choice. The highest variables ranged from 37 care receivers dependent on another for heavy house work and transportation. There were 35 care receivers who were dependent on another to complete shopping task, medication management, and money management. There were 34 care receivers not able to do light house work. There were 33 care receivers who could not prepare meals and 29 who were not able to use the phone.

T-Test

Five independent t-test were completed to ascertain if there was a significant differences in the caregivers needs being met by the use of respite that was provided by Inland Caregiver Resource Center as the dependent variable, and ADL totals, IADL totals, years of caregiving, caregiver age, and care receiver age as the independent variable. Only in one t-test where the means of the two groups was statistically significantly different: in the independent variable ADL total, Mn = 21.75 Mnn = 15.20; t(33) = 2.242, p = 0.32 no significant difference between those who's needs were met by using respite and those who's needs were not met after using respite in four of the test (See Table 6).

Table 6. Need of Caregiver Met

Survey Questions	Mn	Mnn	t	df	p
ADL totals	21.76	15.20	2.242	33	.032
IADL totals	37.52	37.60	-0.51	37	.956
Years of caregiving	9.86	8.70	.298	43	.767
Caregiver age	68.17	62.60	1.326	44	.192
Care Receiver age	75.77	75.20	.106	43	.916

* Indicates significance at the .05 level

Five independent t-test were completed to ascertain if there was a significant differences in the caregivers' use of respite hours offered as the dependent variable, and ADL totals, IADL totals, years of caregiving, caregiver age, and care receiver age as the independent variable. There was no significant difference between those who used all of the respite hours offered and those who did not use all of the respite hours. (See Table 7)

Table 7. Caregiver Use of Respite Hours

Survey Questions	Mu	Mnu	t	df	p
ADL totals	19.53	23.67	-.829	31	.413
IADL totals	37.44	37.50	-.025	36	.980
Years of caregiving	9.95	6.2	.715	41	.479
Caregiver age	66.87	63.80	.541	42	.591
Care Receiver age	75.82	71.80	.566	41	.547

* Indicates significance at the .05 level

Five independent t-test were completed to ascertain if there was a significant differences in the caregivers willingness to use respite again as the dependent variable, and ADL totals, IADL totals, years of caregiving, caregiver age, and care receiver age as the independent variable. There was no significant difference between those who were willing to use respite again and those who were not willing to use respite again. There was only one no response for this categorical variable (See Table 8).

Table 8. Caregiver Willingness to Use Respite Again

Survey Questions	Mw	Mnw	t	df	p
ADL totals	20.8	Missing			
IADL totals	37.71	30.00	1.805	37	.079
Years of caregiving	9.57	6.00	.326	43	.746
Caregiver age	66.98	64.00	.247	44	.806
Care Receiver age	75.68	73.00	.177	43	.861

* Indicates significance at the .05 level

Five independent t-tests were completed to ascertain if there was a significant difference in the caregivers gender and the use of respite as the dependent variable, and ADL totals, IADL totals, years of caregiving, caregiver age, and care receiver age as the independent variable. There was no significant difference between the female caregivers who used respite and the male caregivers who used respite in determining use of respite (See Table 9).

Table 9. Caregiver Gender

Survey Questions	Mg	Mng	t	df	p
ADL totals	19.80	20.80	-.096	33	.925
IADL totals	37.67	37.20	.294	38	.770
Years of caregiving	10.29	7.27	.819	44	.417
Caregiver age	67.00	67.91	-.221	45	.826
Care Receiver age	77.40	70.45	1.379	44	.175

* Indicates significance at the .05 level

Five independent t-test were completed to ascertain if there was a significant differences in the care receivers gender and the use of respite by the caregiver as the dependent variable, and ADL totals, IADL totals, years of caregiving, caregiver age, and care receiver age as the independent variable. There was no significant difference between the female care receivers and the use of respite by the caregiver and the male care receivers and the use of respite by the caregivers (See Table 10).

Table 10. Care Receiver Gender

Survey Questions	Mn	Mnn	t	df	p
ADL totals	21.72	17.94	1.368	33	.181
IADL totals	36.55	38.47	-1.405	37	.165
Years of caregiving	11.70	7.41	1.353	43	.183
Caregiver age	65.22	69.17	-1.124	44	.267
Care Receiver age	77.22	74.26	.677	44	.502

* Indicates significance at the .05 level

Summary

This chapter presents the findings from the Benefits and Satisfaction of Respite survey. The results of survey are a reflection of the perception of benefit from the point of view of the caregiver Section one addressed activities and functions the caregiver completed while using respite services. Section two assessed the internal perception of the caregiver’s belief about the care provider for the care receiver. Section three assessed internal feelings the caregiver had about the respite provider in observed outcomes of the care receiver as they relate to the behavior and acceptance of service provider. Also internal perceptions the caregiver had of guilt in using respite and the belief that the use of respite services had no benefit. Section four assed the services provided by ICRC by type, frequency, reason for use, and other services used during the respite period. Section five assessed demographic information on the caregiver and care receiver. This information included age, health for both groups. The caregiver group also assessed relationship to the care receiver, current employment status, and years of caregiving. The care receiver section assed diagnosis, year of diagnosis, diagnosis made by a physician, and two sub sections that assessed the degree of dependence on another to complete activities of daily living and instrumental activities of daily living. One independent t-test revealed significance between the caregivers needs being met and the level of dependence on another to complete activities of daily living. All other t-test indicated no statistical significance of difference. Between the independent and the dependent variables tested.

CHAPTER FIVE

DISCUSSION

Introduction

This chapter will discuss the findings of the current project and how the findings are useful and necessary to understand what influences the perception of benefit from using respite. The belief system of the caregiver is either influenced positively or negatively with the positive belief seen in trust, satisfaction, and wellbeing; Beliefs are influenced by both internal and external forces. Also the care receivers experience helps to influence the belief system of the caregiver. Similarly, a discussion on ICRC services and a discussion of limitations of the data and the survey are necessary for a complete understanding. This chapter will also provide recommendations for the field of social work. Research practices will also be addressed. The last section of this chapter will be conclusions.

Discussion

The instrument for this study looked to gain an understanding of the perception of benefits the caregiver had after utilizing respite services from Inland Caregiver Resource Center (ICRC). Benefit is the perceived positive satisfaction of respite use. Respite is the temporary relief from caregiving by spending time away from the care receiver. Caregiver burden is a common result of caregiving. The population for this study was all clients of ICRC who live in California’s Riverside County who used some or all of the respite service offered in a six-month period between July and December of 2016.

The health and wellbeing of the caregiver is essential in the delay of institutionalization of the care receiver. Respite provides the caregiver opportunity for self-care that is difficult as the support from others is minimal or nonexistent. Section one assessed the perception of benefit in task undertaken by the caregiver while using respite support services. The ability to make and keep appointments was the highest. Spending time with friends, being physically active and spending time alone was also significant as this represents the majority of the activity. This research has indicated that such activities are important to the caregiver and that the positive results of this research show the perception of a positive respite experience is influenced by the activities that have a positive outcome.

The results from section one of the survey appear to resemble the literature with the importance the caregiver attaches to the activity during the respite period being a predictor of desirability to engage in a specific activity. Desirability of an activity is associated to benefit. The research show that the activity must be desirable and achievable during the respite period before the perception of burden is reduced. Activities like making and keeping appointments interest in friends and enjoying time tracked well with the activities mentioned in the work of Lund et al., (2014) the authors recorded data on activities related to self-care emotionally, physically, psychologically, spiritually and financial. Further when engaging in a desired activity the result is burden is more likely to be reduced as the perception of useful activity is realized (Lund et al., 2014; Roberto & Jarrott, 2008).

The theory that best fits with of the intent of the survey is Maslow’s hierarchy of needs. Maslow’s hierarchy of needs centers on two areas with the first being deficiency and need related to growth. The lower deficiency needs must be met first before higher levels can be met. Stage one is the physiological need, stage two is safety and security, stage three is belongingness and affiliation, stage four is esteem, and stage five is self-actualization. The first four stages fit well with the intent of this survey as perception of met needs by the caregiver from using respite are seen as benefit (Stirling et al., 2014).

The group of questions that assessed beliefs about past respite experience had the highest grouping of “all the time” responses. This suggests that when the belief about the respite provider is positive a perception of benefit is seen. The focus of the questions centered on an external observation of respite provider by the caregiver with the caregiver evaluating the respite service provider. The trust in the provider was essential to answer these questions positively. Our results are similar to the literature in explaining how trust and safety create the positive belief (Stirling, Dwan, & McKenzie, 2014).

The group of questions that asked how the caregiver felt about the respite provider is similar to the section on beliefs in that the observations the caregiver makes are focused on external events and perceptions of events. The difference is the evaluation, for the evaluation is an internal assessment by the caregiver of how the care receiver responds to the respite service provider. The observations track with the literature and with Maslow's hierarchy of needs that is related to self-esteem for the care receiver. The highest response was the provider was caring. Also the perception of guilt and burden responses validated most of the responses for this section as they were inversely proportional to the response of benefit the literature is consistent with this surveys results (Phillipson, Jones, & Magee, 2014; Stirling, Dwan, & McKenzie, 2014).

The work of Stirling, Dwan, and McKenzie, (2014) influenced this research greatly as their work assessed what the caregivers thought and felt about the service provider who assumed responsibility of the care receiver during the respite period. As their work used a mixed design they found themes that indicated caregivers who believed staff was caring, friendly, professional, and attentive to the care receiver. This belief positively influenced the perception of benefit. The researchers did indicate there were times when the caregiver believed the staff were patronizing and treated the care receiver like young children.

The literature indicates the burden of caring for another has health related risk that manifests in high levels of stress and ultimately end in the deterioration of health of the care giver. This research shows the wives of the care receivers represent the highest group of caregivers and the general health of all caregivers is generally poor to good. It appears the caregiver does experience some health concerns. Kim, Chang, Rose, and Kim (2012) state the caregiver is most often a family member who is a wife or daughter who fill this caregiving role. The authors also show how the emotional and physical connection to the care receiver is greater. The reasoning is this is an expected response that is driven by culture and society. Having practical experience with this population affirms there may be substance to the work of these authors, yet this is not conclusive as those caregivers who are male at ICRC also have similar health attributes as those of the female caregivers at ICRC. It is believed the act of caring for persons who suffer from Alzheimer’s and dementia are at a higher health risk given the nature of care this population needs.

It was believed that the activities of daily living and instrumental activities of daily living would influence the caregivers’ use of respite. It was projected that the greater the dependency of the care receiver on the caregiver to accomplish tasks would be significant in conjunction with the use of all respite hours given, the willingness to use respite again, caregiver gender, and care receiver would be reflected in the t-tests done. We are undecided as the results of this study indicated there was no relationship among the ADL and IADL activities and the use of respite at ICRC The literature has studied this with mixed results, so we assert that due to the lack of consistent research this is an area that should be considered more fully in the future (Kim, Chang, Rose, & Kim, 2012).

We hoped to see results that support the hypothesis with the increased burden as seen in dependence being a predictor of using all of the respite hours offered, yet the test did not support the original assumption that all hours of respite use would increase when the dependence of the care receiver was high.

The other multiple t-test to determine statistically significance differences between the means of two groups (i.e., caregivers needs were met, caregiver was able to use all respite hours, caregiver would use respite again, caregiver gender and care receiver gender were tested with these continues dependent variables; ADL totals, IADL totals, years of caregiving, caregiver age, and care receiver age and between the relationships of the independent variables of health and wellbeing, belief about respite, and feelings This lack of significant is due to the lack of variability in the independent variables that were tested. The lack of variability was seen in the positive answer being yes being given to the question in the t-test. It appears the services are well accepted across all group affiliations. The results of the research is consistent with respect to the belief systems of the caregiver that addresses respite providers, respite use, and the prediction of respite use (Phillipson & Jones, 2011; Phillipson, Jones, & Magee, 2014)

One result stands out in that all respondents would use respite again if given the opportunity to do so. The literature suggests the quality of communication between the caregiver and the respite provider is a major contributor and explanation for this result. This also appears to be consistent with the general shape of the data that implies ICRC is meeting the needs of the caregiver by providing information guidance, education, support, short term counseling and respite services. Having witnessed the manner and professionalism of the staff at ICRC best explains this result, for the staff are committed and well trained in providing the highest quality of service to the caregivers who use the services of ICRC. This is consistent with the work of O’Connell, Hawkins, Ostaszkiewicz, and Millar (2012) and Rizzo, Gomes, and Chalfy (2013).

The literature also supports the caregiver respite provider relationship as valuable as the exchange of information brings the value of the relationship to a higher level. Partnerships or collaborations tend to work well as the treatment plan for the caregiver is more realistic and valuable to the caregiver who helps to create it. The caregiver is seen as the expert in the caregiving role. This partnership allows for a sense of equality that engenders trust, and allows for the creation of the plan based on the need of the caregiver: consequently, continued service is guided through evidence based practice

(O’Connell, Hawkins, Ostaszkiewicz, & Millar, 2012; Lund et al., 2014; Lévesque et al., 2010).

Limitations

There are many limitations that occurred in the administration and the design of the survey. The first limitation is in the selection of the sample population. The sample was not represented of the whole population of ICRC. ICRC serves Riverside and San Bernardino Counties this survey assed only Riverside Country, and as a result the findings are not generalizable or predictive. Also the Spanish speaking, reading, and writing only population of Riverside County was excluded as there was no equivalent survey written in Spanish for the Spanish population provided.

As was stated in the literature review of this study the response rate of survey returned was predictably low; consequently, there is the potential of the self-report to be skewed to the positive as was mentioned those who returned the survey might have done so just because of their positive perception of past use of respite. An unforeseen occurrence was with the respondents placing a mark on the informed consent sheet that was attached to the front of the survey. There were eight returned and completed surveys without any markings on the lines that state to not sign by name and only mark with an (X). These surveys were included as it was assumed the respondent read the informed consent and decided to participate without providing a consent mark.

The reason they were used is it is believed if they did not consent the survey would have been discarded and not sent back.

There is a concern that the survey for this study was adopted from an exploratory survey that was created to assess respite services at a day care center in Australia. As a result this survey is considered to be a pilot exploratory survey. Also this survey was not assessed for validity. This is further evidence that the results are not generalizable, yet the statistical procedure to test for reliability for the variables in the first three sections was good at 0.79. Generally, the structure of the study design did not allow for higher order statistical evaluation; consequently, only frequencies and percentages were reported. The results were skewed to the positive making the t-test done unreliable with no significant relationships. Last the question on how many times respite was used was confounding with each category of answers having at least one same choice in each choice, for example 1-2, 2-3, 3-4, etc.

Recommendations for Social Work Practice, Policy and Research

This research is aware of the trend in aging of the population in the United States. What this means the countries citizens is there will be more families and loved ones who will be caring for this population. Also it is understood that there is an increase in the number of adults who are succumbing to such debilitative diseases like Alzheimer’s and Dementia;

consequently, those who care for them will need increased support to provide the highest quality of care. We recommend the work of research needs to continue as the need to assess and evaluate community based nonprofit agencies that provide services to the informal caregiver become a vital function of the agency.

In recent years the economic trend has been away from expanding the reach of these agencies. For the success of the nonprofit respite provider is dependent on research. Research is needed to assist in providing evidence based information on the effects of burden on both the caregiver and care receiver, the psychology of the caregiver personality, and the relationship between the caregiver and the host agency that provides the respite service, as well as the interventions the respite agency provides. There have been attempts to marry research and agency intervention to learn more on these topics so it is hoped that this will continue as the goal of the respite agency is to support the efforts of the caregiver and to delay the institutionalization of the care receiver as long as possible.

This research main interest was in providing information on the perception of benefit the caregiver had from using respite, for the agency where the research took place had no formal screening tool to measure the outcome of having used respite. It is also hoped that this and other agencies that provide respite services can use this work to develop their own screening tools as it is believed that at least three areas may bandit with the agency administration and staff becoming knowledgeable and informed. The second is the creation of policy and interventions at the agency that more fully benefit the agency and the population the agency serves. And third a filtering of information upwards to those in government who create the policy that governs the respite centers.

Conclusion

The purpose of this study was to get a better understanding of the beliefs the caregiver has about respite service that was provided by Inland Caregiver Resource Center. This study examined internal beliefs and feelings that related to activities used during the respite period, the respite service provider, the effects the respite service provider had on the care receiver from the point of view of the caregiver, and relevant demographic information. As a whole it is believed this information will better serve the field of caregiving. It is hoped this work will give research a new direction to move toward. Like caregiving the work is never complete. Last in providing comprehensive service to the caregiver the interaction of the caregiver with the host agency must have meaning, be pleasant, be accessible, and informative with the practices of the agency grounded in practices that are evidence based and evaluated in a meaningful way that assists the client and agency.

APPENDIX A

QUESTIONNAIRE

Sample Number:__________

Benefit and Satisfaction of Respite Survey

This survey is intended to evaluate how satisfaction of respite is perceived and whether the respite used was beneficial. There are no right or wrong answers. Please think about the personal benefit from using respite.

Section 1 The questions in this section address the past use of respite on **your** health and well-being. (Please Choose Best Answer)

Activities and Functions when I used Respite

	I was more…	**Never**	**Almost Never**	**Sometimes**	**All the Time**
1.	Able to make and keep appointments				
2.	Physically Active				
3.	Interested in friends				
4.	Happy				
5.	Able to remember things				
6.	Restless during the daytime				
7.	Restless during the night				
8.	Able to enjoy time alone				

Section 2 This section seeks to understand **your past** respite experience:

(Please Choose Best Answer)

	I believe…	**Never**	**Almost Never**	**Sometimes**	**All the Time**
1.	The quality of respite service received was good.				
2.	My loved one was treated with respect by the respite provider				

	I believe…	**Never**	**Almost Never**	**Sometimes**	**All the Time**
3.	The respite provider was always on time				
4.	My care receiver was safe when I was not present				
5.	The respite provider was well trained				

Section 3 This section seeks to understand **your** feelings about the respite service **you** have used

	I felt that…	**Never**	**Hardly Ever**	**Sometimes**	**All the Time**
1.	The respite provider was caring				
2.	My care receiver liked the respite provider				
3.	My care receiver appeared to be happy after the use of respite.				
4.	My care receiver was easier to care for after a respite session				
5.	My care receiver's acceptance of the respite provider influenced my use of respite				
6.	I experienced guilt after using respite				
7.	I was less tired after using respite				
8.	I was more relaxed after using respite				
9	I did not benefit from respite at all				

<u>Section 4</u> This section looks at respite service used by **<u>you</u>**.

1. I used ___ respite service **(Mark all that apply)**

a. ____ Placement
b. ____ In Home
c. ____ Adult Day Care

2. I used respite for: **(Mark all that apply)**

a. ____ Emergency
b, ____ Counseling
c. ____ Doctors' Appointments
d. ____ Classes/Support Groups
e. ____ Feeling overwhelmed
g. ____ Other ____________________

Questions 3, 4, 5, 6, & 7 (Check best answer)

3. I have used respite the following times in the last 6 months

___(1-2) ___(2-3) ___(3-4) ___(4-5) ___(5-6)

4. I was able to use all of the hours of respite offered.

___Yes **___No**

5. I would use respite again.

___Yes **___No**

6. I feel the staff member who coordinated the respite service at Inland Caregiver Resource Center was courteous.

___Yes **___No**

7. I feel that Inland Caregiver Resource Center has met all of my respite needs.

___Yes **___No**

8. I have used these other **<u>non respite services</u>** at Inland Caregiver Resource Center **(Check all that apply)**

a. ____ Information and Referral
b. ____ Family Consultation
c. ____ Short-Term Counseling
d. ____ Support Groups
e. ____ Educational Workshops
f. ____ Conferences
g. ____ Bereavement Support Programs

h. ____ Senior Support Services
i. _____ Community Based Occupational Therapy Program

<u>Section 5</u> Demographics: This section is interested in who the caregiver and care receiver are.

CAREGIVER DETAILS:

1. My age is; (______)

(Question 2, 3, & 4 check or mark best answer)

2. My gender is:

____ **Male**
____ **Female**
____ **Other** __________

3. My health is:

____ **Poor**
____ **Fair**
____ **Good**
____ **Excellent**

4. My relationship to **care receiver** is:

____ **Husband**
____ **Wife**
____ **Son**
____ **Daughter**
____ **Other-Relative**
____ **Friend**
____ **Other (PLEASE SPECIFY)** ______________________

5. I have been a caregiver for; _____**YEARS**

6. I am employed: **(Mark or check)**

____ **Full-time**
____ **Part-time**
____ **Retired**
____ **Not formally employed**

1. My care receiver is _____ **YEARS** old.

2. Gender: **(Mark or check one)**

____ **Male** ____ **Female**

3. Care Receiver's **Primary Diagnoses** was made by a Doctor: **(Mark or check one)**

____ **Yes** ____**No**

4. Care Receiver's Diagnoses is: ____

5. **Year of Primary Diagnoses** was: _________________

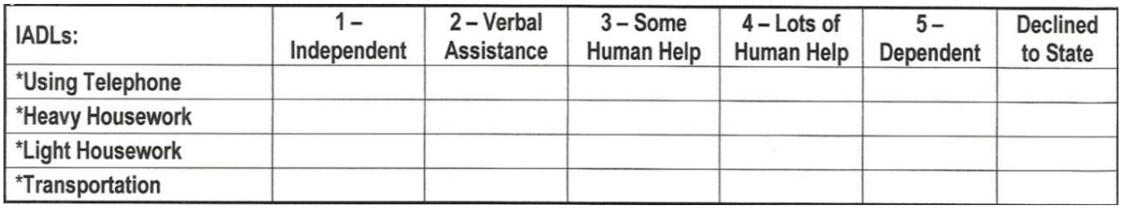
6. The health of my care receiver is: **(Mark best answer)**

___ **Poor**
___ **Fair**
___ **Good**
___ **Excellent**

7. **Care Receiver Activities of Daily Living and Instrumental Activities of Daily Living**

A person's Activities of Daily Living **(ADL),** are what people tend do every day without needing assistance from another person. A person's Instrumental Activities of Daily Living **(IADL),** are tasks that enable people to live independently in their homes and in the community without help from another person. This section will help better understand the level of your **care receiver's** level of independence. **(Mark or check in the box the best answer)**

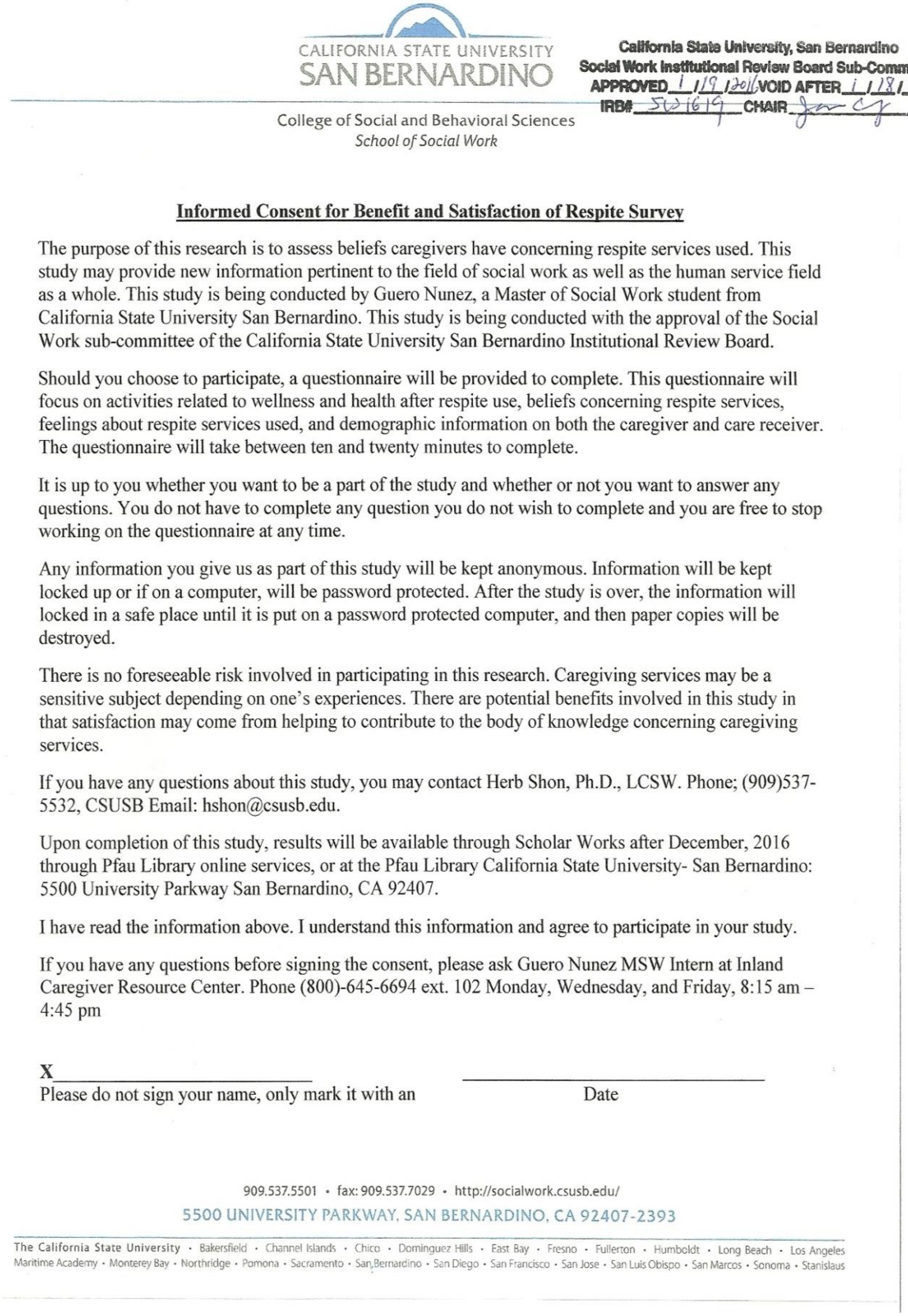
ADLs:	**1 – Independent**	**2 – Verbal Assistance**	**3 – Some Human Help**	**4 – Lots of Human Help**	**5 – Dependent**	**Declined to State**
***Eating**						
***Bathing**						
***Toileting**						
***Transferring In/Out of Bed/Chair**						
***Walking**						
***Dressing**						
IADLs:	**1 – Independent**	**2 – Verbal Assistance**	**3 – Some Human Help**	**4 – Lots of Human Help**	**5 – Dependent**	**Declined to State**
***Meal Preparation**						
***Shopping**						
***Medication Management**						
***Money Management**						



IADLs:	1 – Independent	2 – Verbal Assistance	3 – Some Human Help	4 – Lots of Human Help	5 – Dependent	Declined to State
*Using Telephone						
*Heavy Housework						
*Light Housework						
*Transportation						

APPENDIX B

INFORMED CONSENT



CALIFORNIA STATE UNIVERSITY
SAN BERNARDINO

College of Social and Behavioral Sciences
School of Social Work

California State University, San Bernardino
Social Work Institutional Review Board Sub-Committee
APPROVED 1 / 19 / 2016 VOID AFTER 1 / 18 / 2017
IRB# SW1619 CHAIR

Informed Consent for Benefit and Satisfaction of Respite Survey

The purpose of this research is to assess beliefs caregivers have concerning respite services used. This study may provide new information pertinent to the field of social work as well as the human service field as a whole. This study is being conducted by Guero Nunez, a Master of Social Work student from California State University San Bernardino. This study is being conducted with the approval of the Social Work sub-committee of the California State University San Bernardino Institutional Review Board.

Should you choose to participate, a questionnaire will be provided to complete. This questionnaire will focus on activities related to wellness and health after respite use, beliefs concerning respite services, feelings about respite services used, and demographic information on both the caregiver and care receiver. The questionnaire will take between ten and twenty minutes to complete.

It is up to you whether you want to be a part of the study and whether or not you want to answer any questions. You do not have to complete any question you do not wish to complete and you are free to stop working on the questionnaire at any time.

Any information you give us as part of this study will be kept anonymous. Information will be kept locked up or if on a computer, will be password protected. After the study is over, the information will locked in a safe place until it is put on a password protected computer, and then paper copies will be destroyed.

There is no foreseeable risk involved in participating in this research. Caregiving services may be a sensitive subject depending on one's experiences. There are potential benefits involved in this study in that satisfaction may come from helping to contribute to the body of knowledge concerning caregiving services.

If you have any questions about this study, you may contact Herb Shon, Ph.D., LCSW. Phone; (909)537-5532, CSUSB Email: hshon@csusb.edu.

Upon completion of this study, results will be available through Scholar Works after December, 2016 through Pfau Library online services, or at the Pfau Library California State University- San Bernardino: 5500 University Parkway San Bernardino, CA 92407.

I have read the information above. I understand this information and agree to participate in your study.

If you have any questions before signing the consent, please ask Guero Nunez MSW Intern at Inland Caregiver Resource Center. Phone (800)-645-6694 ext. 102 Monday, Wednesday, and Friday, 8:15 am – 4:45 pm

X____________________________ ________________________________
Please do not sign your name, only mark it with an Date

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The California State University • Bakersfield • Channel Islands • Chico • Dominguez Hills • East Bay • Fresno • Fullerton • Humboldt • Long Beach • Los Angeles
Maritime Academy • Monterey Bay • Northridge • Pomona • Sacramento • San Bernardino • San Diego • San Francisco • San Jose • San Luis Obispo • San Marcos • Sonoma • Stanislaus

APPENDIX C

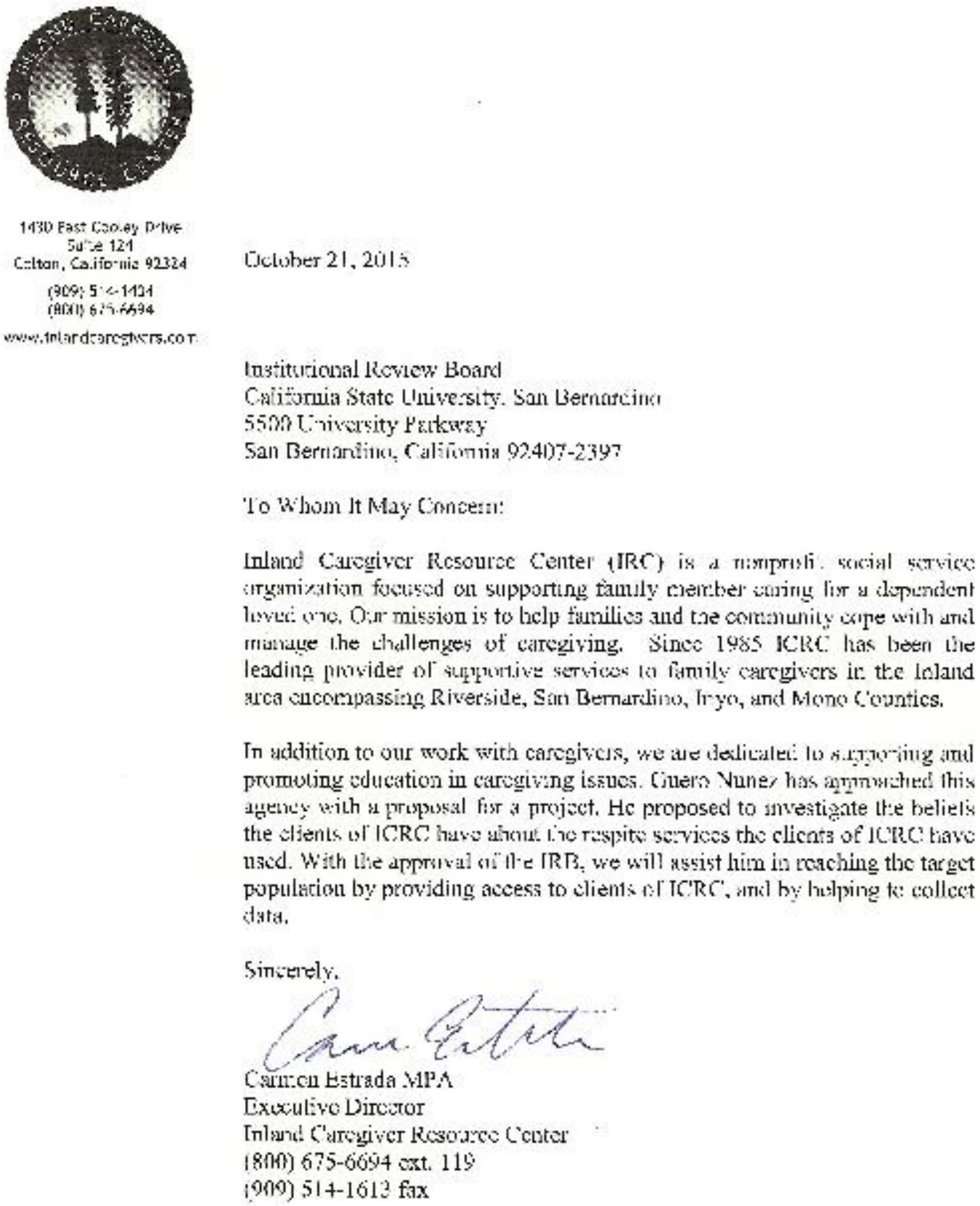
DEBRIEFING STATEMENT

Debriefing Statement for Caregiving Services Beliefs Study

Thank you for your participation in this study. The study you have just completed was designed to assess beliefs caregivers have concerning respite services used. This goal of this study is to assess the perception of benefit of respite service from the perspective of the caregiver. Your participation is not only greatly appreciated by the researchers involved, but the data collected could possibly contribute to the improvement of services available to caregivers as this research will add to the scholarly knowledge base regarding caregivers. Should a participant in this research study desire additional support, the Inland Caregiver Resource Center can be contacted at 1-800-675-6694. Thank you for your participation. If you have any questions about this study, you may contact Herb Shon, Ph.D., LCSW. Phone; (909) 537-5532, CSUSB Email: hshon@csusb.edu upon completion of this study, results will be available at the Pfau Library - California State University-San Bernardino: 5500 University Parkway San Bernardino, CA 92407 at the end of December, 2016.

APPENDIX D

LETTER



1430 East Cooley Drive
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(909) 514-1404
(800) 675-6694
www.inlandcaregivers.com

October 21, 2015

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 (IRC) is a nonprofit social service organization focused on supporting family member caring for a dependent loved one. Our mission is to help families and the community cope with and manage the challenges of caregiving. Since 1985 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 promoting education in caregiving issues. Guero Nunez has approached this agency with a proposal for a project. He proposed to investigate the beliefs the clients of ICRC have about the respite services the clients of ICRC have used. With the approval of the IRB, we will assist him in reaching the target population by providing access to clients of ICRC, and by helping to collect data.

Sincerely,

Carmen Estrada MPA
Executive Director
Inland Caregiver Resource Center
(800) 675-6694 ext. 119
(909) 514-1613 fax

APPENDIX E

TABLES

LIST OF TABLES

Table 11. Respite Service

ICRC Service	N, (%)
Placement	4, (8.3%)
In-Home	34, (70.8%)
Adult Day Care	14, (29.2)
All hours used	40, (88.9%)
Use again	46, (97.9%)
ICRC staff Courteous	48, (100%)
ICRC met CG need	37, (78.8%)

Table 12. *ICRC Respite Services Used for*

	N, (%)
Emergency	3, (6.3%)
Counseling	9, (18.8%)
Doctors’ Appointments	22, (45.8%)
Classes/Support Groups	26, (54.2%)
Feeling Overwhelmed	23, (47.9%)
Other Non-Specified	16, (33.3%)

Table 13. Other Non Respite Services Used

	N, (%)
Information Referral	24, (50%
Family Consultation	8, (16.7%)
Short-Term Counseling	9, (18.8%)
Other Support Groups	16, (33.3%)
Oher Educational Workshops	13, (27.1%)
Conferences	9, (18.8%)
Bereavement Support Programs	1, (2.1%)
Senior Support Services	10, (20.8%)
Occupational Therapy Program	3, (6.3%)

Table 14. Times Respite Used by Caregiver

		N, (%)		
1 - 2	2 - 3	3 - 4	4 - 5	5 - 6
16, (33.3%)	3, (6.3%)	4, (8.3%)	5, (10.4%)	18, (37.5%)

Table 15. Demographic Characteristics of Study Sample

	N, (%)	M
CG Age		67.21
CR Age		75.75
CG Sex		
Male	11, (22.9%)	
Female	36, (75.0%)	
CR Sex		
Male	23, (47.9%)	
Female	23, (47.9%)	
CG Years Caregiving		9.57

Health		N, (%)		
	Poor	Fair	Good	Excellent
CG	1, (2.1%)	16, (33.3%)	25, (25.1%)	4, (8.3%)
CR	16, (33.9%)	16, (33.3%)	11, (22.9%)	1, (2.1%)

Employment	N, (%)		
Full-Time	Part-Time	Retired	Not Formally Employed
4, (8.3%)	4, (8.3%)	26, (54.2%)	11, (22.9%)

Caregiver Relationship to care receiver				N, (%)		
Husband	Wife	Son	Daughter	Other-Relative	Friend	Other
9, (18.8%)	16, (33.3%)	3, (6.3%)	1, (2.1%)	12, (25.0%)	4, (8.3%)	3, (6.3%)

Table 16. Descriptive statistics

	N	Range	Minimum	Maximum	Mean
CG Age	47	54	35	89	67.21
Years Caregiving	46	53	0	53	9.57
CR Age	46	70	32	102	75.74
Diag Year	40	25	1990	2015	2008.92
Valid N (listwise)	39				

Table 17. Care Receivers Primary diagnosis

	N, (%)
Diagnoses made by a physician	46, (95.8%)
Diagnoses	
Alzheimer’s	9, (18.8%)
Alzheimer’s & Dementia	4, (8.3%)
Alzheimer’s & Stroke	1, (2.1%)
Dementia	12, (25.0%)
Dementia & Arthritis	1, (2.1%)
Dementia & Parkinson’s	3, (6.3%)
Cancer	1, (2.1%)
Huntington’s	1, (2.1%)
Stroke	4, (8.3%)
Traumatic Brain Injury	2, (4.2%)
Diabetes & Congestive Heart Failure	1, (2.1%)
Spinal Colum Severed	1, (2.1%)
Kidney	1, (2.1%)

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