

5-2021

EXPLORING INTERVENTIONS RELATED TO CAREGIVER BURNOUT

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HOW CAN FACTORS CONTRIBUTING TO
CAREGIVER BURNOUT BE MITIGATED?

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

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

by
Vanessa Gonzalez
Jakob McCarthy
May 2021

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ABSTRACT

The aging population is rapidly growing within the United States and with advanced age comes an increased likelihood for the need of assistance in completing various activities of daily living. The caregiving literature has thoroughly documented causes and manifestations of caregiver burnout, but there is little mention of interventions for this population. This study utilized a cross-sectional survey of current caregivers to identify sociodemographic factors and descriptive characteristics related to how each respondent fulfills caregiver duties. The survey also measured personal affect, as operationalized by the Negative and Positive Affect Scale (NAPAS) and level of burnout, as measured by the Zarit Burden Interview (ZBI). A one-way between groups ANOVA and independent samples t-test was performed, which revealed no significant relationship between sociodemographic or other risk factors and resulting affect or level of burnout. A correlation analysis was utilized to examine the relationship between affect and level of burnout. Although no significant relationship was found between overall affect and level of burnout, a significant relationship was found between scores on the positive NAPAS subscale and levels of burnout, as well as scores on the negative subscale of the NAPAS and levels of reported burnout. These findings indicate that social workers should continue to explore how positive cognitions can help caregivers achieve resiliency in their role. Limitations and implications for social work policy and practice are also discussed.

ACKNOWLEDGEMENTS

The researchers would like to acknowledge Dr. Herbert Shon for his unwavering support. Dr. Shon, you were truly generous with your time and energy throughout this entire research process, and we will remain grateful for all our days as social workers. The researchers would also like to acknowledge Dr. Barragan. Thank you for all your knowledge and assistance during the development of this research study. Lastly, the researchers would like to acknowledge all caregivers whose continued work and efforts are commendable and do not go unnoticed.

DEDICATION

To my parents, Ruben and Marisol. Thank you for always inspiring me with your resilience and instilling in me the significance of giving back to my community. To my Tíos, Roberto and Noé, who through their life and their memory, have led me where I am today. To my boyfriend, Felipe. Your support and encouragement have been one of my main sources of strength throughout this experience. To Jakob, thank you for being exactly the research partner I needed and for going through this crazy journey with me.

Vanessa Gonzalez

To my wife, Ashlee. Your patience and encouragement has guided me throughout this experience. Thank you for all the Chick-fil-A. To my parents, Jim and Karen. Thank you for instilling in me the values that have made me a social worker. To my sister, Kate. Thank you for providing me with my nieces and nephew to play with whenever I needed to de-stress. To Vanessa, thank you for accommodating my type A tendencies. ¡Felicitaciones, lo lograste!

Jakob McCarthy

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CHAPTER ONE

INTRODUCTION

Problem Formulation

Caregiving is a vital part of all cultures. This is not limited only to the care of the young but to the elderly and disabled as well. In the United States, nearly one in 10 adults between the age of 18 and 24 possesses a severe disability that requires daily personal assistance (US Census Bureau, 2018). This figure increases with age, with three in 10 adults between the ages of 65 and 69 requiring such assistance and over half of individuals over the age of 75. Of important note is the fact that population numbers continue to rise. Between 2020 and 2030, the number of individuals over the age of 65 is projected to increase by over 30% within the United States (US Census Bureau, 2017). Along with expanding numbers, there has also been a shift away from traditional institutional services for older adults and individuals with long-term disabilities toward increased use of home and community-based services (Wysocki et al., 2015). In this country there are now nearly 43.5 million people providing care to a friend or family member over the age of 50 (Hong & Harrington, 2016). With the understanding that this number will continue expanding, it is imperative that attention is given to a common negative effect of caregiving, burnout.

As with any task that is done over an extended period, burnout is an anticipated outcome for caregivers of individuals with chronic conditions (Kokurcan, Yilmaz Ozpolat & Gogus, 2014). Although opinions differ on the

definition and qualifications of burnout, recognition is primarily determined by physical, psychological, emotional, social, or financial consequences (Gerain & Zech, 2019). Manifestations of burnout can include physical injuries, cardiovascular disease, chronic stress, social isolation and development of mental health disorders, among others (Tabeleao, Tomasi & Avila Quevado, 2018). Caregivers carry significant responsibility, which also includes a substantial time demand. On average, 13 days per month are spent completing domestic related tasks for the person being cared for, such as housekeeping, shopping, meal preparation, and laundry. An additional six days per month are spent on personal care for the individual, such as bathing, dressing and feeding (Alpert & Womble, 2015). As Alpert and Womble (2015) stated, unlike many other jobs, however, friends and family members who take on the responsibility of being an informal caregiver tend to receive very little training. This often leaves caregivers in the difficult situation of adapting to the demands of an unfamiliar role without clear expectations. This lack of defined boundaries can lead to difficulty finding sustained fulfillment (Gerain & Zech, 2019).

Failing to address the ongoing issue of caregiver burnout may negate the positive impact that caregivers can have on the population, such as allowing individuals to reside in the least restrictive environment possible. Caregivers have also proven to be cost effective, with informal caregiving in the United States accounting for more than \$600 billion in annual savings versus long-term institutional care (Galiatsatos, 2017). This indicates that further exploration of solutions to burnout has the potential to be beneficial to the country's economy

as well provide a healthier, more empowering process for both the client and the caregiver. Fortunately, there are signs that progress is being made.

In 2000, in response to the growing population of individuals who require a caregiver, as well as increased recognition of caregiver burnout, amendments were made to the National Family Caregiver Support Program (NFCSP), which was originally enacted under the Older Americans Act (Feinberg, Wolkwitz & Goldstein, 2006). These amendments mandate that all 50 states work with public and nonprofit agencies in order to increase availability of services, ranging from education, training, respite, and financial assistance, to older adults as well as their caregivers. Through the NFCSP, California has now established a Caregiver Resource Center (CRC), but conditional restrictions have been put in place. Examples of these restrictions include making services available only to individuals who are caring for a client with a brain impairment that occurred after the age of 18 or a caregiver who is caring for a loved one over the age of 60 who requires assistance with at least two activities of daily living (Inland Caregiver Resource Center, 2019). Although there appear to be efforts toward expanding resources, a noticeable inconsistency in utilization remains due to the obstacles many individuals face when attempting to access these services (Feinberg, Wolkwitz & Goldstein, 2006).

Purpose of the Study

This research study aimed to identify services or interventions that can minimize caregiver burnout. Population numbers are expanding and life

expectancy is growing. Caregivers are going to be needed in greater numbers and for longer durations of time. The recent amendments to the NFCSP are evidence that caregiver burnout is a recognized social issue, but the development of solutions is still in the early stages. This study attempted to build on the current literature on caregiver burnout and examine paths to resiliency for these individuals.

To complete this study, information about caregivers was collected in order to identify the presence of potential risk factors as well as current levels of burnout. This information was obtained directly from the caregivers themselves. In order to properly evaluate the relationship between risk factors, burnout and any other outside variable, a significant sample was required. Considering these circumstances, a survey was recognized as the most efficient research method. The survey provided demographic information to help identify risk factors and also contained an instrument to measure current levels of burnout. A concise survey limited the amount of time required of a caregiver to participate, which allowed for a great number of respondents. Lastly, by utilizing valid and reliable instruments within the survey to measure the necessary data the likelihood of any researcher bias was minimized.

Significance of the Project for Social Work

The phase of the generalist intervention process informed by this study was exploring, specifically examining caregiver demographics and levels of burnout. The findings will allow social workers to be mindful of specific risk

factors and identify potentially useful interventions. The significance of this project for social work practice can be observed on both a macro and micro level.

From a macro standpoint, caregiver research is needed to continue shaping policy that affects the availability of services. Many caregivers and the circumstances of their clients range beyond the restrictive criteria that currently exists for most services at both a county and state level. This study considered a variety of caregiver circumstances in attempt to identify which factors are of the most significance. Ultimately, this provided social workers with the knowledge to advocate for policies that not only expand the number of available services for this vulnerable population but for increased access to these services as well.

The findings of this study can also contribute to social work practice on a micro level. The study has attempted to identify factors that must be considered when working with clients who experience negative outcomes of the caregiving process. With these results, future social workers can be better informed on how to achieve resiliency within the caregiver population and ultimately provide a safe environment for the aging population. With all of this in mind, this research paper addresses the question- How can factors contributing to caregiver burnout be mitigated?

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter will serve as a review and evaluation of the current literature on caregiver burnout. To begin, the potential consequences of taking on the role of a caregiver will be documented in order to highlight the impact of this evolving social problem. This will be followed by a discussion of recent research, including the various impressions of the causes and extent of caregiver burnout, limitations that have been found within these studies, and two popular models that have been developed to describe this process. Lastly, the Broaden-and-Build Theory of Positive Emotions will be presented, which will ultimately guide this study.

Challenges Facing Caregivers

The rise in population of older adults has been seen throughout the past decade. As previously stated, between 2020 and 2030, the number of individuals over the age of 65 within the United States is projected to increase by over 30% (US Census Bureau, 2017). With this growth in the aging population, it is important to note the change in how care is being delivered. Although formal care has long been in place for the aging population, there has been a decrease in utilization of these formal resources. Informal caregivers, primarily family and close friends, have now assumed the majority of responsibility of care. In a

nationally represented sample, it was reported that 63.2% of the aging population are receiving some form of residential care, with 85.9% of these individuals receiving informal care from a close friend or relative (Coward, Cutler & Mullens, 1990). This shift has brought upon two vital implications affecting caregivers, the financial impact as well as the impact on both mental and physical health.

Financial Impact of Caregiving

Many studies assessing the impacts of caregiving have targeted financial burden as a negative impact to caregiving (Bauer & Sousa-Poza, 2015). When an individual assumes the responsibilities of a caregiver, they are ceding opportunity costs in the work field whether they are employed or not at the time of caregiving. The time an individual is engaging in caregiving can significantly reduce the ability to obtain outside employment. If a caregiver does have the resources and ability to balance employment and caregiving, the opportunity cost can come in the form of work interferences. Work interferences include reduced work hours, increased leave time taken, tardiness, and change in shifts, among other disruptions (Colin Reid, Stajduhar & Chappell, 2010). These work interruptions, in turn, also lead to the possibility of termination of employment due to the adverse impact on work performance. The risk of termination is heightened when the caregiver resides with their client and is influenced based on the gender and ethnicity of the caregiver as well (Covinsky et al., 2001). The financial implications that come with caregiving have also been seen to adversely impact

a caregiver's self-esteem and overall mental health (Colin Reid, Stajduhar & Chappel, 2010).

Impact on Caregiver Health

Also widely noted in recent literature are the adverse effects of caregiving on an individual's mental and physical health. It is reported that between 18% to 35% of caretakers perceive their health to be poor or deteriorating since assuming the role of caregiving (Pinquart & Sörensen, 2007). The literature has emphasized caregiver burden and has categorized the effects of caregiver burden to be subjective to stress, depression, and self-assessed health or anxiety. A caregiver's physical health is negatively impacted due to the psychological stress that increases one's vulnerability to infectious agents, putting caregivers at higher risk to suffer from poor health long-term (Pinquart & Sörensen, 2007).

Also emphasized is the importance of a caregiver's self-esteem and view of their role as a caregiver. Research has demonstrated that a higher level of self-esteem has been attributed to combating symptoms of depression and anxiety that are prevalent in the caregiving community (Aggar, 2011). Studies further contend that how an individual chooses to address their stress and well-being effects the individual's capability to meet their own needs. If an individual is able to successfully control the facets of their own environment and build their self-esteem, the adverse effects on caregiving may be combated. However, due to factors including loss of job, social support, and increased social isolation, a caregiver's self-esteem is put at risk.

Studies Focused on Caregiver Burnout

The first study on non-professional caregiver burnout took place in 1986, examining spouses who were caring for a partner with a long-term disabling condition (Ekberg, Griffith & Foxall, 1986; Gerain & Zech, 2018). Since then, studies have evolved to recognize the various relationships that caregivers can have with the care recipient, with the term informal caregiver frequently applied to the individual providing care. Overwhelmingly, these studies highlight the negative consequences caregivers experience, such as deteriorated physical health, higher levels of stress and increased likelihood of mental health problems (Lee & Singh, 2010; Ozkan Tuncay & Kars Fertelli, 2019). Understandably, this has led researchers to attempt to identify risk factors for these negative outcomes. Frequent risk factors reported include being of female sex, higher number of hours spent with the care recipient, and lower levels of education (Adelman et al., 2014).

Although caregiving is widely accepted as a threat to an individual's overall health and well-being, some researchers dispute the magnitude of the proposed negative outcomes as well as the causes of such outcomes (Brown & Brown, 2014; Lopez, Lopez-Arrieta & Crespo, 2005). Brown and Brown (2014) examined recent research and proposed that negative associations of the caregiver role are prominent because, often times, studies simply do not take into consideration positive results of caregiving. This may be, in part, due to the lack of a clear construct of a positive caregiving experience (Lopez, Lopez-Arrieta &

Crespo, 2005). In addition, findings can be limited in the ability to demonstrate cause and effect because differences between caregivers and non-caregivers frequently exist prior to entering the caregiver role. For example, in several studies Brown and Brown (2014) found that those who would go on to become caregivers were already significantly older, had higher levels of depression and were in poorer self-reported physical health than those who would remain continuous non-caregivers. The external validity of caregiver research is also in question, as studies commonly include only those caring for recipients with the same diagnosis, rather than varied or even multiple health problems (Adelman et al., 2014).

The two models primarily utilized throughout the research to discuss caregiver burnout are the Stress Model and the Job Demands-Resources Model. The Stress Model was developed early on to describe how the background & demographics of a caregiver influence the coping skills used in response to various stressors involved in caregiving (Pearlin, Mullan, Semple & Skaff, 1990). When employed in research, however, adjustments to the model are often included to improve external validity (Gerain & Zech 2018). This is due to the fact that the original model was designed based on studies of specifically spousal caregivers of individuals with Alzheimer's disease who were primarily Anglo American. This narrow consideration and the resulting variations in use have created inconsistent findings.

The physical and time demands of caregiving often mirror those of a standard occupation, resulting in adoption of an occupational model of burnout,

The Job Demands-Resources Model (JD-R) (Gerain & Zech, 2018). This model conceptualizes burnout as an imbalance between the demands of a position and the resources available to an individual to meet those demands. This viewpoint has led to increased recognition of need for specific resources for the caregiver. An example of this type of caregiver resource includes recommendation for professional consultation with the care recipient's physician, where the caregiver can be educated on the diagnoses of the recipient as well as expected progression (Adelman et al., 2014; Ozkan Tuncay & Kars Fertelli, 2019). The focus of JD-R and burnout has primarily been on outside interventions up until this point, but there is evidence that the caregiver's personal resources should be considered (Searle & Lee, 2015).

Theories Guiding Conceptualization

Fredrickson (2001) described the role that positive emotions play in achieving resiliency and overall well-being in the Broaden-and-Build Theory of Positive Emotions. Positive affect within an individual leads to higher levels of activity and engagement with one's environment, which leads to a wider range of experiences. Adaptation is increased as people become familiar with new objects, people, and situations. An important distinction between negative emotions and positive emotions is that negative emotions tend to lead to specific actions (Fredrickson, 2001). For example, fear triggers an individual to flee or retreat. Positive emotions have not shown to hold such specific reactions, but instead have a wider thought-action repertoire. Positive emotions increase cognition and are associated with openness, creativity, and efficiency, making

them more valuable to an individual socially, intellectually and psychologically (Fredrickson, 2001; Fredrickson & Joiner, 2002).

The Broaden-and-Build Theory posits that the intrinsic value of positive emotions makes them more durable and enables the positive emotions to act as an antidote to the effects of negative emotions (Fredrickson, 2001). Positive emotions can facilitate a person in finding meaning even in the face of adversity, ultimately increasing resiliency. Labeled as an upward spiral, this psychological broadening continues to build as initial positive emotions lead to increased meaning and resiliency, which in turn leads to additional positive emotions (Fredrickson & Joiner 2002). The Broaden-and-Build Theory will be used to examine whether positive affect of caregivers can be useful in mitigating common risk factors of caregiver burnout.

Summary

As recognition of caregiver burnout has grown, so has the amount of research exploring this topic. There is still plenty to uncover, however, as this is an issue that has only recently started to garner significant attention (Ekberg, Griffith & Foxall, 1986; Gerain & Zech, 2018). This is due, in part, to the modern approach to caregiving and the individuals who now primarily fulfill this role (Coward, Cutler & Mullens, 1990). The chief focus within the research has been on identifying and measuring the negative consequences of caregiving, but a consensus has still not been achieved (Brown & Brown, 2014; Lopez, Lopez-Arrieta & Crespo, 2005). Moving forward, JD-R appears to be a useful model through which caregiver's can use personal resources to meet the demands that

come with this responsibility. In conjunction with the Broaden-and-Build Theory of Positive Emotions, this study examined whether a positive affect can be a serviceable resource.

CHAPTER THREE

METHODS

Introduction

Throughout this chapter, detailed information will be provided that will outline the research process. This will include a description of the design of the study, with consideration of the strengths and limitations. The sampling population will then be discussed from which the data will be collected. To further contextualize the data, the independent variables, dependent variables, and instruments relied upon throughout the research process to measure the variables will be presented. This will be followed by the procedures used to obtain this data, with documentation of the necessary measures to protect the human subjects involved. A summary of the statistical data analysis performed will conclude this chapter.

Study Design

The purpose of this study was to further explore interventions for caregiver burnout. There is a foundation of literature documenting causes and manifestations of burnout, but there is an evident need to expand on services and tools that can be used when working with this population. This study utilized a survey to gather data regarding demographic information, descriptive characteristics of the caregiving relationship, personal affect and levels of burnout directly from current caregivers. The survey was produced in electronic format with use of the Qualtrics program and made available to participants

online. As this study consisted of a single observation of the participants, the research design utilized was a cross-sectional survey.

A strength of the design of this study was the ability to maintain anonymity amongst the participants. This was conducive to gathering reliable responses that were less susceptible to response bias. In addition, a survey was an efficient manner to gather the considerable sample size needed to observe any meaningful relationship between sociodemographic and caregiver circumstances and resulting personal affect and burnout. Lastly, the digital version of the survey utilized technology that was beneficial to collecting and organizing the considerable amount of data for analysis.

Limitations of this study were found in the time constraints. Due to these constraints, a cross-sectional survey was implemented that revealed limited descriptive data which will need to be expanded in the future. Without a longitudinal study consisting of multiple observations, there was also no opportunity to demonstrate a cause and effect relationship. The survey was also only completed by caregivers with availability and access to internet. Of important note, caregivers in the most demanding of circumstances may have been unable to be reached for participation. Lastly, the results are limited in generalizability as respondents were primarily English-speaking residents of the Inland Empire.

Sampling

This study utilized non-random sampling of caregivers primarily in the County of San Bernardino, who either have direct ties to a local caregiver

resource agency or individuals who are members of online caregiver forums. Approval was requested from management at the local caregiver resource agency to share a link to the survey with current caregivers by mass email. In addition, researchers were permitted to attend online caregiver support groups of the agency to promote participation in the study. Convenience sampling was relied upon as well, as researchers also posted links to the survey on online caregiver forums to raise awareness of the ongoing research. The study consisted solely of an electronic survey with a sample of 135 participants. In addition to convenience and availability sampling, researchers utilized snowball sampling by encouraging participants to share the online link to the survey with additional known caregivers.

Data Collection and Instruments

The survey (Appendix A) first established quantitative data regarding each caregiver's demographic and circumstantial risk factors, which include longer lengths of time spent in the caregiver role, as well as lower educational attainment and lower levels of income. Quantitative data was also collected regarding participants' level of burnout and personal affect. The relationship of interest within this study was the caregiver's risk factors for burnout on the resulting affect and levels of burnout. For these purposes, the independent variables consisted of sociodemographic and circumstantial risk factors, while the dependent variables were personal affect and level of burnout.

The most commonly used scale for measuring affect for research purposes, and the one implemented within the survey, is the Negative and

Positive Affect Scale (NAPAS) (Joshnanloo, 2017). The NAPAS measures general affect occurring within the past 30 days. The NAPAS consist of 12 questions, with six questions per subscale. Using a Likert scale, questions 1-6 measured negative affect whereas questions 7-12 measured positive affect. The Likert scale ranges from 1 (none of the time) to 5 (all of the time). A participant's responses were totaled on the Likert scale for questions 1-6 and 7-12 separately. Per the scale, if an individual had a higher score for questions 1-6 in comparison to questions 7-12, the individual was identified to be presenting with a negative affect. Inversely, if the scores for 7-12 were higher than that of 1-6, the individual was presenting with a positive affect. The scale has been proven to be both a valid and reliable tool of measurement. The scale has been found to have strong criterion validity ($\alpha=.87$) for positive affect and ($\alpha=.91$) for negative affect. The scale has also yielded a strong internal consistency reliability with a Cronbach's alpha of 0.84 for positive affect and 0.91 for negative affect (Joshnanloo, 2017).

The scale most frequently utilized to operationalize burnout throughout the caregiver literature is the 22-item Zarit Burden Interview (ZBI) (Bedard et al., 2001; Zarit, Orr & Zarit, 1985). In an effort to minimize the number of questions required of the scale for research purposes, Bedard et al. (2001) developed a shorter 12-item version, which was adopted within the survey. This shortened version consists of 12 questions aimed at identifying an individual's frequency of negative associations with the caregiver role, utilizing a Likert scale ranging from 0 (never) to 4 (nearly always). A cumulative score of 17 or higher indicates significant burnout. For the sake of uniformity, this study maintained the NAPAS

Likert scale of 1 (none of the time) to 5 (all of the time), which then required a score of 29 or higher to qualify as significant burnout. The researchers were confident in employing this shortened version, as it has been found to have both strong internal consistency reliability, with a Cronbach's alpha of 0.88, as well as concurrent validity, with an alpha varying between 0.92 and 0.97 (Bedard et al., 2001).

Procedures

With use of the Qualtrics program, the survey was designed and administered electronically in both English and Spanish. In order to inform the target population of the study, the caregiver resource agency facilitated mass distribution of links to both the English and Spanish versions of the survey through email to all associated current caregivers. Researchers were also granted brief access to online caregiver support groups held by the caregiver resource agency in order to encourage participation. Lastly, links to both surveys were posted to various online caregiver support groups along with a brief description of the ongoing research. Resulting data was securely stored and accessible only by the researchers involved. The researchers gathered responses to the survey from September 2020 to December 2020.

Protection of Human Subjects

Anonymity of all participants was maintained throughout the research process, as no identifying information was collected within the survey. This helped ensure integrity in regards to confidentiality. Prior to completion of the

survey, all participants read and agreed to an informed consent form (Appendix B), documenting their agreement and willingness to participate. The informed consent form was also designed to prevent any minors from participating in the research process. Data gathered throughout the process was stored within the Qualtrics program and accessible only by logins held by the involved researchers. After one year following the completion of the research process, all data will be deleted from the USB drive and Qualtrics program.

Data Analysis

Sociodemographic information provided descriptive and inferential statistics that allowed the researchers to observe the demographic and circumstantial make-up of the sample population as well as better understand which demographic factors are predictors of burnout. These demographic and circumstantial risk factors acted as independent variables, with affect and level of burnout as the dependent variables. A one-way between groups ANOVA was conducted to examine how demographic and descriptive characteristics of the caregiving role impact personal affect and level of burnout. An independent samples t-test was also utilized to explore how use of informal and formal resources influence personal affect and level of burnout. Lastly, a Pearson correlation coefficient was obtained to determine how closely positive and negative affect align with levels of burnout.

Summary

A survey was produced that allowed for collection of vital sociodemographic information as well as operationalization of burnout, with use of a shortened version of the ZBI, and personal affect, through the widely trusted NAPAS. This survey was distributed to caregivers associated with a local caregiver resource agency and members of online forums through convenience and snowball sampling methods. After obtaining a significant sample size, a one-way between groups ANOVA and independent samples t-test were conducted to observe the impact of sociodemographic and circumstantial factors on resulting affect and levels of burnout. A correlation analysis was also utilized to observe the relationship between affect and level of burnout.

CHAPTER FOUR

RESULTS

Introduction

This chapter will begin by presenting the sociodemographic characteristics of those who responded to the survey. This will depict the diversity of participants in terms of age, gender, marital status, race, level of education, and income. In addition, a descriptive analysis of the sample will examine the number of individuals each respondent provides care for, the type of impairment requiring care, consecutive years spent as a caregiver, hours per week spent in the caregiving role, and whether or not participants receive assistance through any type of outside informal or formal resource. A statistical analysis of the sample will then be provided to determine if there is a relationship between any aspects of the caregiver and resulting affect or level of burnout.

Sociodemographic Characteristics

Table 1 provides the ages and self-identified genders of respondents. From this table, it is evident that the sample primarily consisted of older individuals, with 43.8% (n=46) of respondents aged 65 years or older. The mean age was 63 years (SD= 12.75), with a range from 21-83 years old. In addition, respondents were also primarily female, with 79.5% (n= 93) identifying as such.

Table 1
Sociodemographic Characteristics of the Sample: Age and Gender

	n	%
Age		
18-24	2	1.9
25-34	4	3.8
35-44	4	3.8
45-54	14	13.4
55-64	35	33.3
65 and older	46	43.8
Gender		
Female	93	79.5
Male	24	20.5

Table 2 presents the breakdown of the sample by ethnicity. Anglo Americans were the most represented ethnicity within the sample at 31.9% (n= 37), followed by Latinos at 30.2% (n= 35). Asian/Pacific Islander at 6% (n= 7) and Native Americans at .9% (n=1) were the least represented groups.

Table 2
Sociodemographic Characteristics of the Sample: Ethnicity

	n	%
African American	15	12.9
Latino	35	30.2
Anglo American	37	31.9
Asian/Pacific Islander	7	6.0
Native American	1	.9
Other	21	18.1

Table 3 displays the marital status of the sample, along with the highest level of education attained and annual household income. The majority of the sample were currently married, with 71.6% (n= 83) indicating so. Only 9.5% (n=

11) of respondents reported as having never wed. When examining education level attainment, 40.2% (n= 47) had attended at least some college, while 21.4% (n= 25) had graduated college and 22.2% (n= 26) had gone on to graduate or professional school. Annual household income level was the final sociodemographic factor recorded. Within the sample, the highest represented income was between \$25,000 and \$49,999 at 46.9% (n= 53). Only 12.4% (n= 14) of respondents reported a household income greater than \$100,000 per year, while 9.7% (n= 11) reported a household income of less than \$25,000.

Table 3
Sociodemographic Characteristics of the Sample: Marital Status, Education, and Income

	n	%
Marital Status		
Never Married	11	9.5
Married	83	71.6
Divorced/Widowed	18	15.5
Cohabiting	4	3.4
Highest Level of Education		
Less Than High School	1	.9
High School Graduate	18	15.4
Some College	47	40.2
College Graduate	25	21.4
Graduate/Professional School	26	22.2
Income		
\$0-\$19,999	11	9.7
\$20,000-\$49,999	53	46.9
\$50,000-\$74,999	27	23.9
\$75,000-\$99,999	8	7.1
\$100,000+	14	12.4

Descriptive Analysis

Table 4 provides the number of individuals that respondents were currently providing care for, along with the types of impairments. The vast majority were providing care to only one individual, with 82.1% (n= 96) indicating so. Most respondents also reported that care was being provided to individuals with both a physical and cognitive impairment at 64% (n= 73).

Table 4
Descriptive Characteristics of the Sample: Number of Individuals Providing Care For and Type of Impairment

	n	%
Number of Individuals		
1 Individual	96	82.1
2 Individuals	15	12.8
3 Individuals+	6	5.1
Type of Impairment		
Physical Impairment	17	14.9
Cognitive Impairment	24	21.1
Both Physical and Cognitive	73	64.0

Table 5 presents the sample in terms of consecutive years spent as a caregiver and the number of hours per day spent on caregiving duties. Most respondents were relatively new to caregiving, as 55.8% (n= 58) indicated from less than one year to five years of experience. Only 21.2% (n= 22) had spent more than 10 years as a caregiver, with 13.5% (n= 14) having between 11 and 15 years of experience and 7.7% (n= 8) indicating more than 16 years of experience. The mean was 7.13 years spent as a caregiver. Daily time spent on caregiving duties was varied within the sample, with 33.3% (n= 32) providing less

than one hour to five hours of care, 24% (n= 23) providing between six and eleven hours of care, and 20.8% (n= 20) providing between 12 and 23 hours of care. There were 21.9% (n= 21) of respondents who indicated providing care 24 hours per day.

Table 5
Descriptive Characteristics of the Sample: Consecutive Years as Caregiver and Hours Per Day Providing Care

	n	%
Consecutive Years as Caregiver		
>1-5 years	58	55.8
6-10 years	24	23
11-15 years	14	13.5
16+ years	8	7.7
Hour Per Day Providing Care		
>1-5 hours	32	33.3
6-11 hours	23	24
12-23 hours	20	20.8
24 hours	21	21.9

Table 6 reveals the use of informal and formal resources within the sample. Informal resources, such as the help of another family member, friend, or neighbor, was reported to be used by 29.9% (n= 35) of respondents. The use of formal resources, such as respite services or assistance from a paid chore worker, was reported to be used by 23.7 % of respondents (n= 28).

Table 6
Descriptive Characteristics of the Sample: Use of Informal and Formal Resources

	n	%
Use of Informal Resources		
Yes	35	29.9
No	82	70.1
Use of Formal Resources		
Yes	28	23.7
No	90	76.3

Statistical Analysis

A one-way between-groups ANOVA was conducted to explore the impact of a variety of sociodemographic and descriptive characteristics on level of burnout, as measured by scores on the shortened version of the ZBI. There was not a significant difference in level of burnout based on ethnicity $F(2, 84) = 1.89$, $p = .16$. Only African American, Anglo American and Latino were included as there were not enough respondents in other categories. There was also not a significant difference in level of burnout based on marital status $F(3, 111) = 1.37$, $p = .26$, income $F(4, 111) = 1.46$, $p = .22$, number of individuals providing care for $F(2, 113) = .55$, $p = .58$, or type of impairment $F(2, 110) = 2.09$, $p = .13$.

A one-way between groups ANOVA was also conducted to examine whether these same characteristics had any impact on affect, as measured by the NAPAS. There was a significant difference in affect based on ethnicity $F(2, 83) = 8.04$, $p = .001$. There was not a significant difference found in affect and marital status $F(3, 111) = 1.99$, $p = .12$, income $F(4, 107) = 1.95$, $p = .11$, number of individuals being cared for $F(2, 113) = 3.04$, $p = .052$, or type of impairment $F(2, 110) = .5$, $p = .61$.

In order to compare level of burnout and affect across gender, as well as those who do and do not utilize informal or formal resources, an independent samples t-test was conducted. There was no significant difference found in level of burnout for females ($M= 18.75$, $SD= 10.24$) and males ($M= 16.33$, $SD= 9.03$; $t(114)= -1.05$, $p= .29$, two-tailed). There was also no significant difference found in affect for females ($M= 30.24$, $SD= 4.01$) and males ($M= 28.92$, $SD= 9.03$; $t(114)= -1.89$, $p= .13$, two-tailed). There was no significant difference in level of burnout for those who received assistance from an informal resource ($SD= 17.6$, $SD= 10.67$) and those who did not ($M= 18.38$, $SD= 9.74$; $t(114)= -.386$, $p= .7$, two-tailed). There was also not a significant difference in affect for those who received assistance from an informal resource ($M= 29.74$, $SD= 3.94$) and those who did not ($M= 30$, $SD= 3.78$; $t(114)= -.33$, $p= .74$, two-tailed). Lastly, there was no significant difference in level of burnout for those who received assistance through a formal resource ($M= 20.48$, $SD= 10.88$) and those who did not ($M= 17.53$, $SD= 9.65$; $t(115)= 1.35$, $p= .18$, two-tailed). There was also no significant difference in affect for those who received assistance from a formal resource ($M= 30.41$, $SD= 4.35$) and those who did not ($M= 29.8$, $SD= 3.64$; $t(115)= .73$, $p= .47$, two-tailed).

A correlation analysis was used to explore the relationship between the number of consecutive years spent as a caregiver and resulting affect and level of burnout. This was also used to investigate the relationship between number of daily hours spent performing caregiving duties and resulting affect and level of burnout. A Pearson correlation coefficient found no significant relationship

between number of years spent as a caregiver and affect, $r = -.15$, $n = 104$, $p = .14$. A Pearson correlation coefficient also found no significant relationship between number of years spent as a caregiver and level of burnout, $r = .12$, $n = 103$, $p = .22$. A Pearson correlation coefficient found no significant relationship between the number of daily hours spent performing caregiving duties and affect, $r = -.14$, $n = 95$, $p = .18$. A Pearson correlation coefficient also found no significant relationship between the number of daily hours spent performing caregiving duties and level of burnout, $r = .14$, $n = 95$, $p = .18$.

A correlation analysis was also utilized to examine the relationship between respondents' affect and level of burnout, and these findings are presented in Table 7. A Pearson correlation coefficient found no significant relationship between overall affect and level of burnout, $r = .02$, $n = 116$, $p = .8$. Interestingly, however, a Pearson correlation coefficient did find a significant relationship between scores on the positive subscale of the NAPAS and level of burnout, $r = -.63$, $n = 116$, $p = .00$. A Pearson correlation coefficient also found a significant relationship between scores on the negative subscale of the NAPAS and level of burnout, $r = .7$, $n = 116$, $p = .00$. This indicates that the more intensely a respondent identified with perceived positive aspects of the caregiving role, the lower the level of burnout was likely to be, and the more intensely the respondent identified with negative perceived aspects of the caregiving role, the higher the level of burnout was likely to be.

Table 7

Pearson Correlation Coefficients for ZARIT, NAPAS, Positive NAPAS Subscale, and Negative NAPAS Subscale

	M	SD	1	2	3	4
1. ZARIT	18.21	9.98				
2. NAPAS	29.94	3.8	.02			
3. Pos. NAPAS Subscale	16.45	5.15	-.63*	.46*		
4. Neg. NAPAS Subscale	13.49	4.78	.7*	.3*	-.71*	

*p < .01

CHAPTER FIVE

DISCUSSION

Introduction

This chapter will discuss the findings discovered through the study and its implications to social work practice. The chapter will also discuss any limitations that were present in this study and suggestions for future studies regarding caregiver affect and burnout as well as the impact this data could have on practice and policy.

Discussion

Literature highlights the increased risk of negative impact on caregiver health as a result of caregiving. Literature has also identified several risk factors that lead to negative experiences and deterioration in health for caregivers. Risk factors emphasized throughout the literature are being of female sex, higher number of hours spent with the care recipient, and lower levels of education (Adelman et al., 2014). These risk factors were addressed throughout the study within the portion of varying demographic questions.

The results of the study revealed no significant relationship between overall reported affect and reported level of burnout, as well as no significant impact on caregiver affect and reported level of burnout based on sociodemographic factors or descriptive characteristics. With regards to sociodemographic factors that were examined in accordance to reported level of burnout, there were no significant differences found based on gender, ethnicity,

marital status, or income. When examining these same factors with reported caregiver affect, the data indicates that there was also no significant relationship observed. In addition, no significant relationship was found between overall affect or level of burnout based on descriptive characteristics, such as number of individuals providing care for, type of impairment, years spent as a caregiver, or number of daily hours performing caregiver duties.

The results, however, did demonstrate a significant relationship between higher scores on the negative subscale of the NAPAS and increased levels of reported burnout, along with higher scores on the positive NAPAS subscale and decreased levels of reported burnout. What can be drawn from these findings are that participants who reported a more positive affect and perception of their caregiving role also reported lower levels of burnout.

Limitations

A number of limitations were present in the study. One of the limitations, was the inability for the survey to encompass a diverse group of caregivers. The study was primarily comprised of individuals who had ties with a local caregiver resource agency in San Bernardino County and were already receiving a form of formal or informal services through the agency. This may have had an impact on participant's reported level of affect and burnout and these limitations could have been addressed by having a more diverse group of caregivers, such as those residing in neighboring counties of Los Angeles County and Riverside County.

An additional limitation present was the delivery method of the survey and the lack of options to conduct the survey through different methods. The study

was conducted solely online via email and a convenience sample was used. Only individuals who had access to technology and had an active email with the local caregiver resource agency were able to participate in the research. There was an inability to reach clients who did not have an email account due to lack of in-person gatherings per COVID-19 state and agency regulations. The lack of a methodological procedure attributes to the lack of representation of the general population and due the lack of non-probability sampling, there is the possibility of biases as well as an increase likelihood of outliers (Etikan, Musa & Alkassim, 2016).

Another limitation was the lack of responses from Spanish speaking caregivers in comparison to responses from English speaking caregivers. There was a significantly low level of Spanish speaking responses which may be attributed to the delivery of the survey or the number of individuals who receive formal resources from the caregiver resource agency who speak the language. There was an inability to present the research study in Spanish speaking online caregiver support groups which could have increased the number of respondents.

A final limitation to highlight is environment in which the study took place, during the COVID19 pandemic. The role and time caregivers were available to their loved ones may have shifted due to different stay at home orders that were enforced at the time of the survey. Also due to the pandemic there was limitations with promoting the survey with the local caregiver resource agency. The survey could only be promoted at official caregiver support groups via zoom.

Implication for Social Work Policy and Practice

A method of reaching minorities and having an increase in minority participation must be developed in order to account for the diversity of caregivers. There is an overall lack of representation of minorities in research studies and in data collection throughout the United States (Sheikh, 2005). There is also a lack of community engagement and advocacy within the minority populations. In order to reach a broader range of representation and develop a greater scope of caregiver needs there must be more formal invitations and recruitment for minorities to increase participation.

The findings indicate that it is worth continuing to investigate how caregiver resources impact overall perceptions of the caregiver role and levels of burnout. Harnessing the influence of positive affect may be a path to mitigating burnout but will require further exploration. Social workers should continue to advocate for access to services and advocate for policy that supports and grants funding for caregiver resource centers. Increased psychoeducation for novice informal caregivers is also necessary to facilitate preparedness and increase self-perceived competence (Tabeleao, Tomasi & Avila Quevado, 2018). Further research is needed, as the study was unable to confirm or eliminate factors that were hypothesized to influence caregiver burnout and overall affect.

Conclusion

This study was conducted in order to observe risk factors of caregiver burnout and explore possible solutions to mitigate the occurrence of burnout. The study did not find a significant correlation between that of overall caregiver affect

and burnout. The study also did not confirm which sociodemographic characteristics most contribute to higher levels of reported burnout. Considering the limitations and growth that this area of social work will experience, this is an issue that deserves further attention.

APPENDIX A
CAREGIVER SURVEY

For the following questions, please provide or circle your response:

1. What is your current age?

_____ years

2. What is your identified gender?

1. Male

2. Female

3. Decline to answer

3. What is your ethnicity?

1. African American

2. Latino

3. Anglo American

4. Asian/Pacific Islander

5. Native American

6. Other

4. What is your marital status?

1. Never married

2. Married

3. Divorced/Widowed

4. Cohabiting

5. What is your highest level of education achieved?

1. Less than high school

2. High school graduate

3. Some college

4. College graduate

5. Graduate or professional school

6. What is your annual household income?

1. \$0-\$19,999

2. \$20,000-\$49,999

3. \$50,000-\$74,999

4. \$75,000-\$99,999

5. \$100,000+

7. How many individuals do you currently provide care for?

1. 1 individual

2. 2 individuals

3. 3 individuals

8. For the individual(s) you provide care for, please select the type of impairment that requires assistance.

1. Physical impairment- i.e., limited mobility, incontinence, limited use of extremities
2. Cognitive impairment- i.e., developmental delay, memory/orientation/judgment impairment
3. Both physical and cognitive impairments

9. Currently, how many consecutive years have you spent as a caregiver?

_____ years

10. On average, how many hours per day do you spend assisting the individual(s) you provide care for?

_____ hours

11. Do you receive respite or assistance in caring for your loved one through an informal resource, such as a family member, friend or neighbor?

1. Yes
2. No

12. If yes, how many hours per week do you typically receive this type of assistance?

_____ hours

13. Do you receive respite or assistance in caring for your loved one through a formal resource, such as a paid chore worker or adult day program?

1. Yes
2. No

14. If yes, how many hours per week do you typically receive this type of assistance?

_____ hours

We would now like to ask a few questions about how you feel about yourself.
Please circle the appropriate response below.

For this section:

- 1 = None of the time
- 2 = A little of the time
- 3 = Some of the time
- 4 = Most of the time
- 5 = All the time

During the past 30 days, how much of the time do you feel....

1. so sad nothing could cheer you up?	1	2	3	4	5
2. nervous?	1	2	3	4	5
3. restless or fidgety?	1	2	3	4	5
4. hopeless?	1	2	3	4	5
5. that everything was an effort?	1	2	3	4	5
6. worthless?	1	2	3	4	5
7. cheerful?	1	2	3	4	5
8. In good spirits?	1	2	3	4	5
9. extremely happy?	1	2	3	4	5
10. calm and peaceful?	1	2	3	4	5
11. satisfied?	1	2	3	4	5
12. full of life?	1	2	3	4	5

For this section:

- 1 = None of the time
- 2 = A little of the time
- 3 = Some of the time
- 4 = Most of the time
- 5 = All the time

During the past 30 days, how much of the time do you feel....

1. that because of the time you spend with your loved one that you don't have enough time for yourself?

1 2 3 4 5

2. stressed between caring for your relative and trying to meet other responsibilities?

1 2 3 4 5

3. angry when you are around your relative?

1 2 3 4 5

4. that your relative currently affects your relationship with family members or friends in a negative way?

1 2 3 4 5

5. strained when you are around your relative?

1 2 3 4 5

6. that your health has suffered because of your involvement with your relative?

1 2 3 4 5

7. that you don't have as much privacy as you would like because of your relative?

1 2 3 4 5

8. that your social life has suffered because you are caring for your relative?

1 2 3 4 5

9. that you have lost control of your life since your relative's illness?

1 2 3 4 5

10. uncertain about what to do about your relative?

1 2 3 4 5

11. you should be doing more for your relative?

1 2 3 4 5

12. you could be doing a better job in caring for your relative?

1 2 3 4 5

Bedard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J., & O'Donnell, M.

(2001). The zarit burden interview: A new short version and screening version. *The Gerontologist*, *41*(5), 652-657. doi:10.1093/geront/41.5.652.

Joshanloo, M. (2017). Factor structure and criterion validity of original and short versions of the Negative and Positive Affect Scale (NAPAS). *Personality and Individual Differences*, *105*, 233-237. doi:10.1016/j.paid.2016.09.060.

Modified by Vanessa Gonzalez and Jakob McCarthy.

APPENDIX B
SPANISH CAREGIVER SURVEY

En la siguientes preguntas por favor señale o circule su respuesta:

1. ¿Cual es su edad?

_____ Años

2. ¿Con que genero se identifica?

1. Masculino

2. Femenino

3. Sin respuesta

3. ¿Cuál es tu origen étnico?

1. Africano Americano

2. Latino

3. Anglo Americano

4. Asiático/Islas polinesias

5. Nativo Americano

6. Otro

4. ¿Cual es su estatus social?

1. Nunca casado

2. Casado

3. Divorciado/Viudo

4. Unión libre

5. ¿Cuál es su ultimo grado de estudios?

1. Educación primaria/secundaria

2. Preparatoria

3. Carrera Trunca

4. Carrera terminada

5. Titulo Profesional

6. ¿Cual es su Ingreso anual?

1. \$0-\$19,999

2. \$20,000-\$49,999

3. \$50,000-\$74,999

4. \$75,000-\$99,999

5. \$100,000+

7. ¿ Cuantas personas dependen de usted?

1. 1 persona

2. 2 personas

3. 3 personas

8. En el caso de los individuos que dependen de usted, por favor señale el tipo de discapacidad para la cual requiere asistencia

1. Discapacidad física; por ejemplo, movilidad limitada, incontinencia, uso limitado de alguna extremidad.

2. Discapacidad cognitiva; por ejemplo, retraso en el desarrollo, memoria/orientación/capacidad para tomar decisiones

3. Ambas física y cognitiva.

9. ¿Actualmente, Cuantos años consecutivos ha sido usted cuidador

1. Menos de 1 año

2. De 1 a 2 años

3. De 3 a 5 años

4. De 5 a 10 años

5. Más de 10 años

10. ¿En promedio, Cuántas horas por día le dedica a la asistencia y/o cuidado de individuos que dependen de usted?

1. Menos de 2 horas por día 2. Entre 2 y 4 horas por día 3. Entre 4 y 6 horas por día

4. Entre 6 y 8 horas por día 5. Más de 8 horas por día

Nos gustaría saber algunas cosas sobre como se siente usted, por favor encierre en un circulo la respuesta que más se adecue.

Para esta sección:

1 = Nada de tiempo

2 = Un poco de tiempo

3 = Algo de tiempo

4 = La mayoría del tiempo

5 = Todo el tiempo

En los últimos 30 días, Qué tanto se siente usted...

1. Tan triste que nada lo hace sentir mejor?	1	2	3	4	5
2. Nervioso?	1	2	3	4	5
3. Inquieto?	1	2	3	4	5
4. Sin esperanzas?	1	2	3	4	5
5. Que todo es un esfuerzo?	1	2	3	4	5
6. Desvalorizado?	1	2	3	4	5

7. Alegre?	1	2	3	4	5
8. De buen humor?	1	2	3	4	5
9. Extremadamente feliz?	1	2	3	4	5
10. En paz y en calma?	1	2	3	4	5
11. Satisfecho/a?	1	2	3	4	5
12. En plenitud/Lleno de vida?	1	2	3	4	5

Para esta sección:

- 1 = Nada de tiempo
- 2 = Un poco de tiempo
- 3 = Algo de tiempo
- 4 = La mayoría del tiempo
- 5 = Todo el tiempo

En los últimos 30 días, Qué tanto siente usted...

1. Que debido al tiempo que paso con mi ser querido que estoy cuidando, no tengo tiempo suficiente para mi mismo

1 2 3 4 5

2. Estresado entre cuidar a mi familiar y tratar de cumplir otras responsabilidades

1 2 3 4 5

3. Enojado cuando estoy cerca de mi familiar

1 2 3 4 5

4. Que su familiar afecta su relación con otros miembros de la familia o amigos de manera negativa

1 2 3 4 5

5. Tenso cuando esta cerca su familiar

1 2 3 4 5

6. Que su salud se ha deteriorado debido a su relación con su familiar

1 2 3 4 5

7. Que no tiene la privacidad que le gustaría debido a su familiar

1 2 3 4 5

8. Que su vida social se ha deteriorado debido a que usted cuida de su familiar

1 2 3 4 5

9. Que ha perdido el control de su vida desde que su familiar se enfermó

1 2 3 4 5

10. No está seguro de que hacer con su familiar

1 2 3 4 5

11. Debería hacer más por su familiar

1 2 3 4 5

12. Podía hacer un mejor trabajo cuidando a mi familiar

1 2 3 4 5

Bedard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J., & O'Donnell, M.

(2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist, 41*(5), 652-657. doi:10.1093/geront/41.5.652.

Joshanloo, M. (2017). Factor structure and criterion validity of original and short versions of the Negative and Positive Affect Scale (NAPAS). *Personality and Individual Differences, 105*, 233-237. doi:10.1016/j.paid.2016.09.060.

Modified by Vanessa Gonzalez and Jakob McCarthy.

APPENDIX C
INFORMED CONSENT FORM

INFORMED CONSENT

The study in which you are asked to participate is designed to identify and describe factors that lead to caregiver burnout and how they can be mitigated. This is a quantitative study conducted on caregivers, and the study will examine their level of reported burnout and affect. The study is being conducted by Vanessa Gonzalez and Jakob McCarthy MSW students under the supervision of Dr. Shon, Professor in the School of Social Work at California State University, San Bernardino (CSUSB). The study has been approved by the Institutional Review Board Social Work Sub-committee at CSUSB.

PURPOSE: The purpose of this study is to examine caregiver's reported level of burnout and affect.

DESCRIPTION: Participants will be asked to answer some questions on how they are feeling about themselves and burnout.

PARTICIPATION: Your participation in the study is completely voluntarily. You can refuse to participate in the study or discontinue your participation at anytime without consequences.

CONFIDENTIALITY: Your responses will remain anonymous and data will be reported in group form only.

DURATION: It will take 10-15 minutes to complete the survey.

RISKS: There are minimal risks to the participants, such as feeling uncomfortable answering questions about burnout and affect.

BENEFITS: No direct benefits for the participants are expected to occur from completing this study.

CONTACT: If you have any questions about this study, please feel free to contact Dr. Shon at (909)537-5532 email (herb.shon@csusb.edu).

RESULTS: Results of the study can be obtained from the Pfau Library ScholarWorks database (<http://scholarworks.lib.csusb.edu/>) at California State University, San Bernardino after July 2021

***** I understand that I must be 18 years of age or older to participate in your study, have read and understand the consent document and agree to participate in your study.

Place an X mark here

Date

APPENDIX D
SPANISH INFORMED CONSENT

CONSENTIMIENTO INFORMADO

El estudio en el que se le pide que participe está diseñado para identificar y describir los factores que conducen al agotamiento del cuidador y cómo estos pueden mitigarse. Este es un estudio cuantitativo dirigido para cuidadores, y pretende examinar su nivel de agotamiento y afecto reportados. El estudio lo realizan Vanessa González y Jakob McCarthy, estudiantes de MSW bajo la supervisión del Dr. Shon, profesor de la Escuela de Trabajo Social de la Universidad Estatal de California, San Bernardino (CSUSB). El estudio ha sido aprobado por el Subcomité de Trabajo Social de la Junta de Revisión Institucional de CSUSB.

PROPÓSITO: El propósito de este estudio es examinar el nivel de agotamiento y afecto reportado por el cuidador.

DESCRIPCIÓN: Se les pedirá a los participantes que respondan algunas preguntas sobre cómo se sienten acerca de sí mismos y el agotamiento que representa ser cuidador.

PARTICIPACIÓN: Su participación en el estudio es completamente voluntaria. Puede negarse a participar en el estudio o suspender su participación en cualquier momento sin consecuencias alguna.

CONFIDENCIALIDAD: Sus respuestas permanecerán anónimas y los datos se informarán solo de forma grupal.

DURACIÓN: La duración de la encuesta es de entre 10 y 15 minutos.

RIESGOS: Los participantes tienen riesgos mínimos, uno de estos puede ser sentirse incómodo al responder algunas de las preguntas.

BENEFICIOS: No se esperan beneficios directos para los participantes al completar este estudio.

CONTACTO: Si tiene alguna pregunta sobre este estudio, no dude en comunicarse con el Dr. Shon al (909)537-5532 o en el siguiente correo electrónico: herb.shon@csusb.edu.

RESULTADOS: Usted puede consultar los resultados del estudio en la base de datos; Pfau Library ScholarWorks (<http://scholarworks.lib.csusb.edu/>) en la Universidad Estatal de California, San Bernardino después de julio de 2021

.....

Entiendo que debo tener 18 años de edad o más para participar en el estudio, haber leído y comprendido el documento de consentimiento y aceptar participar en su estudio.

Marque con una X aquí

Fecha

APPENDIX E
INSTITUTIONAL REVIEW BOARD APPROVAL



CSUSB INSTITUTIONAL REVIEW BOARD

Administrative/Exempt Review Determination
Status: Determined Exempt
IRB-FY2020-230

Jakob McCarthy Herbert Shen, Vanessa Gonzalez
CSBS - Social Work
California State University, San Bernardino
5500 University Parkway
San Bernardino, California 92407

Dear Jakob McCarthy Herbert Shen, Vanessa Gonzalez

Your application to use human subjects, titled "How Can Factors Contributing to Caregiver Burnout be Mitigated?" has been reviewed and approved by the Chair of the Institutional Review Board (IRB) of CSU, San Bernardino has determined your application meets the federal requirements for exempt status under 45 CFR 46.104. The CSUSB IRB has not evaluated your proposal for scientific merit, except to weigh the risk and benefits of the study to ensure the protection of human participants. The exempt determination does not replace any departmental or additional approvals which may be required.

You are required to notify the IRB of the following as mandated by the Office of Human Research Protections (CHRP) federal regulations 45 CFR 46 and CSUSB IRB policy. The forms (modification, renewal, unanticipated/adverse event, study closure) are located in the Cayuse IRB System with instructions provided on the IRB Applications, Forms, and Submission webpage. Failure to notify the IRB of the following requirements may result in disciplinary action.

- Ensure your CITI Human Subjects Training is kept up-to-date and current throughout the study.
- Submit a protocol modification (change) if any changes (no matter how minor) are proposed in your study for review and approval by the IRB before being implemented in your study.
- Notify the IRB within 5 days of any unanticipated or adverse events are experienced by subjects during your research.
- Submit a study closure through the Cayuse IRB submission system once your study has ended.

If you have any questions regarding the IRB decision, please contact Michael Gillespie, the Research Compliance Officer. Mr. Michael Gillespie can be reached by phone at: (909) 537-7588, by fax at: (909) 537-7028, or by email at mgillesp@csusb.edu. Please include your application approval number IRB-FY2020-230 in all

correspondence. Any complaints you receive from participants and/or others related to your research may be directed to Mr. Gi Iospia.

Best of luck with your research.

Sincerely,

Donna Garcia

Donna Garcia, Ph.D., IRB Chair
CSUSB Institutional Review Board

DG/MG

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