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Psychosocial Challenges on Latinx Caregivers

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PSYCHOSOCIAL CHALLENGES ON LATINX 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

Brenda Perez

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ABSTRACT

The purpose of the research disclosed in this study is to describe the experiences and hardships caregivers in the Latinx community face. In order to understand the psychosocial challenges that Latinx caregivers experience, the study compared Latinx to non-Latinx caregivers in order to answer the question, “What psychosocial challenges do Latinx caregivers experience?” A convenience sample of twelve caregivers were interviewed. The qualitative approach used in this study allowed a better insight into the problem which could bring public awareness and provide better resources to this population. The exploratory study was directed by a series of questions which were open-ended questions that covered topics related to burnout, stress, financial strains, and lack of support systems. The analysis of the data was reviewed and highlighted repeated themes in the interviews. With the lack of research on this population, it allows social workers to consider other possible factors when providing aid to the caregiver population.

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CHAPTER ONE

INTRODUCTION

Problem Formulation

In the Latinx community, families are viewed as primary caregivers for family members who are mentally ill (Guarnaccia et. al., 1992). Most family caregivers are described as informal caregivers. According to reports, there are roughly 43.5 million caregivers who've provided unpaid caregiving to an adult or a child (Family Caregiver Alliance, 2012). Latinx caregivers have a higher reported prevalence of caregiving which is 21% compared to other ethnic groups also, Latinx experience more burdens and spend more time caregiving compared to other ethnic groups (Family Caregiver Alliance, 2012). It is common for more Latinx caregivers to experience mild or more severe depression due to the persistent demands they experience while providing care to others (Family Caregiver Alliance, 2012). Many caregivers tend to sacrifice their own mental and/or physical needs to care for others however, that ultimately can lead to a decrease in their mental health.

There are many components that have been found in contributing to the impact of mental health in caregivers at the individual and policy levels. Latinx caregivers face unique challenges, and many of the challenges they face are due to low socioeconomic status, poor housing, and poor health due to limited access to health insurance and additional resources (Berkman, 2006). It is reported that cultural values can cause an individual to consider the well-being of a family member rather than considering their own well-being (Berkman, 2006). A study conducted by Evercare and the National Alliance for Caregivers (2008), showed that one third (36%) of Latinx households have at least one or more caregiver in the family, with a reported mean of 1.83 caregivers in every household and approximately 8,147,000 Latinx caregivers in the United States (National Alliance for Caregiving, 2008). The same study (National Alliance for Caregiving, 2008) reported that approximately 84% of Latinx caregivers indicated that because of their upbringing, their role as a caregiver is expected and 70% reported that it would be seen as shameful in their family if they would not accept the role of a caregiver. Therefore, caregiving is seen more as a cultural obligation in Latinx groups. Environmental stressors such as legal status play a role in the high risk of depressive symptoms in Latinx caregivers. Undocumented caregivers face problems due to their legal status such as poverty, low education, language barriers along with lack of education/knowledge of services in their community (Berkman, 2006). This has implications for policy in that there should be adequate training, services, and assistance for Latinx caregivers. As a result, the lack of knowledge and resources can play a factor in the distress of caregivers. Distress can be expressed differently in different ethnicities. Consequently, limited research on how distress is expressed differently amongst different ethnicities makes it difficult for social workers to properly assist and treat their clients of various ethnicities. Therefore; it is important to have further research conducted to see the effects of psychosocial challenges on the Latinx community to better assist that ethnicity.

Purpose of the Study

The purpose of the study is to identify the psychological challenges that caregivers in Latinx communities face compared to non-Latinx caregivers. Latinx caregivers have expressed how their cultural factors have an influence on how to care for another member of their family who struggles to perform basic tasks. Latinx individuals who have a difficult time performing activities of daily life rely on family members to tend to their needs. Within the Latinx community, it is an obligation to care for its members, in particular, their older members in the family until they pass (Mahoney, Cloutterbuck, Neary, & Zhan, 2005). The strain that is directly put on the caregiver in the family can be detrimental to their mental health as their effort and time become dedicated to the individual being cared for. Cultural factors contribute to the way the caregiver cares for the individual as well as the guilt that the caregiver carries if they do not provide the best care. Other societal and economic factors such as income, education, employment, and social support play a role in the outcome of the caregiver's mental health.

Latinx caregivers have multiple cultural factors that shape the outcome of their mental health. In this study, the research data will be collected through one on one interviews with voluntary respondents. With the findings of this research, there will be an increase in public awareness within this population and better resources can be provided to caregivers. Educating caregivers in Latinx communities can help improve physical and mental health.

Significance of the Project for Social Work

The findings from this study will have major contributions for the practice of social work, for both the micro and macro level. At a micro-level caregivers, with the help of social workers, will be provided with services to support families. The profession of social work is trained to help advocate and support family caregivers (National Association of Social Workers, 2009). Being said, social workers will be able to contribute and provide caregivers in Latinx communities with training and support in coping with burnout, depression, and guilt. At the micro-level, the findings can also contribute to better outcomes in providing care. A caregiver who is likely to manage time and take care of oneself would be likely to better address the needs of the other individual who can no longer address their own needs.

At the macro-level social workers who rely on the NASW ethical principles are aware of providing service to others above self-interest (National Association of Social Workers, 1999). It is important to advocate and bring awareness to policymakers to provide help for caregivers who need help and support whether it is physical or mental health. Agencies may make use of the findings from this study to implement support for caregivers in Latinx communities that will increase a better quality of life and better address the needs of others. Therefore, the research question is as followed: What psychosocial challenges do Latinx caregivers experience?

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter will explore research that is relevant to the psychological challenges experienced by caregivers in the Latinx population. The subsections in the chapter will include the financial strains, social support, and gender disparities amongst Latinx caregivers. Another subsection will include studies focusing on the psychological challenges on Latinx caregivers. Lastly, the final subsection will include theories guiding conceptualization which will include the Stress Process Model and the Informal Caregiving Integrative Model (ICIM), which will help give a better understanding on the psychosocial challenges experienced by this specific population.

The Psychosocial Challenges on Caregivers in Latinx Communities

Latino caregivers often face stress and burnout when caring for their loved ones. An estimated 45% of Hispanics experience higher caregiving burdens compared to 33% of non-Latino white caregivers (National Hispanic Council on Aging, 2017). Additionally, Hispanic/Latino caregivers perform more personal care tasks connected to activities of daily life versus non-Hispanic/ Latino caregivers (Llanque & Enriquez, 2012). Many caregivers in Latino households are likely to face more detrimental tasks causing more stress and burnout to the caregivers. Many factors play a role in how caregivers receive assistance or resources to prevent caregivers from experiencing emotional stress due to the many hours spent caring for their loved ones. Financial strain, the lack of social support, and gender are factors that affect caregivers and their mental health.

Financial Strain

According to NHCOA (2017), Hispanic caregiver household income is $38,600, which is lower than the national median. This is important to consider since many Latinx family households struggle financially and usually rely on minimum-wage paid jobs. Apart from their jobs, the caregiver has to consider the expenses to meet the needs of the individual being cared for, as well as others living in a multigenerational household. Low-income Latinx family caregivers disburse approximately 44% of their earnings on caregiving (NHCOA, 2017). The financial problems that occur in the home affect the caregiver due to the constant worry of not having enough money to purchase basic needs. The American Association of Retired Persons and National Alliance for Caregiving (2015) survey stated that 36 percent of caregivers of older adults disclosed average to high levels of financial burden. The results indicate that caregivers worry about the finances that will determine the necessities needed to care for their loved ones. Due to the excessive worry and being overworked by caring for another individual can be detrimental to the caregiver’s mental health.

Social Supports

Caregivers lack support from society and family members. Many Latino families do rely on other family members for support and caring for their loved ones. According to Aranda and Knight (1997), the elderly Latinos who require care rely heavily on informal sources of support compared to organized services. The informal caregivers of these elderly Latinos are members that usually live with them, 77% of Latinos with long-term impairments received care from their spouse or child compared to 14% who cared for themselves (Aranda & Knight, 1997). Caregivers are likely to be family members of the older adult or impaired individual, and the support needed is due to the limited access to programs or information. Out of every five seniors who qualify for SNAP, three do not participate in the program, which states that 5.2 million individuals will miss out on receiving benefits from the program (NHCOA, 2017). The lack of information on social support given out to caregivers has been minimal. The services and programs being provided to help the individuals being cared for have not reached out to obtain these services. If more information on programs and services were provided, caregivers would worry less about meeting the needs of the individual being cared for.

Gender

There are significant gender disparities among caregivers in Latinx communities. Ford et al. (1997) have reported that females are likely to take on considerably more caregiver roles for elder relatives, including other individuals with disabilities. Many of the tasks that caregivers perform are said to be influenced by gender roles and are likely to be supported by cultural norms. Women are expected to perform personal care tasks that involve dressing, bathing, and preparing food (Allen,1994). The jobs that women perform to care for an individual are said to be considered "nurturing," while men are likely to perform instrumental tasks (Ford et al., 1997). The number of tasks that are performed by female caregivers is likely to be overwhelming, which can raise concern towards the female caregiver’s mental health.

Studies Focusing on The Psychosocial Challenges on Latinx Caregivers

The research on caregivers is highlighting the causes of mental health, and studies have shown multiple ways to help meet their needs. Therefore, this study will review research focusing on the mental health of caregivers, investigate different approaches of research, and compare Latinx's mental health to other groups.

The study in this research evaluated the mental health as well as the quality of life of these specific caregivers (Wadhwa et al., 2013). The studies researchers accomplished this by evaluating factors predicting caregiver quality of life and mental health. The study resulted in caregivers' mental health experiencing substantial distress due to the constant care provided to these cancer patients (Wadhwa et al., 2013). The strengths the study were using the quality of life measure for caregivers and other related factors. Some limitations to this study resulted in receiving data from a highly educated and high-income population of predominantly European ethnicity. Although this study focused on caregivers with multiple advantages, another study comparison can be made with a different caregiver population to examine the different results and factors they face.

An empirical study compared the influence of two separate interventions on Anglo and Latino caregivers who care for elder relatives with dementia (Gallagher-Thompson et al., 2003). The study consisted of 213 female caregivers in which 122 were Anglo and 91 were Latino caregivers, who attended two psychoeducational programs to educate them on either specific cognitive behavioral skills or empathic listening to develop mutual support within the group. The study results showed that caregivers who are females benefited more from a skill-building approach to help them manage their distress compared to a support group (Gallagher-Thompson et al., 2003). Other results from this empirical study showed that amongst Latino caregivers, daughters were more likely to be the caregiver and care for female individuals, and Anglos were more likely to be wives and provide care to male individuals. The comparison of this research between two ethnicities has shown the different factors they go through and the type of programs that will better suit them to help manage their distress.

Caregiver mental health is important when providing care to an individual. A study was conducted to measure potentially harmful behavior by examining anger, resentment, and anxiety among caregivers (MacNeil et al., 2010). The study results suggested that depression and resentment had a direct influence in potential harmful behavior (MacNeil et al., 2010). This information must be considered. By providing programs that can help caregivers with mental health, it can prevent potentially harmful caregiving behavior.

These studies can help indicate a need to study caregivers due to the issues caregivers face when providing care for multiple hours a week. The stress and burden caregivers experience become detrimental to their mental health. The data collected can help generate programs that can support caregiver's mental health in the long term. The mental well-being of caregivers in Latinx communities also requires more research due to the lack of studies and representation.

Theories Guiding Conceptualization

Theories that have guided past research and will guide this research in the psychosocial challenges of caregivers are the following; stress process model and informal caregiving Integrative model.

For past research on caregivers, the adaption of Lazarus and Folkman's (1984) stress process model has been dominant in most of the research. The stress process model has been previously used to navigate the relationships amongst caregiving stressors, caregiver well-being and psychosocial resources (Goode et al., 1998). Through the stress process model, researchers use the model to predict changes in caregivers' emotional and physical well-being over time during stressors (Goode et al., 1998). The stress process model has prompted two major types of research which are; analyzing the process in how people respond to challenging life situations and second, to analyze the origin of the distress (McLeod, 2012). Past research such as Anachensem et al. (1995) applied the stress process model to research the encounters of family members caring for an individual with Alzheimer’s. Therefore, this model helps outline the encounters of informal caregivers caring for an individual with a mental health illness.

A proposed theoretical model framework for future studies on informal caregiver burnout is the Informal Caregiving Integrative Model (ICIM) (Gerain & Zech, 2019). The reasoning behind the Informal Caregiving Integrative Model is to take into consideration the multiple determinants of informal burnout such as; the caregiver, the setting of the caregiving and environmental factors. ICIM takes into consideration the caregiver stress model and the job demands-resource model. By doing so, ICIM makes it possible to identify the important factors that should be taken into consideration when researching informal caregiver burnout. ICIM focuses on six concept which are; (1) take into consideration the multiple pressures and resources in the caregiving environment and in the psychosocial attributes of the caregiver (2) consider the relationship between the individual being cared for as an important component in understanding the caregiving experience (3) burnout should be taken into consideration as a key negotiator between the stressor and the outcome (4) caregiver assessments should be incorporated as a center element in the model (ICIM) (5) personal burden should be take into consideration as a measure of appraisal and lastly, (6) include any positive or negative feedback (Gerain & Zech, 2019). Many elements of ICIM have been explored to date by studies focusing on burnout in informal caregivers therefore, ICIM will help guide this research to identify the psychosocial challenges that Latinx informal caregivers experience.

Summary

The study will explore the psychosocial challenges the Latinx population experiences when caring for another individual. Being a caregiver especially in the Latinx community causes many psychosocial effects such as stress, burnout, financial strain, and lack of social support that can affect their mental health. There are a great number of barriers for this population which was stated in the literature. The Stress Process Model and the Informal Caregiving Integrative Model (ICIM) can help social workers, other professionals, and agencies to better help and understand the challenges experienced by this population when caring for others. The study attempts to add social workers' conception into the literature to help better understand the challenges in this population.

CHAPTER THREE

METHODS

Introduction

This study examined the psychosocial challenges that Latinx caregivers experience and seek to identify the resources needed to overcome the barriers. This chapter includes the details of how this study was executed. The following sections are included in this chapter; study design, sampling, data collection and instruments, procedures, and protection of human subjects.

Study Design

The purpose of this study was to explore the psychosocial challenges that are experienced by Latinx caregivers compared to non-Latinx caregivers. By doing so, this study can bring awareness to the challenges Latinx caregivers experience and assist agencies with additional resources for the Latinx community. The study design that was best to research the psychosocial challenges that Latinx caregivers experience is qualitative. Through a qualitative approach, the researchers gained an understanding of the psychosocial challenges experienced by Latinx caregivers through the respondent’s own words and experiences. Therefore, the study was exploratory. The study was guided by the answers of the respondents and gained valuable information as there is very limited information in the area of psychosocial challenges in Latinx caregivers.

A strength in using an exploratory, qualitative approach is that the researchers were able to ask open-ended questions. The researchers asked open-ended questions to Latinx vs. non-Latinx informal caregivers to compare their psychosocial challenges. Consequently, a few of the Latinx respondents were Spanish speakers. Therefore, through a qualitative approach, the researchers were able to ask the questions in Spanish and helped the respondent feel comfortable sharing their answers. Also, qualitative research is much more flexible as researchers were able to adapt questions to improve responses.

A limitation of using a qualitative approach is the sample size. Having a small sample size brings up concerns such as whether the sampling will provide true reflections of the entire Latinx community. Also, with COVID-19, conducting qualitative research was challenging as it limited the way in which the researchers were able to interview the participants. Therefore, it might have limited the respondent in providing their answers over the phone.

Sampling

The study collected qualitative research through snowball and convenience sampling. Snowball sampling was used to collect qualitative data. Through snowball sampling, respondents referred people through word of mouth to the study. The researchers asked the respondents to refer Latinx or non-Latinx caregivers that they might know. Therefore, it was also a convenience sampling as it was based on voluntary respondents. People were sampled simply because they were caregivers and were convenient for the study. The respondents were chosen by their willingness to participate in the study. There was a total of 12 participants, six participants were Latinx and six participants were non-Latinx.

Data Collection and Instrument

Qualitative data was collected by interviews done via phone calls and live video chat. Demographic information such as their ethnicity, gender, and employment, was asked. Through open-ended questions, the researchers seeked to collect barriers such as; stress, social support, and cultural factors that shape the outcome of their mental health to gain a better understanding of their challenges. For example, a question used in the study was, “How would you describe your experience as a caregiver?” Open-ended questions allowed researchers to ask follow up questions. Other open-ended questions that were included was regarding their support system and how their responsibilities might contribute to their challenges as a caregiver.

Procedures

For this research study, the researchers asked acquaintances which they believe were a good candidates for the study. The researchers asked the respondents to refer them to any other Latinx or non-Latinx caregivers that they believed were good candidates for the research study. Therefore, this method was considered as convenience sampling as it was based on voluntary participants. This research was focused on using qualitative research methods, therefore consisted of interviewing twelve participants. The interviews were one-on-one interviews and were recorded by the researchers.

Both researchers split the interviews therefore, each researcher conducted six interviews to collect the data. The researchers asked a series of questions related to the purpose of the study. Respondents who agreed to participate were able to select a time for their interview and had the option to either perform the interview through a phone call or live video chat due to current circumstances related to COVID-19. Respondents were made aware that they were being recorded with a voice recorder and assured them that the voice recordings were used for research purposes only. The interviews took approximately 30 minutes to an hour to obtain as much data as possible. The interviews took place in the researcher’s private room to maintain confidentiality and avoid any interruptions while the interview was in session. The participant was also encouraged to seek a private room in their home to avoid any interruptions as well. The participants in this study were able to withdraw from the study at any time. The interviewing process began in early December 2020 and stopped collecting data in early spring 2021.

Protection of Human Subjects

This research focused on interviewing human subjects therefore, it was essential that researchers were familiar with the ethical principles that protect the rights and welfare of the research participants. The data collected from this study protect the confidentiality of the participants by using pseudonym names. Any identifiable information was removed from the study to protect the identity of the participants. Participants who agreed to be interviewed through phone calls were on speaker to record the phone calls using a voice recorder. The researcher emailed, or verbally went over the informed consent explaining confidentiality to allow respondents to participate in the study and the participant provided a verbal consent. Both researchers had access to the data collected in order to analyze the data. Any other individuals did not have access to this data.

When researchers began one-on-one interviews, the researchers considered the environment where all phone calls or video chats took place. Researchers made sure that they had a safe space to collect any confidential data. All interviews were made in a private room with the researcher and interviewee over phone in order to protect confidentiality. Participants were made aware that they were being voice recorded for research purposes only. Participants were able to withdraw from the study if they did not want to be voice recorded. Following these procedures allowed protection among the research participants. All data files were safely put away and were only used for research purposes. Once the study was completed all audio recordings as well as any transcriptions or data were erased or shredded.

Data Analysis

The data gathered in the interviews was analyzed with thematic analysis. The audio recordings from the interviews were transcribed into a written form. Once transcribed both researchers examined the written form and pinpoint any patterns in the transcriptions. The statements received in the interviews were sorted according to the themes and subthemes that emerge from the transcription. The themes and patterns generated from the data were then coded. Both researchers re-read the data collected and refined any codes until both researchers were satisfied. Any unique experiences from each participant was analyzed further deeply to identify a possible category that may contribute to the research findings. All coded data was then utilized to create frequencies and proportions to better understand the coded themes.

Summary

The research methods used in this study allowed researchers to gain in-depth scope of the proposed research question. Latinx and non-Latinx caregivers may face different challenges when caring for an individual. This study explored those challenges and factors that have caused stress among these two different groups of caregivers. Conducting interviews allowed researchers to understand those challenges caregivers face. Through the use of qualitative methods, it was important to consider the procedures it takes to conduct research interviews. It was important to consider the protection of the participants who were willing to provide information regarding their experiences and emotions that occur when caring for another individual. The instruments used in this study allowed a better collection of data and helped provide a better scope of the problem.

CHAPTER FOUR

RESULTS

Introduction

This chapter presents the results of the study regarding the psychosocial challenges that Latinx caregivers experience. The results were gathered by asking a series of questions to two different groups, to help identify the challenges Latinx caregivers experience in comparison to non-Latinx caregivers. Comparing both groups will give light to the challenges that Latinx caregivers experience. Latinx versus non-Latinx caregivers were given the same questions to find out who they care for, their experiences, responsibilities, support systems, employment, well-being, and their overall view as a caregiver. Caregiver's responses were acquired through qualitative interviews. Specific themes were gathered from the interviews such as broad challenges, social supports, living arrangements, gender, financial, and resources. The researchers used participant quotes to highlight the themes that were listed. The participant's quotes provide a better insight and understanding on each of the caregiver's experience on their well-being and experiences associated with caring for an individual.

Demographics

The participants gathered in this study are caregivers of an older child, older parents, older grandparents and spouses. The sample populations for this qualitative study included 6 Latinx caregivers and 6 non-Latinx caregivers. From this sample, all 12 of the participants were women who were caregivers to family members with chronic illnesses. Four out of the six Latinx caregivers cared for their older mothers and the remaining two cared for their older father and spouse. Five out of six non-Latinx caregivers cared for their older mothers and one cared for their older child. Nine out of the twelve caregivers work full time jobs while 3 are either retired or get paid to care for full time. All participants are over the age of 18. The participants that identified as part of the Latinx population, 2 were fully Spanish speakers and 4 of the Latinx participants were bilingual speaking both English and Spanish. For the non-Latinx participants, all 6 were English speakers.

Qualitative Interview Data

Researchers reviewed the informed consent with participants. The interviews ranged from 30 to 60 minutes each. The participants were asked to describe their experiences, responsibilities, support systems, employment, well-being, and their overall view as a caregiver. The caregivers were asked about the challenges they faced and what could have helped them become a better caregiver. The following themes were used to further explore the psychosocial challenges of the caregivers: broad challenges, financial, gender, social support, living arrangements, and resources.

Broad Challenges Amongst Latinx and Non-Latinx Caregivers

All participants were asked what challenges they experience as caregivers, the participants in the study, six Latinx and six non-Latinx caregivers, experienced similar challenges. Nine out of the twelve caregivers who worked full-time jobs outside from being a caregiver mentioned time management was a struggle in both Latinx and non-Latinx. For example, participant 10 said:

> So I would say, balancing my time between my own family and like work because I work full time and then I have my own family to take care of. But then I feel pressure to help take care of my mom, and make sure that my dad is taken care of as well. So it would be more like balancing my time and then making sure that she's emotionally okay.

A Latinx caregiver who worked fulltime had a difficult time managing her time due to having to ask her sister in law to help her care for her mother in law. For example, participant 1 said:

> So sometimes, like if she has appointments, and you know, because I work, I have to coordinate with my sister in law to see if she can take her. Sometimes my mother in law has gone by herself. That's a big challenge, is just kind of finding the time right now.

Of the twelve participants all mentioned feeling stressed after being asked how they would describe their well-being before becoming a caregiver. Participant 9 said:

> Sometimes I stress out and I get really worried, like when it’s time for me to go to bed or time for me to leave, or even if it’s like a weekend I need off, I am so scared that something is going to happen or she doesn’t get the care that she's usually expecting. Or I'll be scared like if this will be the day I'm going to walk in and find her without life. Just stresses around something happening to her.

A Latinx caregiver also mentioned the stress she experiences caring for her mother and the knowledge she lacks in the medical field due to all the medical issues her mother struggles with. For example, participant 4 said:

> I think that I was in better health before. I mean, also stress, you know, being a caregiver is stressful. Because, you know, umm…like, not being in the medical field and everything, not knowing what goes on, and what's the outcome of a certain disease processes and stuff like that, you know, it's a lot of stress on me.

Three out of the six Latinx caregivers have families to care for and four out of the six non Latinx caregivers have families to take care for. Some of these caregivers had a difficult time meeting their roles in their immediate families. Seven out of the twelve caregivers are mothers or wives that still have to take care of the needs of their families. Participant 5 said:

> The challenges for me at the time, of course, I was a single mom. So I had my daughter in high school, I wanted to make sure that, you know, I was taking care of her needs as well, making sure there was food in the house, making sure that, you know, she went to her sports, you know, things and her, you know, making sure that she was doing okay, emotionally, and then me… trying to be there for my dad as he was diagnosed with cancer at the time, and then trying to also manage my work at the office, it was… it was a pretty crazy time.

A non Latinx caregiver had a difficult time trying to fulfill her role as a mother and wife due to always having to take care of her mother. Participant 10 said:

> Going back to like feeling like I'm pulled in a million different directions with my time and still having to work to help support my family and still trying to be a mom and a wife I think it just takes like an emotional toll where it is kind of exhausting.

Financial

Four out of the six Latinx caregivers receive financial help for caring for their older mothers with chronic illnesses. One out of those four Latinx caregivers caring for their mothers uses that money to help pay for expenses of the person she is caring for. Participant 2 said:

> Yes, I'm employed but I also receive a stipend for being my mom's caregiver. I do not do it for the money, but it is an extra help to cover her expenses.

One of the Latinx participants had to become a caregiver in the middle of a pandemic due to a paid caregiver being unable to help provide care to the participants mother in law. Participant 1 said:

> We became her caregiver when COVID-19 first hit, because her regular caregiver did not want to come back to work. And her daughter did not want to do anything. So we kind of in a sense took over, no one else at the time did it because of COVID. We took some classes in the beginning and did like training stuff and it is paid. Even though before we were kind of doing the same stuff anyways.

Another Latinx caregiver has an option of having a job that pays well, but due to the amount of care her mother requires prevents her from not being able to work another job. Participant 4 said:

> I think the most challenging thing is that the type of care that my mom requires, I am not able to work. So, I'm in the IHSS program. So, I do get paid, but I stopped working for, you know, what I went to school for and I can make more money that way. But I think that's the biggest challenge for me. But other than that, you know, everything is simple. It's just normal things here at the house. But I, I have, maybe I can save time, you know, time could be an issue because she has so many appointments, and we're constantly going, you know, it's never been home.

Some financial issues that caregivers have encountered still require extra financial assistance to make ends meet. The participants from this study have other fulltime jobs apart from caretaking to cover expenses. A Latinx caregiver struggles financially to care for her husband who is unable to receive much help to cover for both of their living expenses. Participant 6 said:

> He receives Social Security. He owned a small business before, and he doesn't get no retirement. So, we really struggle. If he was going to be by himself, he would really struggle because he won't make enough. He doesn't make enough.

<u>Gender</u>

As previously mentioned, the participants from both groups Latinx and non-Latinx were all women caring for a relative with a chronic illness. From the six Latinx participants three out of the six women had male siblings or male figures in their immediate family, however, did not take the responsibility of being the caregiver. Participant 5 from the Latinx group reported:

> I'm the only daughter. My brother's had to help my dad with our family business. My dad will not go with anybody except me. And I'm probably the bossiest one out of my brothers. And I'm like the one that will get the information from the doctors and make sure that everything's taken care of.

In comparison, from the non-Latinx group two out of the six participants had male siblings or male figures in their immediate family however, the women were the main caregivers. Participant 6 reported:

> When it comes to the caregiving aspect, I need the help and support with that. I would say it's really poor, it's just pretty much myself. Oh, and my husband as much as he can lend a hand.

Social Support

During the interview participants were asked about their social support, of the twelve total participants, five reported having good social support in which they can count on when it comes to caregiving. The other seven of the participants reported either not having a support system or their support system not being enough. Those that mentioned having a good support system stated having extra help and counting on others when needed. For the Latinx group three out of the six participants stated having a good support system. Participant 2 reported:

> I feel very fortunate with my husband who has been very supportive and helping in every way he can. We are eight siblings but mainly myself and three sisters have been involved throughout the care of my mother.

Participant 5 reported the following:

> Oh my gosh, it was amazing. I'll be honest with you. It was amazing. My mom helped me a lot with my daughter. So, we were all together working as a family.

Two out of the six Latinx participants reported having very limited or no support, with participant 4 reporting the following:

> I mean, it's just me. So, you know, I don't really have like, a backup plan. Like, if something happens to me, then there's really nobody else. I really don't have help like that.

One out of the six participants stated not asking for help because she feels like a bother, reporting,

> I don't like to be bothering people. I'm an old fashioned lady that I don't like to be bothering anybody. (Participant 6)

In comparison to the non-Latinx caregivers, four out of the six non-Latinx participants reported not having enough social support. Participant 7 stated, “It’s very poor.” Therefore, reporting having very limited time for themselves and experiencing burnout. The other two participants stated having good social support. Participant 12 reported the following:

> I have a great support system. And my family is very supportive, they help me a lot. And I've met a lot of doctors that are very supportive.

Also, non-Latinx participants reported conflict within their families due to caregiving. Two out of six non-Latinx reported conflict within families. However, Latinx participants did not report any conflict amongst their families.

Living Arrangement

During the interview, participants reported whether the individual they cared for lived in the same household as them or lived separately. Seven out of the twelve participants reported living with the individual they care for. Five out of the six Latinx caregivers reported living with the individual they care for. Participant 1 reported,

> I think yeah, there's a little bit less time that I get to do things that I enjoy. Especially having the person you care for live with you, then there's been less privacy and just kind of takes too much time.

Participant 2 reported:

> My experience caring for my mother has changed my life in every aspect. I think, like I mentioned I had to accommodate my house for her. Also, like I had to accommodate my schedule and priorities to her needs. It’s difficult.

In comparison to the non-Latinx caregivers, only two out of the six participants live with the individual they care for. The other four participants commute from their house to the individuals house that they are caring for. Participant 8 reported:

> So now it's just her. But she lives in a large house, and she can't do a lot of walking. So, she needs the extra assistance. It's difficult for her. So, I go about one day a week. And I've been doing that for several years. And sometimes it's been, you know, an extra day during the week.

Resources

Three out of the six Latinx caregivers mentioned wanting to know more about resources when asked what could have helped them become a better caregiver. Some of the participants mentioned classes on how to care for individuals with certain health conditions. Participant 1 said:

> So maybe like classes for like her specific problem. And understanding sometimes, like, with her condition, she's in a lot of pain, like, things like that. So just kind of understanding that and sometimes it is difficult, because you're thinking like, well, you can you can do that. But, you know, she's like “well I can’t”. I guess that's kind of a little bit frustrating. So yeah, classes. Even like, like a resource center, where you can just call and say, Hey, you know, what, do I do with this? Okay, you know, she might need this.

Participant 2 said:

> I’m not sure, maybe classes or workshops for my mother’s Alzheimer’s and how to better care for her. It is difficult caring for someone in general but then caring for someone with an illness makes it more difficult and stressful. So maybe just some guidance would be helpful.

Similarly, participant 3 said:

> Personally, I think it would help me if they gave us some training classes, to know what to do in case of an emergency, also classes on how to learn to speak with patients to help them improve their self-esteem, since due to their age they often see life without joy. And I feel that it is very difficult to see that so I would like to learn more. And another thing, also that the classes should be in Spanish because most of the help provided are in English so it would be a very good help to be able to attend classes in my language.

Conclusion

Chapter four presented the results of this study regarding caregivers experiences, responsibilities, support systems, employment, well-being, and their overall view as a caregiver. The results were gathered from a sample size of twelve participants who identified as caregivers of individuals. The questions presented to the participants were open-ended responses which allowed researchers to ask follow up questions to further capture hidden themes. The results were later transcribed by both researchers and themes were color coded during analysis. The results of this study will be discussed in more detail in chapter five.

CHAPTER FIVE

DISCUSSION

Introduction

This final chapter will discuss the major themes of the study presented in the research. This chapter will examine the psychosocial challenges of Latinx caregivers and discuss whether the results do or do not support the findings of studies cited. In addition, limitations of the study, and recommendations for social work practice and future research will also be presented in this chapter.

Broad Challenges Amongst Latinx and Non-Latinx

In the broad challenges amongst both Latinx and Non Latinx caregivers all had similar challenges such as time management, stress, and meeting their roles. This study found out that nine out of the twelve caregivers who worked full-time jobs outside from being a caregiver mentioned time management was a struggle. Caregivers who work full time job are more likely to not meet high care provision for those they care for. Navaie-Waliser et al. (2001), found that formal caregivers who only focus on caring for the individual is likely to provide higher intensity care. The participants in the study worked other fulltime jobs which eventually cause lack of care for the individual being cared for. Being able to manage time among caregiving and other work will help in providing better care but also less stress on the caregivers' mental health.

Stress was also a broad challenge among both groups in the study. Caregivers explained how stress emerges due to the amount of work needed to provide for the individual being cared for. Distress from caregiving may be expressed differently among people of varying ethnic backgrounds (Adams et al.,2002). Many of these caregivers in particular Latinx families are very family oriented, therefore the stress in trying to care for the individual affects them as they also try to balance time with work or family. Caregivers from this study struggled with their outside roles of being a caregiver. Three out of the six Latinx caregivers have families to take care of and four out of the six non Latinx caregivers have families to take care of. Many of the caregivers begin to lose their role in their families due to the dedication in being a caregiver. All participants were female and seven out of the twelve were mothers who still needed to care for their children after caring for an individual. This requires multitasking and filling other roles in the family.

Financial

The caregivers recorded in the study explained how many of them struggle and needed to work fulltime jobs just to take care of expenses. Four out of the six Latinx caregivers receive financial help for caring for their older mothers with chronic illnesses. Two out of the six Latinx caregivers did not receive any payment for caring for the individual. Those caring without compensation miss out on the opportunities in receiving extra support. This considered both of those caregivers to be informal caregivers and are a tremendous social resource, providing an estimated $196 billion in uncompensated care (Arno, Levine, and Memmott 1999). The uncompensated help misses out on the extra financial help that the two out of the six were unable to receive. Low-income Latinx family caregivers disburse approximately 44% of their earnings on caregiving (NHCOA, 2017). One out of the six Latinx caregivers who received a stipend use that money to cover other caregiving expenses, this caregiver contributes to the 44%.

Gender

As for gender, as mentioned in chapter 4, the participants of this study from both groups Latinx and non-Latinx were all women caring for a relative with a chronic illness. Research shows, that there are significant gender disparities among caregivers in Latinx communities. Ford et al. (1997) reported in their study that females are likely to take on considerably more caregiver roles for elder relatives, including other individuals with disabilities. Many of the tasks performed by caregivers are said to be influenced by gender roles and are likely to be supported by cultural norms. However, results in this study conclude that not only women are the main caregivers in the Latinx community but also the main caregivers in other populations. Both might be influenced by cultural expectations of gender roles as women are portrayed as being more nurturing and empathic.

Social Support

In regard to social support, five of the twelve participants reported having a good social system. Within those five participants, three participants were from the Latinx group and two from the non-Latinx group. All of the participants that reported having a good social support system expressed their gratitude and appreciate towards those that help them. Latinos tend to rely on other family members for support when caring for a loved one. The participants from the Latinx group that stated having a good support system received assistance from other family members. In comparison, the majority of non-Latinx caregivers stated having some sort of support from a friend rather than a family member. Aside from being a caregiver most of these participants were mothers, wife and or had full time jobs. Therefore, in regard to their well-being, those caregivers that have a good social support expressed having a little extra time to fill the multiple other roles they have. Those participants that reported having a good social support system decreased their stress a bit in comparison to those who reported not having a good social support system.

As previously mentioned in chapter 4, some participants from the non-Latinx group reported conflict within their families due to caregiving. However, the Latinx caregivers did not reports any conflict within their families. Studies have shown that within the Latinx community, it is an obligation to care for its members, in particular, their older members in the family until they pass (Mahoney, Cloutterbuck, Neary, & Zhan, 2005). Therefore, the Latinx community tend to have closer ties. As reported, the study presents that Latinx caregivers have better social support.

Living Arrangements

In regard to living arrangements amongst the caregiver and the person they are caring for, the majority of the participants that reported living in the same household with the person they care for were Latinx caregivers. As previously reported, caregivers of elderly Latinos are members that usually live with them, 77% of Latinos with long-term impairments received care from their spouse or child compared to 14% who cared for themselves (Aranda & Knight, 1997). Consequently, those who do live with the individual they care for reported having less privacy, less time for themselves if lacking extra support, and more stress and burnout as their loved one needs 24/7 care.

Resources

In the study three out of the six participants reported that they would have liked to have classes or other trainings to help care for the individuals they care for. Some of these caregivers expressed their concerns of not being qualified due to the care they provide in medical care. A few caregivers expressed they would like to attend classes to learn more about the illness they help care for. By having more knowledge about the illness their loved one has, it can help the caregiver take better care for them. By doing so, it will decrease the stress and other factors due to having knowledge on how to treat and care for the individual with that illness. One study found that caregivers who made environmental changes in the home, such as assistive devices in the bathroom and special locks on outside doors, were less likely to institutionalize their family member with dementia (Spruytte et al., 2001). Educating caregivers about the illness as well as providing information on how to care for can help decrease stress associated with the care they provide. Within the Latinx caregivers, some participants reported the need for bilingual classes for caregivers as most services and resources are primarily in English. Lastly, many participants reported the difficulty in obtaining the services that are out there for caregivers. Organizations make it difficult for caregivers to qualify and receive the services. Therefore, making resources more accessible for both the Latinx and non-Latinx caregivers would benefit the caregiver and the individual they are caring for. By making them more accessible the resources can assist the caregivers in decreasing their stress levels and increasing their well-being.

Limitations

This research had a few limitations that should be considered. One limitation was the sample size which included only twelve participants total. Within those twelve participants only six were Latinx and six were non-Latinx. Therefore, this study might not reflect all the challenges experienced by caregivers in these populations as the sample size was small. Another limitation was the lack of male involvement in this study. All participants were women therefore, men caregivers might experience different challenges when caring for a relative. Lastly, another limitation are the guidelines and restrictions regarding COVID-19. All interviews were conducted over the phone therefore, the lack of face to face interviews does not allow to capture their affect and personal appearance. Also, the face to face interviews will have allowed to capture the affect and personal appearance of the participants. Also, the face to face interviews could create more personal interviews that allow more in-depth insight of their personal emotions.

Recommendations for Social Work Practice, Policy, and Research

Based on the findings of this study there are multiple recommendations for social worker practice, policy and research which include at the micro, macro and mezzo level. One of the recommendations for the micro level is for social workers to become aware of the challenges Latinx caregivers and caregivers in general experience. By doing so, social workers would be able to provide better services and find better ways to support caregivers. At a macro level, agencies should provide more resources for Latinx and non-Latinx caregivers. By implementing support for caregivers in Latinx communities, it will increase a better quality of life not only for the caregiver but also the individual being cared for. Although there are resources available to caregivers, agencies make it difficult for caregivers to apply and receive the services. Also, agencies should provide trainings and classes in both Spanish and English to better assist the Latinx caregivers and their psychosocial challenges. There is currently a lack of information on social support given to caregivers, therefore, this study and similar studies can help organizations understand how to better support caregivers. For future research, this study can help provide insight on some of the challenges that caregivers face specifically Latinx caregivers. Due to the limited research on challenges Latinx caregivers face this research will bring light and understanding on the psychosocial challenges both Latinx and non-Latinx experience.

Conclusion

This study identified the psychosocial challenges Latinx caregivers experienced in comparison to non-Latinx caregivers. This chapter discussed the themes including the broad challenges amongst both Latinx and non-Latinx, financial, gender, social support, living arrangements and resources. The limitations and recommendations for micro, macro and mezzo levels were also addressed in this final chapter. There continues to be a lack of research in the Latinx caregiving community. Therefore, this study can assist with understanding the challenges Latinx caregivers experience in comparison to non-Latinx caregivers.

APPENDIX A

INFORMED CONSENT

CSUSB WE DEFINE THE Future
School of Social Work
CALIFORNIA STATE UNIVERSITY, SAN BERNARDINO
5500 University Parkway, San Bernardino, CA 92407
909.537.5501 | fax: 909.537.7029
http://socialwork.csusb.edu

INFORMED CONSENT

The study in which you are asked to participate is designed to examine the psychosocial challenges amongst Latinx caregivers vs. non-Latinx caregivers living in the Inland Empire The study is being conducted by Ingrid Lopez and Brenda Perez graduate students, under the supervision of Dr. Armando Barragán, Assistant Professor in the School of Social Work at California State University, San Bernardino (CSUSB). The study has been approved by the Institutional Review Board at CSUSB.

PURPOSE: The purpose of the study is to examine the psychosocial challenges that Latinx caregivers experience.

DESCRIPTION: Participants will be asked of a few questions on their experience and challenges of being a caregiver, their support system and their well-being.

PARTICIPATION: Your participation in the study is voluntary. You can refuse to participate in the study or discontinue your participation at any time without any consequences.

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

DURATION: It will take 30 minutes to one hour to complete the survey.

RISKS: Although not anticipated, there may be some discomfort in answering some of the questions. You are not required to answer and can skip the question or end your participation.

BENEFITS: There will not be any direct benefits to the participants. However, findings from the study will contribute to our knowledge in this area of research.

CONTACT: If you have any questions about this study, please feel free to contact our research supervisor, Dr. Barragán at (909) 537- 3501.

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 agree to have this interview be audio recorded: _____ YES _____ NO *(required if you are recording interview for qualitative or mixed*

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

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FORMULARIO DE CONSENTIMIENTO

El estudio en el que se le pide que participe está diseñado para examinar los desafíos psicosociales entre los cuidadores Latinx frente a los de cuidadores que no Latinx que viven en el Inland Empire. El estudio está siendo realizado por estudiantes graduados Ingrid López y Brenda Pérez, bajo la supervisión del Dr. Armando Barragán, profesor asistente de la Escuela de Trabajo Social de la Universidad Estatal de California, San Bernardino (CSUSB). El estudio ha sido aprobado por la Junta de Revisión Institucional de CSUSB.

PROPOSITO: El propósito del estudio es examinar los desafíos psicosociales que experimentan los cuidadores Latinx.

DESCRIPCION: A los participantes se les harán algunas preguntas sobre su experiencia y desafíos de ser cuidador, su sistema de apoyo y su bienestar.

PARTICIPACIÓN: Su participación en el estudio es voluntaria. Puede negarse a participar en el estudio o interrumpir su participación en cualquier momento sin ninguna consecuencia.

CONFIDENCIALIDAD: Sus respuestas serán confidenciales y los datos se informarán solo en forma grupal.

DURACIÓN: Tomará de 30 minutos a una hora completar la encuesta.

RIESGOS: Aunque no se anticipó, puede haber cierta incomodidad al responder algunas de las preguntas. No es necesario que responda y puede omitir la pregunta o finalizar su participación.

BENEFICIOS: No habrá ningún beneficio directo para los participantes. Sin embargo, los resultados del estudio contribuirán a nuestro conocimiento en esta área de investigación.

CONTACTO: Si tiene alguna pregunta sobre este estudio, no dude en comunicarse con nuestro supervisor de investigación, el Dr. Barragán al (909) 537-3501.

RESULTADOS: Los resultados del estudio se pueden obtener de la base de datos ScholarWorks de la biblioteca de Pfau (http://scholarworks.lib.csusb.edu/) en la Universidad Estatal de California, San Bernardino después de julio de 2021.

Acepto que esta entrevista se grabe en audio: _______SI ______NO

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

____
Coloque una marca X aquí Fecha

APPENDIX B

INTERVIEW QUESTIONS

Research Questions

1. What does a caregiver mean to you? And do you consider yourself a caregiver? Who are you caring for?
2. How would you describe your experience as a caregiver?
3. What do you feel are the challenges you experience as a caregiver?
4. What made you take that responsibility of becoming a caregiver? Aside from being a caregiver, are you employed?
5. How would you describe your support system?
6. How has becoming a caregiver affected your well-being? How would you describe your well-being before becoming a caregiver?
7. What would help you become a better caregiver?

(Created by Brenda Perez & Ingrid Lopez)

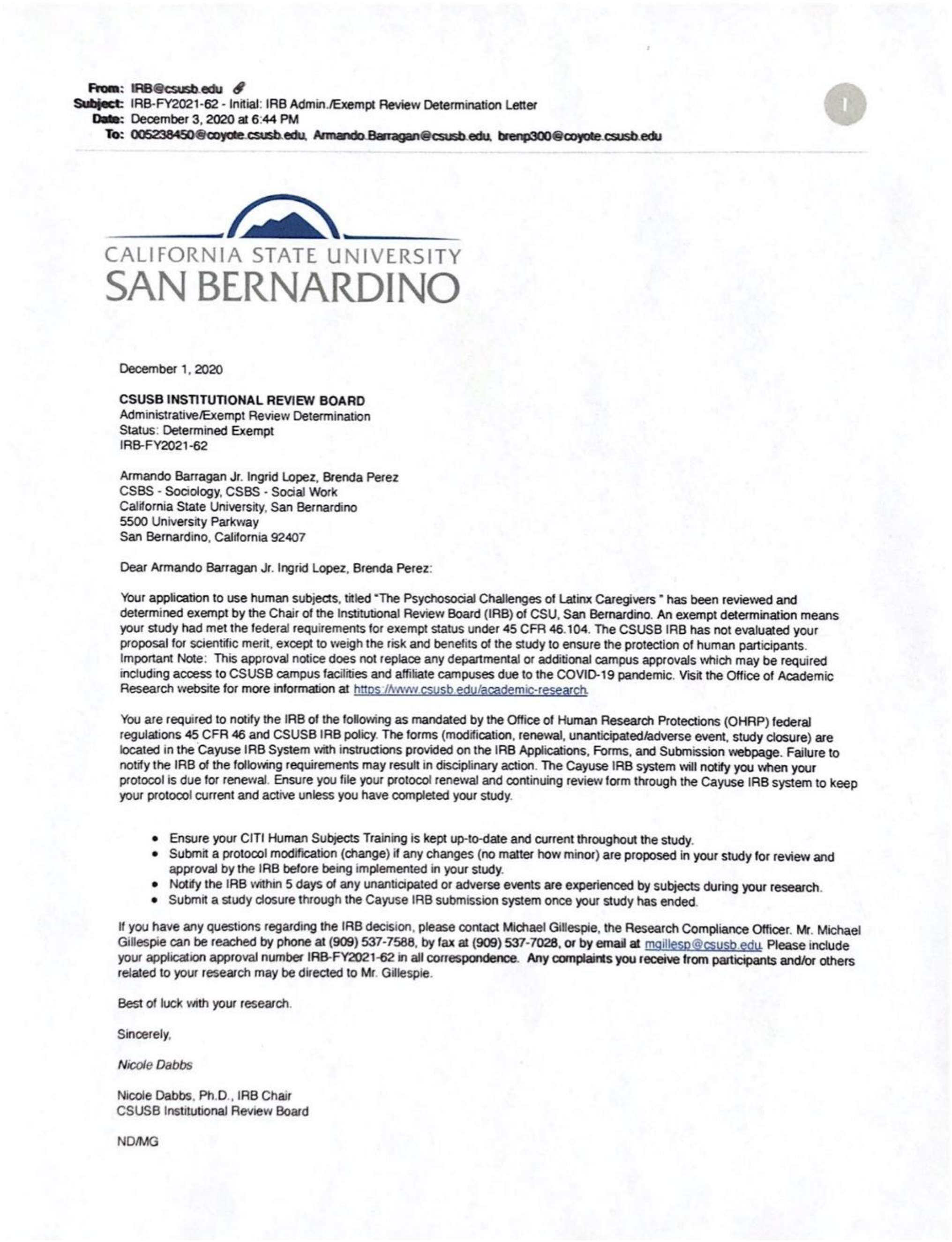
Preguntas en Espanol

1. ¿Qué significa un cuidador para usted? ¿Y se considera un cuidador? ¿A quien cuida?
2. ¿Cómo describiría su experiencia como cuidador?
3. ¿Cuáles cree que son los desafíos que tiene como cuidador?
4. ¿Qué le hizo asumir la responsabilidad de convertirse en cuidador? ¿Aparte de ser cuidador, este empleado?
5. ¿Cómo describiría su sistema de apoyo?
6. ¿Cómo ha afectado su bienestar convertirse en cuidador? ¿Cómo describiría su bienestar antes de convertirse en cuidador?
7. ¿Qué le ayudaría a convertirse en un mejor cuidador?

(Creado por Brenda Perez y Ingrid Lopez)

APPENDIX C

INSTITUTIONAL REVIEW BOARD APPROVAL



From: IRB@csusb.edu

Subject: IRB-FY2021-62 - Initial: IRB Admin./Exempt Review Determination Letter

Date: December 3, 2020 at 6:44 PM

To: 005238450@coyote.csusb.edu, Armando.Barragan@csusb.edu, brenp300@coyote.csusb.edu

CALIFORNIA STATE UNIVERSITY
SAN BERNARDINO

December 1, 2020

CSUSB INSTITUTIONAL REVIEW BOARD
Administrative/Exempt Review Determination
Status: Determined Exempt
IRB-FY2021-62

Armando Barragan Jr. Ingrid Lopez, Brenda Perez
CSBS - Sociology, CSBS - Social Work
California State University, San Bernardino
5500 University Parkway
San Bernardino, California 92407

Dear Armando Barragan Jr. Ingrid Lopez, Brenda Perez:

Your application to use human subjects, titled "The Psychosocial Challenges of Latinx Caregivers " has been reviewed and determined exempt by the Chair of the Institutional Review Board (IRB) of CSU, San Bernardino. An exempt determination means your study had met 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. Important Note: This approval notice does not replace any departmental or additional campus approvals which may be required including access to CSUSB campus facilities and affiliate campuses due to the COVID-19 pandemic. Visit the Office of Academic Research website for more information at https://www.csusb.edu/academic-research.

You are required to notify the IRB of the following as mandated by the Office of Human Research Protections (OHRP) 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. The Cayuse IRB system will notify you when your protocol is due for renewal. Ensure you file your protocol renewal and continuing review form through the Cayuse IRB system to keep your protocol current and active unless you have completed your study.

- 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-FY2021-62 in all correspondence. **Any complaints you receive from participants and/or others related to your research may be directed to Mr. Gillespie.**

Best of luck with your research.

Sincerely,

Nicole Dabbs

Nicole Dabbs, Ph.D., IRB Chair
CSUSB Institutional Review Board

ND/MG

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ASSIGNED RESPONSIBILITIES

Researchers, Ingrid Lopez and Brenda Perez have shared the same amount of responsibilities throughout this project. Both researchers have agreed on all decisions and actions taken and have provided each other with feedback. Lopez and Perez wrote all documents together and collaborated on all aspects of the writing and application process. Lopez and Perez agreed on times to meet to discuss and work on the project. Both Lopez and Perez interviewed six participants which included three Latinx and three non-Latinx. Both shared responsibilities on coding, analyzing and transcribing data. Lopez and Perez shared writing responsibilities throughout the chapters. Researchers worked great as a team and did not encounter any issues.